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## **Governing through Health: The Biomedical and Public Health Management of Drug Using Bodies**

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## ABSTRACT

Focused on the intersection of health, drug use, and poverty, this dissertation closely examines the use of discursive registers in the conceptualization of health among low-income people who inject drugs in New York City. Using qualitative in-depth interviews with 40 people who inject drugs, 13 health care practitioners who provide care for drug-using patients, and 4 researchers of drug use, the governmentality of a public health risk population—people who inject drugs—is traced. To historicize this population a genealogy of the “injection drug user” is conducted through the examination of public health research publications from the 1980s and historical literature on the HIV/AIDS epidemic. This dissertation sought to answer such questions as: How did the emergence in the 1980s of the “injection drug user” function as an act of governmentality? How do health care practitioners understand drug use among their patients and what are the implications of these understandings for the management of their health and their selves? How have risk discourse and particularly harm reduction discourse produced concepts of health and governed the bodies of low-income people who inject drugs? And, what can be done about health concerns that fall outside of risk discourse? The findings of this dissertation interrogate discourses of risk, such as harm reduction, and the discourse of addiction as disease by pointing to the narratives of illness offered by people who inject drugs. These narratives reveal that these individuals prioritize chronic health conditions from which they currently suffer over concerns of risk for infectious disease or the disease of addiction. Despite this, people who inject drugs are entangled in a complicated web of power through bio-political discourses of risk and disease that renders them subjects of disciplinary and pastoral technologies of power.

GOVERNING THROUGH HEALTH: THE BIOMEDICAL AND PUBLIC HEALTH  
MANAGEMENT OF DRUG USING BODIES

by

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B.A., University of Michigan 2001

M.A., Syracuse University 2010

Dissertation

Submitted in partial fulfillment of the requirements for the degree of Doctor of  
Philosophy in Sociology

Syracuse University

May 2015

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## Chapter One

### Introducing the Project: Risk, Disease, Illness and Governance

“They have the risk factors of people not using clean needles. Hepatitis C and HIV.”

- Elaine, M.D.

“Drug use is a chronic disease and like all chronic diseases it needs to be paid attention to. It’s not ever going to really completely go away.”

- Christine, M.D.

“My main health concerns? Pretty much just my diabetes. It won’t affect me now. It’ll affect me later—your legs chopped off and this and that.”

- Dan

This project is an exploration and an analysis of the meaning of health for economically marginalized people who inject drugs. By conducting qualitative interviews with low-income people who inject drugs, health care practitioners who provide primary care for drug users, and public health researchers who study drug use, this project sought to understand how health-related practices and discourses can govern the bodies of low-income drug users. To historicize this research project, a genealogical analysis of the formation of the “injection drug user” risk category was conducted. Based on archival research and qualitative interviews with four researchers, this historical analysis aimed to understand how acts of public health governmentality create and manage populations.

The quotes from study participants featured above represent three ways of discussing the health of people who inject drugs that emerged during interviews with 40 economically

marginalized people who inject drugs and 13 health care practitioners. These interviews, conducted between January 2012 and May 2013 in New York City, revealed that the health of those who use drugs is understood in at least three ways—1.) through reference to health risks, 2.) through reference to addiction as a disease, and 3.) through reference to chronic illnesses provoked and made worse by economic hardship. My goal in analyzing these conceptualizations was to understand how certain discourses function as mechanisms of power with implications for material practices. I wanted to track invisible forms of power that work through the desire of health care practitioners to provide more access to well-being, and through the desire of people who inject drugs to be healthy. Power works through these desires for optimization and maximization of health. Foucault's concept of governmentality provided guidance in understanding how various constructs and practices of health could be tied to forms of power that manage and regulate people and populations. I applied this Foucauldian analytic to the lay knowledge, illness narratives, and doctor-patient relationships depicted by interviewees.

Governmentality can be understood as a rationality that constitutes society and in doing so makes the governance of society on the population- and individual-level possible (Foucault 2007a). By introducing the concept in the late 1970s, Foucault was attempting to explain the preponderance of internalized self-governance emerging in that decade (Rose, O'Malley and Valverde 2006). Neoliberal rationalities of governance that emerged at that time and continue today promote personal responsibility, governing-at-a-distance (Petersen and Lupton 1996), and regulated autonomy for the individual (Petersen 1997).

Understanding the health of people who inject drugs as related to risk, as Elaine, who practices medicine at an inpatient drug treatment center, does in the quote above, allows for governing-at-a-distance because it means that drug using individuals must tend to their own

potential for risk, and thus govern themselves. The interviewees who inject drugs also spoke about their health in relation to risk. For example, when asked about her main health concern, Karla, a 48-year-old Latina, said: “The only thing I’m worried about now is hepatitis. I want to do the test. I want to find out more about that because I really don’t know much about that.” As a person who injects drugs, Karla<sup>8</sup> was aware of her risk for contracting hepatitis, and wanted to monitor this risk by getting tested. Other drug injecting interviewees voiced risks for illnesses unrelated to drug use. James, a 34-year-old white homeless man, responded to the question about his main health concerns by saying: “Diabetes runs in my family. I don’t eat sweets.” Later in our interview he re-stated his concern about this risk and mentioned how he is addressing it: “I cut down on sugar in my coffee, which I need to cut down even more because diabetes runs in my family, and this is around the same age my mother got it. I have to be careful of that.” Elaine, Karla, and James present examples of conceptualizing health through a discourse of risk.

Understanding the health of drug users as defined by the disease of addiction, as Christine, who provides care in the context of a methadone clinic, does in her introductory quote above, means that this group is managed through drug treatment programs that may or may not employ pharmaceuticals, but most definitely require abstinence. The discourse of addiction as disease calls forth disciplinary technologies of power apparent in drug treatment programs that re-build and re-educate selves into drug-abstinent citizens (Gowan and Whetstone 2012; Kaye 2012b). Though the disease model of addiction has achieved limited acceptance even within biomedicine (Campbell 2013; Courtwright 2010; Meurk et al. 2013; Tiger 2013), many of the health care practitioners used the language of disease to discuss drug use. Alex, a physician-researcher, who practices medicine and prescribes buprenorphine, a replacement therapy pharmaceutical for opiate users, at a community health care clinic, embraced the disease model,

but said: “I think acceptance of the idea that drug dependence is a chronic disease, the same way that diabetes and hypertension is, I think acceptance of that idea is still rare in society and the medical community.” Christine and Alex provide examples of how drug user health can be conceptualized through the lens of addiction as a disease.

Conceptualizing health through reference to chronic illness was predominantly enacted by drug user interviewees as exemplified by the introductory quote from Dan, a 22-year-old white homeless man. These narratives of illness did not reference infectious disease spread through drug use or the disease of addiction. Instead, depictions of these experiences usually involved chronic conditions, such as diabetes or hypertension, which are associated with social disadvantage (Akinbami et al. 2012; Banks et al. [2006] 2013; Gottlieb, O’Connor, and Beiser 1995; Rabi et al. 2006). When asked about his main health concerns, Russell, a 52-year-old white homeless man, answered that he was concerned about hypertension. He said: “Right now, it’s high blood pressure. I know I have high blood pressure.” Russell went on to explain that during his annual physical at his methadone program a reading of one-ninety over one-fifty was observed. Having “a fear or like an anxiety type of thing with doctors,” Russell buys medication for his hypertension on the street. Like many of the drug injecting interviewees suffering from chronic conditions, Russell took measures to treat his illness despite living in the difficult conditions of extreme poverty and being disconnected from health care due to fear of stigmatization for his drug use.

Noting these three problematizations of drug user health: 1.) health as defined through risk, 2.) addiction as a disease, and 3.) chronic illnesses provoked or made worse by economic hardship, offers the opportunity to re-think the ways constructs of health govern individuals and offers nuance to current theorizations of health that hinge largely on risk (e.g., Dumit 2012;

Petersen and Lupton 1996). In addition to risk, the construct of disease and the bodily experience of illness are significant to the conceptualization and management of health for low-income people who inject drugs. The framing of health implies the way it is to be managed and it also serves to obscure other ways of understanding health. This occurs when drug users voice health concerns, such as chronic illnesses like diabetes, though the predominant frameworks of understanding for drug user health have largely to do with risky drug use practices and addiction as a disease.

Discursive formations can be understood as frameworks that form and guide beliefs, utterances, and practices. The relationship between discourse and practice is dialectical in that practices are formed and guided by pre-existent discourses, and pre-existent practices engender discursive supports. In the Foucauldian understanding of discourse, practices are made intelligible and possible through discourse. Foucault (1990) saw discourse as both an instrument and an effect of power. It is an instrument in that it governs material practices. It is an effect of power because its utterance is the result of technologies of power, or practices, which produce and discipline subjects. This means that my analysis of discourse is intimately tied up with practices. The discourses that my interviewees spoke were evidence of prior brushes with powerful practices, as well as intimations of practices to come. Furthermore, the act of speaking a discourse is a practice. This speaking act produces subjectivity at the same time as it materializes and reproduces vectors of social power.

The primary risk discourse that addresses the health of people who inject drugs is harm reduction. As a social movement and a public health project realized by researchers, health

promoters, social workers, activists, and drug users themselves, harm reduction<sup>1</sup> is largely concerned with protecting and improving the health of people who use drugs. Through offering education, material resources, and other behavioral interventions, harm reduction aims to reduce the harms associated with drug use. Needle exchange was a foundational manifestation of harm reduction in the United States, but harm reduction is also actualized through health promotion materials, peer-to-peer (or drug user-to-drug user) educational efforts, and the provision of Naloxone, a drug that reverses opiate overdose, among other things. The prevention of HIV transmission through safer and more sterile injection practices was the impetus for the consolidation of harm reduction research and practice in the United States in the 1990s (Heller and Paone 2011). Since then, hepatitis C and overdose have become central concerns of the movement, along with an on-going concern over the stigmatization of drug use and drug users.

Upon beginning this research project, I had assumed that the rationality of harm reduction, with its focus on disease transmission, would be the predominant medium through which notions of drug user health were expressed. However, I quickly learned that this was not completely the case. The drug users voiced myriad other health concerns that did not align with the infection prevention interventions offered by harm reduction, and the health care practitioners spent much time talking about the disease of addiction. Harm reduction was not the singular paradigm through which health was understood.

This project addresses the following broad questions:

- How and why did the category of people who inject drugs emerge in the 1980s and 1990s? How did this function as an act of governmentality along bio-political and neoliberal lines, and what were the specificities of this act of governing power? In other

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<sup>1</sup> The term “harm reduction” can signify a variety of things from drug using techniques that reduce harm to a collectivity of people concerned with drug user rights. Unless otherwise

words, what were the particular acts of governmentality that produced and managed certain bodies through this drug user categorization?

- How do health care practitioners understand drug use among their patients who inject drugs? In what ways do health care practitioners deploy harm reduction discourse and practice? How do they discuss addiction as disease? How might differing concepts of health imply differing forms of power that manage and regulate drug using bodies?
- How have risk discourse and particularly harm reduction discourse produced concepts of health and governed the bodies of low-income people who inject drugs? How does the neoliberal logic of personal responsibility function within individual health maintenance? What can be done about health concerns that fall outside of risk discourse?

In exploring conceptualizations of health and disease, I often used the analytic frame formed by Foucault's theorization of governmentality, but this dissertation should function as more than an example of the governance of drug users. By featuring the thoughts and ideas of people who inject drugs, health care practitioners, and public health researchers, this work contests the narrow parameters of health set down by harm reduction and addiction-as-disease renderings of drug user health. The sociological analysis presented here offers to biomedical and public health research and practice an interrogation of health that goes beyond disease prevalence, risk factors, and health beliefs. By simply asking drug users and health care practitioners how they define and understand health and drug use, I was able to see the vectors of power put in motion by practices of governance. However, I also saw the effects of poverty and the domination of disease ideology. In this way, the work featured in the following chapters functions to broaden analyses of health, as well as governance.

Prior to beginning this project, I was employed as a research assistant for a public health study of hepatitis C among people who inject drugs. In this study, risk for hepatitis C was a main focus. I administered lengthy surveys that asked questions about drug use history and practices, among other things. Through this work, I began to realize that there was much more going on health-wise for the interviewees than just the possibility of risky drug use. The surveys were incredibly detailed, yet they did not cover many aspects of the interviewees' lives that could affect health, such as social and economic marginalization, which could block access to health care and put particular strains on the body. I also noticed that my attempts to provide information in a harm reduction mode, by discussing the transmission of disease and less risky drug use practices, only seemed to apply to a small corner of the drug users' lives. These individuals voiced other concerns, such as lack of housing or compassionate health care, with more urgency. These concerns played a formative role in the creation of this project, which was broadly conceived as a way to sociologically understand the self-described health concerns of economically marginalized people who inject drugs and to critically analyze the ways health care providers managed their drug using patients through discourses of health. Through immersing myself in the literature on health, drug use, and harm reduction, as well as following my interest in Foucauldian-style analysis, an image emerged of "injection drug users" as a group that had been governed and disciplined through the use of a variety of rationalities with harm reduction and addiction being key in this governance. Thus, I embarked on an exploration that would result in the work presented here.

## THE ANALYTIC SUBSTANCE

### *Lay Knowledge*



In deciding to conduct qualitative interviews with economically marginalized people who inject drugs I was building off a foundation set by decades of work in medical sociology. My initial concern for how drug users define health can be situated within a broad swath of literature that uses qualitative methods to examine “health beliefs” (e.g., Blaxter 1990; Pierret 1993; Radley and Billig 1996), or what is now called “lay knowledge” (Lawton 2003; Williams 2013). Lay knowledge as defined by Williams (2013) refers to, “... the ideas and perspectives employed by social actors to interpret their experiences of health and illness in everyday life” (p. 119). Initially referred to as “lay beliefs,” a recent transition in terminology to “lay knowledge” places more value on the perspectives offered by those outside of the medical field (Williams and Popay [1994] 2006). There is much to be analyzed within presentations of lay knowledge, from contestations of scientific expertise to reflections of current cultural values and ideological interests (Williams 2013) to declarations of normativity (Radley and Billig 1996). When people talk about health and illness they are reflecting not only their individual perspectives but also the way that society constructs these issues (Radley and Billig 1996; Werner, Widding Isaksen and Malterud 2004; Williams 2013). In asking drug users questions that might offer an outline of their conception of health, I was able to access perspectives on various socially-generated constructions of drug user health, such as that which is primarily interested in the prevention of infectious disease. Analyzing lay knowledge offers the opportunity to access different frameworks for interpreting health and illness (Williams 2013). The drug injecting interviewees offered this analytic opportunity by interpreting their health through frameworks of risk and frameworks of illness.

Qualitative research that examines the lay knowledge of people who use drugs finds that many actively seek out ways to maintain and improve their health (Drumm et al. 2005; Duterte et

al. 2001; Olsen et al. 2012). Drumm et al. (2005) found that "...street drug users do not passively accept the health consequences of use, but rather actively engage in behaviors that attempt to ameliorate damage to their health as well as behaviors specifically designed to improve their health" (p. 608). Illicit drug users' health attitudes and concerns tended to mirror those of the general population and many employ a variety of health practices, including exercising, taking vitamins and healthy eating (Duterte et al. 2001; Olsen et al. 2012). This research into attitudes about health among drug users and their participation in healthy behaviors documents the ways drug users adopt normative standards of health maintenance separate from and despite their drug use.

### *Illness Narratives*

In asking low-income people who inject drugs to talk about their health, I was offered narratives of experiences of illness, which forms another broad field of inquiry in medical sociology. In contrast to Parsons' (1951) foundational theorization of the sick role, which takes an outsider's perspective toward the experience of the patient, research that examines illness experiences takes an insider's perspective and seeks to understand the subjective meanings patients give to their illness (Conrad 2009). Examining narratives of illness "... draws scholarly attention away from medical settings and medical perspectives on disease and toward the nonmedical settings and nonmedical perspectives of everyday life" (Bell 2000: 184). The meaning of the construct of "illness" is made clearer when the distinction between disease and illness is delineated. Disease is understood as the physiological manifestation of a condition, while illness is the experience a person has with a disease (Eisenberg 1977). Investigations of experiences of illness reveal how illness is socially constructed and more specifically that "... people enact their illness and endow it with meaning" (Conrad and Barker 2010: S71). Some

prominent works in this subfield of study have examined how people make discoveries about the self in illness (Charmaz 1999), how illness can function as a biographical disruption (Bury 1982), how social movements and disease regimes impact the illness experience (Klawiter 2004), and how sufferers might evoke the trope of heroically fighting their chronic illness (Kelly and Dickinson 1997). The study of illness experience is linked to the “narrative turn,” whereby knowledge is constructed through the telling of stories. The telling of illness narratives reveals that there are multiple truths constructed by knowers who are socially and historically located (Bell 2000). In relating narratives of illness, patients are often making efforts to “integrate or reintegrate [themselves] into their social worlds” (Bury and Monaghan 2013).

As mentioned, I encountered illness narratives when I spoke to drug users about their health, which served to show that their sense of health was not immediately related to the concerns of the harm reduction movement (such as risk for HIV/AIDS and hepatitis C). Rather, they were struggling with illness in settings of poverty that worsened their conditions and made efforts to address their health difficult. There has been some concern that sociologists’ depictions of illness narratives do not examine the ways social structure impacts the experience of illness (Pierret 2003). My analysis of illness narratives in chapter five addresses this concern by opening up a discussion of the potential for structures of inequality to provoke and worsen illness.

Research into the illness narratives of drug users who are positive for hepatitis C has found that they can express a sense of unconcern about their hepatitis infection, which may be related to desensitization to the health problems it poses due to the high prevalence of this infection among injectors (Harris 2009; Olsen et al. 2012). Some individuals may feel they have bigger and more immediate problems than their hepatitis C infection (Olsen et al. 2012). Whether hepatitis C presents a biographical disruption in the lives of drug users is contextual and

may depend on previous experiences of illness, marginalization, and hardship (Harris 2009). Similarly, it has been found that, in relation to other traumatic life events, HIV infection may not be as devastating a biographical disruption as might be expected (Ciambrone 2001). Illness experiences are, indeed, embedded within particular local contexts, broader social structures of inequality, and individual life course trajectories that mediate the meanings and level of importance individuals assign to their illness.

### *Social Inequality and Health Disparities*

More than impacting the meanings assigned to health and illness, social inequality has been linked to disparities in health. It has long been known that lower socioeconomic status is associated with ill health (Adler and Ostrove 1999; Link and Phelan 1995) and that poverty is associated with higher mortality rates (Menchik 1993; Haan, Kaplan and Camacho 1987). Warren and Hernandez (2007) report that researchers have recognized links between socioeconomic status and aggregate morbidity and mortality rates for nearly 200 years. In their fundamental causes theory, Link and Phelan (1995) argue that social factors such as socioeconomic status and social support are fundamentally linked to health because they allow access to important resources, and that this fundamental link will stay intact despite interventions to reduce proximate risks for disease. Warren and Hernandez (2007) tested the temporal endurance of this fundamental link across the 20<sup>th</sup> century, and found that socioeconomic gradients in morbidity and mortality declined only modestly. In their exposition of Link and Phelan's (1995) theory, Freese and Lutfey (2011) affirm that any study of disease risk factors must be placed in a larger context of history and inequality. Link's (2008) "social shaping of population health" approach proposes that the success of advances in medical technology and knowledge is unevenly distributed, such that those with more resources of knowledge, money,

power, prestige, and beneficial social connections benefit more from these advances. He emphasizes the importance of social processes in determining “whether health-relevant information and technology is effectively deployed and how long it takes to spread through populations” (Link 2008: 379). Link (2008) cites health disparities based on race, level of education, and family income and avers that health-enhancing discoveries will result in a “powerful social shaping of health disparities” (p. 374). Clarke et al. (2010) refer to a similar concept--“stratified biomedicalization”--where the benefits of biomedicalization, a process that refers to the co-construction of biomedicine by advances in technoscience, commodification, risk surveillance, and medical enhancement, are unequally distributed and “may exacerbate rather than ameliorate social inequalities along many different dimensions” (p. 29).

Trying to figure out the social factors that may lead to population-level health disparities is a major preoccupation of medical sociologists. The stress paradigm (Pearlin, Aneshensel and Leblanc 1997; Thoits 2006; Umberson, Liu, and Reczek 2008) has aided in explaining how upstream social and psychological factors, namely those related to stress and stress proliferation, may be associated with negative outcomes in mental and physical health. Those living in situations of economic and social marginalization may experience levels of stress that ultimately impact their physical health and leave them vulnerable to illness.

Cumulative disadvantage over the life course can help to explain disparities in well-being and health at the population level, as well. First emerging as a way to understand heterogeneity among cohorts (Dannefer 1987), cumulative disadvantage theory posits that disadvantages (or conversely, advantages) may compound over the life course and lead to worse (or better) outcomes in various areas, including health (Ferraro and Kelley-Moore 2003). The chain of compounding disadvantages may be difficult to disrupt with evidence showing that even early

life military participation, an activity that could plausibly improve one's life chances and health outcomes, may not provide benefits concerning mortality later in life (London and Wilmoth 2006). Depictions of processes of cumulative disadvantage were present in my interviews with low-income people who inject drugs, as they often started out economically disadvantaged in life and through a compounding series of hardships and barriers to resources ended up living in destitute situations that made caring for their health difficult.

### *The Doctor-Patient Relationship*

Another way health may be impacted by social inequality is through the doctor-patient relationship. This relationship can be experienced as difficult for both low-income drug injectors and their health care providers due to mutual mistrust (Merrill et al. 2002), practitioner ignorance and prejudice (Brener et al. 2010; Ding et al. 2005; Edlin et al. 2005; Paterson et al. 2007, Weiss et al. 2004), and patient fear and anxiety in anticipation of poor treatment (McCoy 2005; Merrill et al. 2002). Removing drug use from the picture, incongruities in class background can hinder communication between patient and doctor, with economically marginalized patients tending to be more passive in their interactions with doctors (Cockerham 2004). Though the professional authority of physicians may have been tempered by payment structures such as managed care organizations (Heritage and Maynard 2006; Waitzkin 2000), hospital physicians still develop methods to "get rid of patients," especially undesirable or difficult ones (Mizrahi 1985), and may discharge low-income drug users before they are fully healed (Bourgois 2010). These efforts are not completely explained by the attitudes and prejudice of physicians, as there exist institutional financial pressures to limit the care patients receive (Bourgois 2010; Mizrahi 1985). However, careful examination of doctor-patient relationships has found that physicians may communicate normative standards of healthy living when treating drug-using patients and ignore the social

contexts of drugs use, choosing instead to direct the conversation on a technical track. In this way, physicians exercise an almost hidden form of social control by implicitly encouraging patients to adapt to the social contexts that may be the cause of their trouble (Waitzkin 1991).

Health care practitioner ignorance and prejudice regarding people who use drugs may provide underlying reasons for drug user avoidance of health care (Weiss et al. 2004). Some physicians hold negative attitudes toward people who inject drugs (Ding et al. 2005) and may feel that they should be able to control their drug use (Brener et al. 2010). While it has been found that doctors with more experience caring for people who inject tend to express more favorable attitudes toward these patients (Brener et al. 2007; Ding et al. 2005), it has been hypothesized that more contact might cause physicians to expect negative behavior, such as lack of adherence (Edlin et al. 2005; Paterson et al. 2007).

Ethnographic research has revealed hospital staff disparagingly referring to patients who inject drugs as “frequent fliers” and using them as teaching tools, since the surgical removal of abscesses provide a good teaching opportunity for interns (Bourgois 2010: 242-7). Other qualitative research found that doctors expressed discomfort and uncertainty in caring for these patients. They were fearful of deception by drug using patients, and thus avoided conversations about pain in order to preclude any patient requests for opiate-based pain medication (Merrill et al. 2002). A lack of standardized medical approaches to providing care for patients who inject drugs may be responsible for some of their discomfort (Merrill et al. 2002). On the other side of the doctor-patient relationship, it has been found that drug users experience fear and anxiety in anticipation of the interpersonal and medical treatment they will receive (McCoy 2005; Merrill et al. 2002). As I discuss in chapter four, the health care practitioners I interviewed expressed concern for the compassionate treatment of their drug using patients and used the disease model

of addiction to de-stigmatize drug use when speaking to their patients, as well as other medical professionals. Though I was not able to directly observe the doctor-patient relationship in my fieldwork, I asked questions of both low-income drug using interviewees and health care practitioner interviewees that revealed aspects of this relationship and how drug user health was constructed through doctor-patient interactions.

Through analyses of lay knowledge, illness narratives, the social structural dimensions of health, and the doctor-patient relationship, I was able to begin seeing an outline of the diffuse technologies of power at work in discourses of health mobilized by economically marginalized people who inject drugs and health care practitioners. Accounts of what health means given by both groups of interviewees revealed when and how harm reduction discourse governs thoughts and practices. Narratives of illness offered by people who inject drugs revealed times when harm reduction discourse did not provide a vocabulary for discussing health. Through these articulations of experiences of illness, I was able to see direct links between poverty and ill health, and how a variety of cumulative hardships could render care of one's health nearly impossible. Asking health care practitioners to describe how they understand their drug-using patients' actions and how they related to them during medical visits, showed that discourses of harm reduction and addiction as disease and the practices associated with these approaches were present in these interactions. This accumulation of observations led to the use of governmentality as a theoretical lens for understanding how power flowed through definitions and enactments of health by way of the pre-packaged discourses of harm reduction and addiction as disease. Of course, these discourses did not appear out of thin air. They were created by activists, scientists, scholars, health care practitioners, people who use drugs, and many others who work in a variety of contexts from bureaucratic institutions to the streets of New York City. And, they were



certainly not created as mechanisms specifically for the deployment of power over people who use drugs and health care practitioners. However, as discourses with certain vocabularies of reason and ideology, they have come to produce and modify the thoughts and actions of drug users and doctors as they construct their own notions of what health means and how it might be medically addressed.

## HISTORICAL CONTEXTS

### *Health as Risk*

People who use drugs by injection came into sharp focus as a particular type of drug user in the 1980s when they were identified as a risk group for AIDS, though at the time the illness did not have a formal name yet. As epidemiologists and other public health workers tracked the dynamics of the disease's transmission, they divided its sufferers into risk categories that were to take on a preponderance of cultural meaning, mostly negative. The act of risk categorization enabled a proliferation of research studies that in seeking to understand the cultural characteristics of people who inject drugs also proposed ways to govern these individuals to abate disease transmission. These governing activities, which produced the "injection drug user," took place within a social context that was beginning to define notions of health with reference to risk and evoke morality in the maintenance of health through the securing of risk.

While the imperative of health has been present in U.S. society since at least the 1700s, when Protestant culture began to focus on concerns of the material (rather than spiritual) world, its urgency and range has gradually increased, such that health is now a "super-value" connected to personal responsibility and an expansive moralization (Crawford 2006: 410). How did we arrive at such a frenetic state? Clarke et al. (2010) describe a process of biomedicalization wherein the concept and practice of health is multiply-constructed by the life sciences,

biotechnology, pharmaceutical development, and capital. In an atmosphere of “market medicine,” patients are refashioned as consumers who demand the right to consume health (Patton 2010:xiii). Just as consumption within advanced capitalist economies becomes intimately tied to identity (Reith 2004), health as a perpetually out-of-reach status also becomes intertwined with identity (Crawford 2006). In fact, so much so that social groups are formed based on health status and biological characteristics (Rabinow 1996) and claims of citizenship are made (Petryna 2004).

Health’s connection to morality and identity was underscored by the swing towards personal responsibility instantiated by the neoliberal turn of the 1970s, which effectively dismantled a burgeoning political impetus toward universal health care (Crawford 2006). This individualizing trend made it possible to blame those whose health status had been negatively impacted by socially structured inequality. Berlant (2007) couches the act of blame within networks of power: “Biopower operates when a hegemonic bloc organizes the reproduction of life in ways that allow political crises to be cast as conditions of specific bodies and their competence at maintaining health or other conditions of social belonging; thus this bloc gets to judge the problematic body's subjects, whose agency is deemed to be fundamentally destructive” (p. 765). In discussing the “crises” of obesity, Berlant (2007) points to a politicized practice of mischaracterizing morality and agency with respect to populations of workers caught up in the demands of economic speed-up in late capitalism. In summarizing the implications of current conceptualizations of health, Metzl (2010) writes, "... 'health' is a term replete with value judgments, hierarchies, and blind assumptions that speak as much about power and privilege as they do about well-being. Health is a desired state, but it is also a prescribed state and an ideological position" (pp. 1-2).

It is clear from previous research, which documents the pro-health activities of drug users (Drumm et al. 2005; Duterte et al. 2001; Olsen et al. 2012), as well as that presented here, that people who inject drugs are affected by and participate in this moral economy. Those living in conditions of social and economic marginality still take responsibility for maintaining a healthy lifestyle and still manifest personal responsibility when dealing with ill-health produced in many instances by structured vulnerability. Many of the interviewees made efforts to highlight their personal ethics by discussing their careful attempts to maintain their health and minimize health risks. For instance, most interviewees made it clear that they had taken very few risks when injecting drugs and that they made attempts to seek medical care, though these attempts were not always successful.

Angela, a 29-year-old white woman who injects methadone, provides an example of how she works to protect her health while injecting. Her statement also provides an example of how lay knowledge may reveal perceptions of social values. Angela felt there was irony in her efforts to inject methadone safely. In describing the caution she takes in selecting the formulation of methadone she will inject, she said: “Every [methadone] program besides the one I'm on, which is great that I'm on this one, actually puts water in [the methadone they distribute]. I wouldn't do it if it had water in it because water has minerals and all this other stuff. It sounds stupid, I know, coming from someone like me.”

The moralized personal maintenance of health also has roots in a contemporary notion of health as being composed of a conglomeration and calculation of risk factors that necessitate personal monitoring. A calculus of risk factors has come to stand in for health in biomedical and epidemiologic contexts and subsequently the interpersonal relationship between patient and doctor has transformed into matrices of risk (Castel 1991; Dumit 2012). On the individual level

this means that health is determined by quantitative and qualitative measures of risk for future ill health. On the population level health is ascertained through surveillance, which works to conceptualize and standardize risks that in turn rationalize more surveillance (Clarke et al. 2003). The constant proliferation of risks generates a sense of insecurity that becomes normalized—“To be normal, therefore, is to be insecure. . .” (Dumit 2012: 1). Originally conceived as a category of individuals at risk for HIV/AIDS, people who inject drugs are therefore inherently located within a risky and insecure state. Harm reduction places their risk for disease transmission at the center of its mission though the drug users themselves may voice health concerns other than the risk for HIV/AIDS.

A focus on risk factors as indicative of health also bears connection to the neoliberal rhetoric of personal responsibility. A focus on risk factors compels individuals and populations to participate in self-care practices, which moderate the burden of individuals on society (Petersen 1997). Risk plays a crucial role in neoliberal societies by employing the agency of subjects in their own self-regulation (Petersen 1997). This is precisely the task of what Petersen and Lupton (1996) identify as the new public health, which focuses on the environment (in its broadest sense) and lifestyle as sources of risk. Thus, people whose lifestyle includes the use of drugs by injection are enjoined to self-regulate based on the presence of risks. While risk ostensibly gives people a choice, “. . . the rhetoric in which the choice is couched leaves no room for maneuver” (Lupton [1993] 2013: 492). Given this “duties discourse” and the presence of scientifically-generated risk factors, “. . . ‘health’ has come to be used as a kind of shorthand for signifying the capacity of the modern self to be transformed through the deployment of various ‘rational’ practices of the self” (Petersen and Lupton 1996: xiv). Indeed, harm reduction

has offered drug users the ability to transform one's self into an ethical drug user through practices that address health by lowering risk.

In the context of risk proliferation and its meaningful hold over “health,” a drug user who chooses to inject, and is thus considered “at-risk” for infectious disease, could be perceived as inherently unhealthy. The creation of the “injection drug user” risk category is certainly indicative of reformulations of the meaning of health to include risk factors. However, as my research will reveal, the health of this group was complicated by concerns beyond their status as a group at risk for contracting HIV/AIDS. By asking low-income drug users, as well as health care practitioners who care for them, to put forth their own understandings of health, this dissertation interrogates and in some ways contests a reliance on risk factors as signifiers of health status.

### *The Emergence of a Risk Category*

It is within this context of the reconceptualization of health as connected to risk that the “injection drug user” came into view in the early 1980s as a risk group for AIDS. When the Centers for Disease Control (CDC) released its first report on AIDS in 1981, drug use researchers had been suspecting for several years that some type of ailment was impacting people who inject drugs as they were seeing a rising number of pneumonia-related deaths (Des Jarlais 2009). Prior to AIDS, it was clear to public health workers and injectors alike that hepatitis B was spread through the sharing of needles. This knowledge was applied to the new condition, referred to as “walking pneumonia,” and injectors began to adjust their drug use practices (Des Jarlais 2009; Des Jarlais, Friedman, and Hopkins 1985). Beyond their association with hepatitis B, people who used drugs by injection had not received much attention as a coherent group by researchers. Most of the prominent social science literature on drug use before

HIV/AIDS focused on the type of drug used or simply on “addicts” (e.g., Agar 1973; Becker 1963; Feldman 1976; Preble and Casey 1976).

Using an epidemiological approach, the CDC developed a risk group schematic to organize the sufferers of AIDS and in doing so created the category of people who inject drugs. By creating such a schematic the CDC contributed to an understanding of the disease that placed the onus of infection and transmission onto certain groups of people (homosexual men, drug injectors, Haitians, among others) regardless of whether they participated in practices that could lead to infection (Glick Schiller, Crystal and Lewellen 1994; Oppenheimer 1988). Although the language of the risk group label has shifted over the last three decades, the categorization of people based on injection has persisted.

Beginning in 1984, this group began to have a salient presence in the public health research literature, initially being referred to as “intravenous drug abusers,” which reveals the moral shading of the risk group by use of the word “abuser.” Through examining the popular research literature, a process of construction and governance is revealed, as the person who injects drugs is surveilled, described, and subjected to behavioral interventions. Early literature puts forth a concern that people who inject drugs will spread AIDS to their non-injecting sexual partners and children (Des Jarlais, Friedman, and Hopkins 1985; Ginzberg 1984; Marmor et al. 1984), thereby setting up a boundary around this group and placing them in opposition to two socially-sanctioned groups—non-injectors and children. Also, in these early articles, researchers hesitantly propose that AIDS is spread between injectors through sharing needles and other injection related materials (Ginzberg 1984; Marmor et al. 1984). These nascent ideas present pathways of intervention that demonstrate the early stirrings of governmentality by highlighting individual-level, malleable behaviors.

In 1986, literature began to appear that outlined the cultural traits of the “subculture” of people who inject drugs. An air of hopelessness was present as researchers described the social bonding that needle sharing enabled among injectors (Des Jarlais, Friedman, and Strug 1986; Friedman, Des Jarlais and Sotheran 1986). The act of describing these cultural traits functioned as a way to further delineate this group, and thus allow for more relevant governing. In fact, simply focusing on injection drug using culture and lifestyle opened a surface upon which interventions could spread.

The literature that followed in 1987 and 1988 focused more precisely on behavior change, both that initiated by public health workers and that initiated by people who inject drugs. People who inject drugs were now thought to be fully malleable, and thus were subjected to behavioral interventions aimed at preventing the transmission of HIV/AIDS. In one proposed behavioral change framework, an aim was to attach new cognitive and emotional meanings to sharing needles (Des Jarlais and Friedman 1988), thus revealing that behavior change went below the surface of the body to modify people’s thoughts and emotions. Behavioral interventions were also becoming more widespread as the federal government provided wide scale funding to support a research endeavor, the National AIDS Demonstration Research project, which assigned research participants to risk reduction interventions (Page and Singer 2010).

Around this time, people who inject drugs were beginning to advocate for themselves and push to legalize syringe exchange. Though public health researchers had supported and in some instances worked to initiate these efforts (Friedman et al. 1987), people who inject drugs were now fashioning themselves as self-advocating and self-governing subjects. Linking their identity to civic responsibility, these activist injectors exemplify a neoliberal cultural rationality that

connects personal goals to “the public good” (Petersen 1997: 203). By supporting and collaborating with current and former drug users, researchers realized they could spur self-governance among this group. Through the interplay of research activities and grassroots actions, the image of the person who injects drugs as an activist began to form.

The loosening in some localities of restrictions on syringe possession also worked to fashion the person who injects drugs as self-governing. With fewer legal restrictions to hamper injection drug use, injectors were offered more autonomy, though this was buttressed with expectations of self-regulation. Key research in the early 1990s that critiqued earlier fixations on pathological drug user culture by noting that people share needles because the legal system impedes access to new syringes, as well as the ability to carry syringes (Koester 1994), implies the reduction of regulations over injection drug use. Despite their socially marginal status, the person who injects drugs was being swept into the current political and economic impulse to make individuals responsible for maintaining their health by identifying risks and securing them.

Later research of the 1990s and early 2000s acted to expand bio-political and governing power over this subject position by focusing on a new concern—hepatitis C—and re-organizing the risk category. The high prevalence of hepatitis C among people who inject drugs caused concern for the economic burden this might pose to our health care system (Edlin et al. 2005) and brought forth new types of surveillance and behavioral intervention. Concurrently, findings from public health research revealed that the HIV prevalence of people who use heroin and cocaine but do not inject is similar to that of those who do inject (Des Jarlais, Arasteh and Friedman 2011). With this in mind, researchers began to focus on the non-injection drug user, NIDU, and, going further, suggested that people who inject drugs and people who use drugs by other means be combined into one risk category. This serves to consolidate certain types of bio-



political power over drug users as a whole and thus, refashions the early risk group schematic put in place by the CDC.

It is at this precarious moment for the “injection drug user” risk category that my research project began. Noting the potential insufficiency or irrelevance of the grouping of drug users I had chosen to study, I asked the health care practitioners if this categorization was relevant to their work. Most said that it was meaningful to the care they provided patients because this type of drug user had heightened risk for HIV/AIDS and hepatitis C. However, one health care practitioner, Christine, felt that this categorization was not necessary. When asked about the services her facility provides for people who inject drugs, she replied: “I am sort of curious why this separation of people who inject drugs? I see this as a very academically derived group because from the bottom I don't see that as a very distinct group.” She went on to explain that she screens all of her drug-using patients for HIV and hepatitis figuring that it’s likely they injected at some point. Taking into account Christine’s viewpoint, along with current findings on HIV prevalence and drug use, it must be noted that a degree of ambivalence has emerged with regard to the salience of this risk category. The research and interventions that once focused on people who inject drugs may now be expanding to touch all drug users and thus, continue the perpetual formation and re-formation of categories for governance.

### *Harm Reduction*

Following alongside the emergence of the “injection drug user” in public health research were gradual efforts by activists to implement harm reduction’s foundational intervention—syringe exchange. The first, albeit illegal, syringe exchange in the United States emerged in 1983 in New Haven, Connecticut when Jon Stuen Parker, a medical student and former heroin user, began to distribute syringes (McLean 2013). This coincides with early appearances of the

“intravenous drug abuser” in public health research literature. However, harm reduction’s roots are often traced to the 1970s formation of the *Junkiebond*, or Junkie League, of Rotterdam, which functioned as a type of trade union with an orientation toward drug user rights (Marlatt 1996). Though input from the *Junkiebond* stimulated the Dutch movement toward a “pragmatic” and “humane” approach to stemming the AIDS epidemic among injectors, the initial goals of the *Junkiebond* were much broader. As stated in Marlatt (1996), Wijngaart (1991) explains:

The starting point of the “Junkiebond” is to look after the interests of the drug users. The most important thing is to combat the deterioration of the user or, to put it another way, to improve the housing and general situation of the addict. Their philosophy is that drug users themselves know best what their problems are. The work of the “Junkiebond” involves consultations with government officials about matters like the distribution of methadone, the availability of free sterile syringes, the policy of the lawmakers and police, and housing problems (p. 39).

The inclusion of housing and the “general situation of the addict” in the concerns and mission of the *Junkiebond* is instructive for understanding the roots of harm reduction and how the movement differs in its purpose in the United States. The initial approach of the *Junkiebond* was political and service oriented, interested in drug user rights and basic needs.

The term “harm reduction” was subsequently coined in Liverpool, Merseyside, England in the early 1980s as health officials responded to a moral panic over heroin use and HIV/AIDS. In this setting and as applied by health authorities, harm reduction became more institutionalized and public health-oriented. McLean (2013) explains: “Where the Rotterdam union framed its mandate in terms of users’ rights, Merseyside health officials emphasized the public health and public order benefits of harm reduction...” (p. 22). Positioning harm reduction securely under

the auspices of public health authorities has shaped its practices and politics ever since, and further cemented a disconnection from the movement's anarchist roots (Smith 2012; Stoller 1998). The institutionalization of particular components of the harm reduction approach, mainly those having to do with interventions into the techniques of drug injection, steered the movement away from its earlier mission of mutual aid and an expansive approach to bettering the general situation of the drug user.

Harm reduction's importation to the United States occurred soon after its christening in Liverpool with Jon Stuen Parker's illegal needle exchange in New Haven (McLean 2013). In New York the powerful presence of the AIDS Coalition To Unleash Power (ACT-UP) aided drug user activists in their attempts to establish legitimate syringe exchanges through public and controversial direct action techniques (Lune 2007). This connection to ACT-UP is perhaps partially responsible for the harm reduction movement's emphasis on HIV/AIDS prevention to the detriment of the earlier mission to improve the general situation of drug users. Further, as Heller and Paone (2011) note, "... 'winning' arguments for the expansion of syringe access have been rooted in the crisis of HIV/AIDS, rather than the need for a continuum of care and treatment services addressing problems of drug use" (p. 140). Preventing the spread of HIV/AIDS was and continues to be the catalyzing force behind harm reduction activities in the United States, which limits the possibilities for this movement to address other causes of ill health among drug users, such as structured inequality.

The first legal syringe exchange in New York City was piloted in 1988 by the Department of Health and did not involve people who inject drugs or their advocates in its planning or implementation, though it had come about in part due to pressure exerted by activists involved with the Association for Drug Abuse Prevention and Treatment (ADAPT), the first

HIV/AIDS community-based organization in New York City committed to harm reduction (Anderson 1991; Heller and Paone 2011; Lune 2007). Two years were spent planning and redesigning what was initially conceived as a clinical trial to test the efficacy of syringe exchange in the prevention of HIV transmission (Anderson 1991). The supposed objectivity of medical research was mobilized as a means to sidestep contentious policy debate over syringe exchange (Anderson 1991). Unable to secure a more suitable location, the clinical trial pilot syringe exchange program was located at the Department of Health headquarters across the street from One Police Plaza (Anderson 1991). A myriad of restrictions were placed on the practices of this syringe exchange by city officials concerned about the possibility that access to syringes might spur increased injection drug use (Anderson 1991). Potential participants were accepted on referral from drug treatment programs to ensure that participants were not new users. Further, participants had to carry photo ID cards identifying them as injection drug users and submit to medical exams that included blood testing. The blood within returned syringes was tested to ensure that no participants had shared their syringes with others (Anderson 1991; Lune 2007). Attendance was low at this syringe exchange and after a year it was closed when a new mayor, David Dinkins, was elected and brought with him a health commissioner “ideologically opposed” to syringe exchange (Anderson 1991).

After the closure, three channels of organizational activity—ACT UP, ADAPT, and John Stuen Parker along with Rod Sorge—forged the way toward legitimating syringe exchange by operating illegal, underground syringe exchanges. In 1990 eight activists, who became known as the “needle eight,” arranged for their arrest by taking out an ad announcing their intent to distribute clean needles for free in the Lower East Side of Manhattan. Their arrest initiated a major court challenge to the State law criminalizing needle possession (Heller and Paone 2011).

The eight defendants were acquitted on the basis that their syringe exchange activities constituted a “public health necessity.” This ruling along with findings from a New Haven study on the effectiveness of needle exchange in the prevention of HIV, eventually led to the establishment of the syringe exchange waiver system whereby programs gain exemption from the legal requirement for prescriptions in the dispensing of sterile injection equipment (Heller and Paone 2011; Lune 2007). The waiver system is still in use today though syringe exchange remains illegal at the federal level. There are currently fourteen syringe exchange programs operating in New York City.

Syringe exchange focuses on a singular concern of injection drug use—injection practices that can lead to illness and injury. While harm reduction centers typically offer social services, meals and basic supplies such as soap and socks in addition to syringes by exchange, the harm reduction movement in the U.S. has largely maintained a focus on narrow public health interventions which do little (if anything) to address the structural inequality that leads to risk vulnerability and poor health among economically and socially marginalized drug users. In part SEP administrators hesitate to pursue more progressive or radical approaches to improving the general situation of the drug user because syringe exchange is politically unfavorable and administrators fear losing the minimal resources they do have, if they were to push the envelope (Lune 2007: 99).

The continued framing of harm reduction as a public health approach has disconnected it from its more radical roots. Smith (2012) writes “...the resultant disconnect between contemporary public health policy and the oppositional roots of harm reduction practice has sanitized the latter, actively drawing attention away from the role of structural factors underpinning the phenomena of drug dependence” (pp. 209-210). Describing the founding

philosophy of harm reduction as reflecting anarchist values and practice, Smith (2012) states, "... harm reduction discourse might therefore be seen as a disguised language developed to describe an emergent anarchist model of care for capitalism's most oppressed, yet symptomatic victims" (p. 213). Smith's commentary and analysis of the current state of harm reduction in North America exhorts us to look back to the roots of harm reduction for guidance in re-shaping the movement into one that addresses the holistic concerns of drug users and the structural roots of their oppression.

Through its efforts to improve and recast the health of drug users, harm reduction is a manifestation of governmentality that regulates and normalizes bodies and creates subjectivities by implicating people who inject drugs in technologies of the self. Through harm reduction health promotion campaigns, people who inject drugs are instructed to take care of themselves by refusing to share needles and following sterile techniques of injection that involve alcohol swabs and new tourniquets among other items (Fraser 2004). In many ways, those laboring under the banner of harm reduction, researchers and activists alike, helped to produce the "injection drug user" subject who enacts an ethical identity through self-governance. In particular, ethnographers participating in federally-funded HIV prevention research helped to create this subject position by isolating behavioral factors of HIV risk and offering instruction on safer injection techniques as they conducted research (Campbell and Shaw 2008: 696).

The governance of drug users through harm reduction policies and practices works in part through a reformulation of the discourse around drug use. Drug use is recast as a normal activity, but with a preferred range of behaviors and actions (O'Malley 1999). Through this normalization, illicit drug users are enjoined to self-govern so that their drug using practices fall within the range of acceptability. In this way, the will of each individual drug user is aligned to

the project of harm reduction (McLean 2011; O'Malley 1999). Since much of the knowledge produced through harm reduction research efforts relies on risk calculations, drug users are enticed to accept harm reduction educational interventions through their appeal to truth by way of probabilistic statistics (O'Malley 1999: 196). The production of statistics indicates that harm reduction is a bio-political project with an interest in health and vitality on the population level, as well as on the level of the individual (McLean 2011).

Harm reduction interventions interpellate certain types of drug using subjects. As technologies of the self, rituals of needle exchange and safe injection may positively influence drug user subjectivities (Fraser 2004; McLean 2011). Situated in a neoliberal context of individual responsibility, harm reduction practices allow drug users to assume a subject position that aligns with the prevailing culture of regulated self-care (Fraser 2004). For example, needle exchange programs shape drug users' subjectivities by labeling them as "clients" and positioning them as rational subjects interested in preserving their health (McLean 2011: 76). Harm reduction fashions the illicit drug user into both a "biomedicalized drug user" and a "public health citizen" (Vitellone 2010: 872). Drug users are also positioned as ethical subjects who are interested in "doing the right thing" in terms of their own drug use practices, as well as through those of others, through proscriptions of needle sharing (Campbell and Shaw 2008; Vitellone 2010). Drug users may perform their ethical subjecthood through answering questions about their drug use practices by resort to standard harm reduction mantras (of never sharing needles or always cleaning needles with bleach, for instance) despite not always being able to follow prescribed harm reduction behaviors (Campbell and Shaw 2008).

Much of the governmentality exhibited by harm reduction occurs through the paradigm of the biomedical. As Roe (2005) sees it, harm reduction is now defined by medical programs,

professionals, and policies, which puts it at odds with those who see harm reduction as a platform for broader and more structural social change. There are in fact two camps within harm reduction—the medical, which focuses on the individual and the promotion of health, and the activist, which decries the medicalization of social problems (Roe 2005). However, it appears that “medical” harm reduction is winning the battle to define harm reduction, in part, perhaps, because the medical approach aligns nicely with neoliberal efforts to reduce societal costs by enjoining individuals to self-regulate (Roe 2005; Smith 2012). There has been a call from the activist formulation of harm reduction to refocus the movement’s efforts on the structural causes of harm (Smith 2012) and the effects of damaging policies, such as drug prohibition (Roe 2005). McLean (2011) makes the case for an inclusive effort by both harm reduction camps: “An investment in the health of IDUs—and drug users at large—is not incompatible with a broader concern for social justice, the macro-level determinants of drug use and addiction, and the larger context of risk” (p. 78). These calls function to counter the individualizing effects of the governing rationality of harm reduction by drawing attention to the systematic and structured inequalities that produce vulnerability, risk, and harm. In chapter five, I echo these calls with regard to inequitable access to resources that support health.

### *The Disease Model of Addiction*

While harm reduction may have offered an alternative way to think about drug use, the disease model of addiction is still very much present in explanations of drug use. By referring to certain practices of illicit drug use as diseased, this model is pertinent to conceptions of drug user health. Most of the health care practitioners I interviewed referred to addiction as a disease or at least discussed the neurological qualities of drug use. Thus, it was revealed to me as I conducted my interviews that harm reduction, along with its focus on infectious disease, was not the only



way health care practitioners understood the health of their drug-injecting patients. Many of them were concerned with the disease of addiction and the way it disallowed their patients from resisting drug use. The absence of agency that this disease entails runs counter to the creation and bolstering of autonomy evident in harm reduction education and interventions. Despite this apparent contradiction, the health care practitioners expressed no dissonance in their support of both harm reduction and the disease model of addiction.

Dating back to at least the early 19<sup>th</sup> century, the notion that addiction is a disease or disease-like was initially put forth by the temperance movement, which located the source of addiction in the drug or substance itself (Levine 1978). Toward the end of the 19<sup>th</sup> century, through a convergence of interests between the industrial state and the medical profession, the notion of addiction as a disease of the will appeared. This was a “moral-medical” model rooted in the need for productivity, labor discipline, and self-regulation during industrialization. At this time, the loss of control evident in excessive consumption was seen as “anathema to reason” and understood as a “clear threat to the moral and political order of industrial society” (Reith 2004: 288). Evidence of the effort to locate addiction in the individual body (Levine 1978) is provided by prohibition-era, federally-funded research that pointed to psychopathology and personality disorders as the root causes of addiction (Courtwright 2010: 139). The disease concept of addiction gained further traction through the Addiction Research Center, a congressionally mandated narcotics rehabilitation and research farm that opened in 1935 and supported research into the physiological components of addiction (Campbell 2007). Methadone maintenance treatment, which was developed in the 1960s through a system of clinics, also served to support the disease model of addiction by using a so-called medication to aid addicts in stabilizing their lives and their relationship to opiates. The idea behind methadone treatment was partially based

on the belief that opiate addicts created a permanent biochemical change in their physiology (Conrad and Schneider 1992: 135).

Current understandings of the disease of addiction center on the brain and construct narratives of brain activity that involve chronic relapse and permanent or semi-permanent neurochemical changes. This iteration of the disease model is referred to as Chronic Relapsing Brain Disease (CRBD) and considered the “NIDA paradigm,” NIDA being the National Institute on Drug Abuse (Dingel, Karkazis, and Koenig 2011). Strongly tied to elaborations in technoscience and institutional structures, the application of neuroscience to the study of addiction (Campbell 2010; Hammer et al. 2013; Vrecko 2010) produced an “expansion of the biological” that displaced previous distinctions between physical and psychological drug dependence (Keane and Hamill 2010: 55-6).

Despite addiction’s firm grounding in medical and biological discourse, social and cultural critics point out that it remains, at least in part, a social and cultural construct. Keane (2002) reminds us that a medical framing of addiction still has social normalization and improvement as its goal. A disease rendering of addiction relies upon culturally constructed parameters of addictive desire and behavioral practice that reinforce norms and allow addiction to be seen in the body (Keane 2002; Kaye 2012a). Violations of norms of consumption are linked to an ambivalent notion of freedom apparent in the neoliberal, cultural construction of the subject, wherein the individual is enjoined to act freely, but within certain limits. Addiction, or a culturally constructed notion of addiction, is one of these limits (Reith 2004). Keane (2002) affirms that our notion of addiction is tied to “a particular notion of the unique and autonomous individual” (p. 6). While it is important to recognize the potential usefulness of biological information or even biological intervention in responding to addiction, we must “. . . re-situate

these material possibilities in relation to cultural and political realms that socially materialize the biological and bring it ‘to matter’” (Kaye 2012a: 43).

While addiction was discussed primarily as a disease by the health care practitioner interviewees in this project, it must be pointed out that the complete medicalization of addiction has not yet occurred (Campbell 2013; Courtwright 2010; Tiger 2013). Many people who use drugs are punished by the criminal justice system and/or become involved in 12-step addiction treatment regimes (Tiger 2013). Furthermore, the adoption of the disease model has been resisted by some social scientists, police, and political actors (Courtwright 2010). None of the people who inject drugs that I interviewed described their drug use as a disease. I did not ask them direct questions about this association, nor did I directly ask the health care practitioners if they thought addiction was a disease. It is likely their professional position and medical training disposed them to this way of understanding addiction. Exploring the way drug use is understood as a disease by health care practitioners and what this implies for technologies of power that address people who inject drugs is a goal of the exploration of “health” in this project.

## THEORETICAL CONTEXTS

Much of the work in this dissertation is informed and supported by a general theory of governmentality, a concept that emerged as a way to analyze the rationalities, practices, mentalities, and art of governance. I see low-income people who inject drugs as governed in particular ways by particular discourses of health. Some of the specificities of their governance engage other forms of power identified by Foucault, such as bio-politics and anatomo-politics. The current logic guiding the acts of governance observed in this dissertation can partially be explained by the neo-liberal turn in the 1970s, which instilled the rationalities of personal-responsibility and self-governance in individuals. However, there are times and places where the

governance of drug users falls outside of this logic and edges toward top-down disciplinary power. In this section, I contextualize and explain the theories that grounded my analyses.

### *Governmentality*

Akin to Foucault's quest to outline the technologies of power that manifested in the practices of psychiatry and penology and the identification of sexuality, the concept of governmentality allowed Foucault (2007) to conduct an analysis that sought to move "outside of the state" in order to envisage "an encompassing point of view with regard to the state as there was with regard to local and definite institutions" (p. 118). In some ways, the broad and general technology of power that materializes in the state and its population underwrites the technologies of power that have their manifestation in various societal institutions of domination, such as the prison and mental hospital (Foucault 2007a: 118). In its original theorization, governmentality denotes a broad swath of power or "an encompassing point of view" (Foucault 2007a: 118) that emanates from the state and in doing so constitutes the state. For the purposes of the analyses of this project, it is best to focus on the *quality* of power that Foucault theorizes rather than its mediator, the state, because, as I will discuss, the political-economic context of neoliberalism has meant that forms of direct state power have given way to less direct, governing-at-a-distance (Harvey 2007; Petersen 1997; Rose 2001). Despite this, governmentality, as a theoretical lens, remains useful because it details a particular type of power regardless of its proposed origin. In order to explain and contextualize the formation of this theory some description of its relationship to the state must be discussed.

Examining the early modern state, Foucault (2007) discerned that the emergence of the concept of a population enabled a new, fledgling rationality of governance. Population becomes the ultimate end of government, which places its attention on, ". . . the welfare of the population,

the improvement of its condition, the increase of its wealth, longevity, health and so on. . .” (Foucault 1994: 216-7). Population forms the “scene of a newly ‘real’ social body” that can be submitted to calculations and statistical analyses and is a surface for the application of social policy (Orr 2010: 549). It is through the concept of population that a governing sort of power can get to the individual.

In tracing the roots of this type of governing power, Foucault introduces pastoral power, a power interested in the “conduct of each and of all” (Rose, O’Malley, and Valverde 2006: 83). With its roots in the pre-Christian East and then in the Christian East, pastoral power appears in two forms: first, in the idea of a beneficent shepherd guiding a flock, and second, in the practice of spiritual direction, “the direction of souls” (Foucault 2007a: 123). Pastoral power is an individualizing power in that the shepherd directs the whole flock, but he can only do so through accountability to each individual sheep (Foucault 2007a: 128). In its second form, pastoral power “. . . demands a knowledge of the ‘truth’ of one’s self in exchange for the spiritual guidance and protection of a pastoral figure” (Orr 2010: 549). Foucault (1988) traces this to a historical monastic ritual of contemplation and constant scrutiny of the consciousness, which transmutes into “technologies of the self,” those practices that permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being (p. 18).

While governmentality of the mid-18<sup>th</sup> century produced the concept of population, this does not prevent it from focusing on the individual as well. Rather, it is through governance aimed at the population that power can be had over the individual. Governmental technologies take shape at the intersection of a science of administering society in its totality and in caring for the flock through individualizing knowledge of each member (Orr 2010: 549). Pastoral power

exhibits simultaneous concern for the flock and its individual members. Foucault (2007) writes: “It looks after the flock, it looks after the individuals of the flock, it sees to it that the sheep do not suffer, it goes in search of those that have strayed off course, and it treats those that are injured” (p. 127). In practices of governance, there is a convergence of this type of power with what is referred to as police power, or a science of administration at the population level (Dean 1999: 92). It is these two types of power—policing and pastoral—that constitute the social and allow power to “move *between* managing social relations and governing individual conduct” (Orr 2010: 549).

Though much of Foucault’s work on governmentality was concerned with the rationalities of the state in constituting itself in conjunction with a concept of population, his focus on the individualizing and productive capacity of power provides useful analytics for my work here. Using governmentality as a type of analytic approach provides “. . . a language and a framework for thinking about the linkages between questions of government, authority and politics, and questions of identity, self and person” (Dean 1999: 13). As a productive force governmentality sees its subjects as “resources to be fostered, to be used and to be optimized” (Dean 1999: 20). With these goals in mind, practices of governance work to enjoin individuals to produce certain socially and politically desirable identities and identifications. In this way, governance takes place “without the full awareness of the people” (Foucault 1994: 217). Dean (1999) explains further:

Regimes of government do not *determine* forms of subjectivity. They elicit, promote, facilitate, foster and attribute various capacities, qualities and statuses to particular agents. They are successful to the extent that these agents come to experience themselves

through such capacities (e.g. of rational decision-making), qualities (e.g. as having a sexuality) and statuses (e.g. as being an active citizen, p. 32).

One of the clearest ways to see governmentality of the individual among drug users is to examine harm reduction discourse, which makes appeals on the individual level and facilitates personal responsibility for health among drug users (Fraser 2004). In an act of ethopolitics (Rose 2001), harm reduction enjoins needle users to fashion themselves as ethically responsible citizens by way of participating in certain sterile or otherwise pro-health practices (Campbell and Shaw 2008; Vitellone 2010). Through interviewing economically marginalized people who inject drugs, I saw evidence of the governing effects of harm reduction in the ways some discussed their health. They did this by articulating health concerns that aligned with the prioritized health concerns of harm reduction interventions—HIV/AIDS and hepatitis C—and by describing ethical behavior that aligns with harm reduction teachings.

The creation of the “injection drug user” risk category in the 1980s enabled the governance of a certain group of individuals such that they could be regulated as a population and governed-at-a-distance as individuals to diminish the spread of HIV/AIDS. One of the first steps in this governing process was to describe this group by conducting ethnographic observation that aimed to discern why individuals were at increased risk for HIV transmission. This research endeavor sought to get at the “‘truth’ of one’s self” (Orr 2010: 549), or for example, the “truth” of why one might share needles, in order to provide pastoral guidance toward a less risky drug using lifestyle.

### *Neoliberalism*

While the concept of governmentality elucidates a form of power that registers at both the population and individual level, the concept of neoliberalism brings into view a particular

rationality of governance. The rationality behind current modes of governance is tied to beliefs about the necessity of a liberal economic market, where individuals are offered certain types of freedom as a cost-saving measure and as a way to compel entrepreneurialism and instill personal responsibility. Part of neoliberalism's work is to produce citizen-subjects who think of themselves as individual entrepreneurial actors who are responsible for their own survival (Brown 2003; Ong 2007). This subject has no claims on the state and must fend for his or herself through enterprise, which neoliberal governance nurtures through certain optimizing technologies aimed at producing subjects who are self-animating and self-governing (Ong 2007).

Low-income drug users may not be envisioned as potential entrepreneurial subjects, but they can at least participate in practices that reduce their economic burden to society. The risk discourse of harm reduction offers this possibility by engaging people who inject drugs in self-monitoring and self-care. By appealing to drug users to protect their health and by providing them with low-cost ways of doing so, harm reduction interventions enjoin drug users to take responsibility for their health. The self-animating discourse of neoliberalism played a role in self-organizing among drug users in the 1990s that helped usher in legal syringe exchange programs. This had implications for the subjectivity of the “injection drug user,” which included a connection to activism and self-governance.

However, harm reduction strategies of needle exchange and overdose prevention education, for example, are not inclusive forms of care, but are rather the bare minimum (Garcia 2010). They are neoliberal tools that facilitate self-governance among low-income drug users who may have limited means to access quality, compassionate health care. While they may extend the capacity of drug users to take care of themselves, many economically marginalized drug users are still lacking access to basic health care and, furthermore, the basic essentials



needed to survive, such as housing. Some interviewees told of illness experiences that were initiated and exacerbated by a lack of stable housing. Even in these desperate times, the interviewees described concerns over their limited capacity to be personally responsible for their health. This is indicative of the hold neoliberal rhetoric has over every day rationalities. Neoliberal governance has spawned a hegemonic belief system that, "... has pervasive effects on ways of thought to the point where it has become incorporated into the common-sense way many of us interpret, live in, and understand the world" (Harvey 2005: 3).

Neoliberalism as a "marketized" governmentality is both an indirect, in that it regulates through individual freedom, and highly cost-effective form of normalization of the population (Gowan 2012/2013). However, it must be noted that this practice of governmentality may be mainly directed at the broad middle classes of more industrialized countries, leaving socially and economically marginalized populations to be normalized through "old-fashioned disciplinary institutions," such as the criminal justice system (Gowan 2012/2013). Foucault (1994) himself points out that an interest in discipline was never fully displaced by the new focus on governing the population. Discipline is a technology of power situated within a particular governing context that utilizes its techniques, rationalities, and institutions (Dean 1999: 19-20). As I will discuss further, economically marginalized people who inject drugs are recipients of both neoliberal governance and disciplinary power. As individuals with a disease, the disease of addiction, drug users can be made subject to the disciplinary power of abstinence-only drug treatment programs.

### *Bio-power*

Bio-power, which signifies a particular type of governing power, affects the experiences of people who inject drugs in specific ways as they are managed and disciplined through reference to their health and drug use. The proliferation of public health research on people who

inject drugs in the 1980s and 1990s, which monitored drug users as a population and re-fashioned their subjectivity, exemplifies an act of bio-power that both regularized a population and harnessed individual capacities. Bio-power consists of two types of power--anatomo-politics, which focuses on the individual body and works to form and shape it through discipline and surveillance (Foucault 1979), and bio-politics, which focuses on the species-body and looks to regularize the variability of human vitality at the population level (Foucault 1984). Foucault (2003) does not see these two types of power as necessarily distinct from one another, but rather that bio-politics uses anatomo-politics by, "... infiltrating it, embedding itself in existing disciplinary techniques" (p. 242).

As with governmentality, bio-politics emerged with the constitution of the population as a field of knowledge, regulation, and action (Dean 1999). Bio-politics takes the population as its primary focus and views it through the lens of biological processes. Thus, normalizing and regularizing power is directed at the "species body." This is the body "... imbued with the mechanics of life and serving as the basis of the biological processes: propagation, births and mortality, the level of health, life expectancy and longevity, with all the conditions that can cause these to vary" (Foucault 1984: 262). The type of power Foucault (1984) describes through the concept of bio-politics is a positive power that seeks to optimize and multiply life. In this way, bio-politics is interested in health and expresses this through its goal of affecting collective human existence (Rabinow and Rose 2006: 197). People who inject drugs were and continue to be the subjects of large-scale bio-political projects aimed at reducing the spread of HIV/AIDS. These projects, often funded by the federal government, report on factors relevant to the vitality of people who inject drugs and in doing so construct the subjectivity of this particular type of

drug user. This type of monitoring feeds into the creation of localized interventions that aim to impact the health of the species-body.

Constituted by the disciplining of bodies through institutional practices, anatamo-politics focuses on how bodies are rendered docile and then optimized to strategic ends through training, surveillance, and examinations. Foucault's (1979) theorization of anatamo-politics examines how these disciplining tactics take place in the institutions of education, military, hospital, and factory. In explaining the disciplinary use of surveillance Foucault (1979) writes: "In discipline, it is the subjects who have to be seen. Their visibility assures the hold of the power that is exercised over them" (p. 187). Another tactic, normalizing judgment ". . . compares, differentiates, hierarchizes, homogenizes, excludes. . ." bodies in processes that work to establish "normal" levels by marking gaps and creating hierarchies (1979: 183). Through these disciplinary practices of anatamo-politics bodies are molded, such that their forces and capacities can be put to use in various institutional projects. Public health and harm reduction programs that involve drug users in educational interventions can be understood as disciplinary projects that produce certain types of subjects whose forces and capacities are put to work in the maintenance of individual health (McLean 2013). In the context of drug treatment programs, drug users may be subject to anatamo-politics through disciplinary practices of normalizing judgment and surveillance that function to mold subjectivity and refashion subjects into a particular, often racially-coded, image of a productive citizen (Gowan and Whetstone 2012; Kaye 2012b). The use of the disease model of addiction by health care practitioners implies the need for disciplinary power in its linkage to abstinence-based addiction treatment programs.

Sorting through the types of power that form the subjectivities of economically marginalized people who inject drugs and impact their understanding of health and the practices

of health care providers, it is clear that differing technologies of power are not always so different and thus do not function in mutual exclusivity. Governmentality offers an image of power that functions on the population and individual level and aids with understanding how the “injection drug user” subject position was formed and how individuals were implicated in their own self-governance through this formation. Bio-politics as a technology of power shows how health is involved in the governance of populations and works to explain how power manifests in state and local projects that aim to promote the health of people who use drugs. Anato-politics explains how people who inject drugs are shaped by institutional practices that discipline drug consumption. These technologies of power are infused with the rationalities of neoliberalism that emphasize personal responsibility and self-governance. This can be seen when drug user health is managed through a discourse of risk that enjoins individuals to participate in technologies of the self to affect changes on their selves and the health practices, such as safer injection, that accompany this new identification. People who inject drugs are caught up in various webs of power that shape their identity and practices. Looking at how their health is conceptualized is one way to begin understanding the power that produces their subjectivity and informs their actions.

## CHAPTER OVERVIEWS

### *Chapter Two*

Before analyzing the data I collected, I begin in chapter two by discussing *how* I collected it. I chose to conduct my research through the use of in-depth interviews because I was hoping to gain access to the meanings research participants gave to health and the discourses they mobilized to discuss their perspectives. The power of discourses is what I sought to understand in this research project and conducting in-depth interviews allowed access to the space of

discourse. In this chapter, I discuss power asymmetries between the researcher and participants, and reflexivity, using a post-structural approach toward understanding power. While there were certainly status and power differentials between myself and the individuals I interviewed, I experienced power as flexibly practiced during the interviews and thus not fixed by preconceived ideas of who held the most power. I took the perspective that power was expressed relationally and interactionally, and depended on the particularities of the person I was interviewing and the discussion that took place. With that in mind, reflexivity became more of a practice to be carried out during fieldwork and less of a way to write myself into the research post-hoc. This chapter critiques any stable or fixed representations of research participants and self, but also seeks to note the variety of power relations present in my interviews with both a socially marginalized group (low-income people who inject drugs) and two socially elite groups (health care practitioners and public health researchers).

### *Chapter Three*

Chapter three offers background on and analysis of the emergence of the HIV/AIDS risk category “injection drug user” or as it is now known “people who inject drugs” by understanding it as a practice of governmentality. I deploy Foucault’s concept of governmentality to analyze the intersection of power that is interested in populations and power that impacts on the individual level. Using archival research, which entailed the review of public health journal articles from the early 1980s to the present, and interviews with public health researchers, I piece together a history of governmentality that begins in the early 1980s and follows the category of person who injects up to the present. This chapter notes early efforts to describe this population, the development of behavioral interventions based on these descriptions, sociological critiques that dispelled the early descriptions, efforts by researchers to promote personal responsibility

among drug users, and the continued governance-at-a-distance of this population. The category was created and animated by public health and social science researchers as part of a humanitarian effort to prevent the spread of HIV/AIDS. In this endeavor, the category functioned both as a way to govern and as evidence of the governance of a bounded group of socially marginal people. This chapter traces the specificities and nuances of this particular act of governmentality. Through early efforts to describe the culture of people who inject drugs, the subjectivity of this type of drug user was made pliable to bio-political concerns. Later research, which noted the legal obstacles to health maintenance through the use of new syringes, played into contemporary trends of neoliberal governance-at-a-distance by offering people who inject drugs a sphere of regulated freedom. Through further examples, this chapter demonstrates that the creation of the “injection drug user” was an act of governmentality that continually fashioned and re-fashioned a particular drug-using subject.

#### *Chapter Four*

Chapter four explores the concurrent use of harm reduction practices and the discourse of addiction as disease among health care practitioners who provide care for drug users. Based on interviews with 13 health care practitioners, this chapter sought to understand the ways these health care practitioners understood the health and drug use of their patients and how these understandings may be implicated in governing power. All of the practitioners interviewed proclaimed their use of harm reduction, which recognizes and encourages agency among drug users so that they can self-govern their drug use. Many of the practitioners also subscribed to the notion of addiction as a disease and thus saw drug use as disconnected from “choice” or “psychological will”. This chapter argues that these two approaches implicate the will of the drug user in conflicting ways. The will of the drug user is recognized in some instances and

dismissed in others. As governing projects, addiction as disease and harm reduction call forth differing technologies of power—disciplinary and pastoral respectively. The docile body of an addict faces institutionalization in an abstinence-only drug treatment facility, while the self-animating drug user of harm reduction must learn how to regulate autonomy.

### *Chapter Five*

Chapter five examines narratives of risk and illness put forth by economically marginalized people who inject drugs as they described their main health concerns. This chapter is based on interviews with 40 low-income people who inject drugs in New York City. The analysis of these interviews is staged by an interrogation of contemporary risk-based understandings of health and their connection to neoliberal cultural logics of self-governance and responsabilization. This chapter explores how both types of narrative operate to mobilize certain types of selves within low-income drug injectors' discussions of health, and what the implications are for societal efforts toward addressing the health and well-being of people who use drugs. Among a minority of narrations of risk, there emerged an affinity with the foci of harm reduction interventions—HIV/AIDS, hepatitis C and overdose. Thus, the health interventions offered by harm reduction aligned with the primary health concerns of these individuals. I understand this as partially due to the governance enacted through harm reduction, which enjoins drug users to think about their health in terms of risk for infectious disease. However, most of the health concerns expressed by the interviewees were unrelated to drug use, HIV/AIDS, hepatitis C or overdose, having more to do with other health risks and chronic conditions whose impact is often stratified by class, such as diabetes, hypertension, and obesity. When discussing their health risks or chronic conditions, interviewees were able to construct themselves as personally responsible for managing and monitoring their health or illness. This chapter closely examines three narratives of illness that

articulate a direct link to poverty, and which work to reveal the narrow potential of harm reduction as a pro-health intervention. These narratives also reveal the efforts put forth to be personally responsible for managing one's illness, despite living in conditions of poverty that obstruct access to resources supportive of health. By examining narratives that include harm reduction discourse and those that do not, this chapter reveals both the impacts and the failures of the current iteration of harm reduction-as-public-health-intervention, and through this, urges a reflecting back upon the original mission of harm reduction's foundation to improve the general situation of the drug user. I conclude by suggesting that harm reduction as a movement could re-vision and expand upon the meaning of harm to include the structured impacts of poverty, and form networks of care with other organizations and movements to provide a broader range of interventions and services that address such issues as housing instability, unemployment, and nutrition among other disadvantages. In this way, harm reduction could work to mitigate the harm caused by situating a cultural and institutional emphasis on personal responsibility in a social environment structured to produce inequality.

#### IN/CONCLUSION

By examining what health means for people who inject drugs, this project aims to dispel any simple conclusions that health is signified by a conglomeration of risks or that health is the absence of disease, for instance. By noting that discourses of health can imply certain technologies of power, we can see why contemplating the many meanings of health matters. For bodies, such as those of low-income people who inject drugs, whose vitality is negatively impacted by structured inequality and social marginalization due to stigma, acts of governance can mean the difference between life and death. Governance through risk as a way to maintain the health of people who use drugs offers individualized ways of taking care of the self, but



neglects broader social forces that leave bodies vulnerable to disease. Thus, for low-income people who inject drugs, health is often measured by experiences of illness with conditions brought on or made worse by poverty. For health care practitioners, the health of drug-using patients is at least partially measured by reference to the disease of addiction, which similar to the discourse of risk, only sheds light on a narrow component of health and leaves unexamined structured vulnerabilities to disease and addiction. Understanding health through the lens of addiction as disease also links drug users to the disciplinary institutions of drug treatment. Just as the technologies of power that address the drug using body are diverse, so are the ways to understand drug user health. In exploring this diversity of power and meaning, this project aims to open up a space for discussing health that moves away from narrow foci that inculcate bodies in self-care and toward the social processes that underlie health.

## Chapter Two

### This Research Cannot Be Fixed: The Contextual Instability and Fluidity of Power and Self in Qualitative Research

In January of 2012, I began fieldwork for this project with the goal of interviewing economically marginalized people who inject drugs and health care practitioners who provide primary care for active drug users. I wanted to understand the discourses that structure the power relations embedded in efforts to define the health of people who inject drugs. Through the use of in-depth interviews, I was hoping to gain access to the meanings drug injectors and health care practitioners assigned to the concept of health, and within these meanings notice over-arching discourses. The first person I interviewed for this research project was a doctor, and like many of the health care practitioners I subsequently interviewed, she practiced medicine in a setting where drug treatment was also provided. In fact, eight of the practitioners I interviewed prescribed buprenorphine, and two of those practitioners also worked in methadone clinics. Over the course of the next 12 months, I interviewed 12 more health care practitioners. Most of the interviews took place in their offices in New York City, at the institutions where they worked. The second interview I conducted for this project occurred in late February of 2012 and was with a young person who injected drugs. As with a few of the other interviews with people who inject drugs, this interview took place at the field site of a separate research study. However, I found the most luck recruiting and interviewing these interviewees at two harm reduction organizations in Manhattan. This meant that these interviewees had at least some contact with the ideas of harm reduction. Since harm reduction was an object of inquiry for this project, I benefited from interviewing individuals in these settings. In all, over the course of 14 months, I interviewed 40

people who inject drugs. The final leg of my fieldwork began in May of 2013, when I interviewed four public health researchers about the risk category that denotes people who inject drugs in order to historicize the group of people around which this research centers.

Initially, choosing to conduct this research project using qualitative methods seemed like an obvious choice to me as I conceived of this project. However, this choice was based on several under-articulated epistemological beliefs I held. First, I believed that knowledge could be created in an exploratory mode. Rather than determining fixed variables on which to focus, and in some ways constructing the outcome I expected to find, I wanted to use the flexible methods of qualitative research to seek out the discourses that my interviewees used to talk about the health of people who inject drugs. Since qualitative methodology allows for flexible research design, often researchers do not know what to look for and what questions to ask until they've spent time with their subjects of interest (Taylor and Bogdan 1998:8). Even once the research has formally begun, qualitative researchers will continually become aware of things they had not anticipated and will need to adjust their research model to make the account they produce a more careful one (Becker 1996; Katz 1997). Through the acceptance of new ideas and theories, and the ability to be flexible in use, qualitative methods reach toward a careful fit between the data and its depiction without excluding a diversity of viewpoints and experiences.

Qualitative methodology in its broadest sense refers to research that produces descriptive data and for the most part what are described are viewpoints and meaning. As Taylor and Bogdan (1998) assert: "The important reality is what people perceive it to be" (p. 3). To add to this, the important meanings are the ones people give to the experiences, phenomena, and objects in their social spheres. Practicing these beliefs insists on the co-construction of research findings and knowledge generated through interactions between the researcher and study participant. If

the perspectives and meanings deployed by the participants are at the core of the research, then they are rightfully authors of the products of the research. This is not to obscure the place of the researcher in interpreting and subsequently constructing the viewpoints and meanings she is presented with during the conduct of research. Rather, it is to show another under-articulated epistemological belief I had about social science research—viewpoints and meanings, which structure and guide social life, should be included in the production of knowledge. This dovetails with the importance of counting everyday experience as part of the knowledge production process. Qualitative researchers are concerned with how people think and act in their *everyday* lives, which includes the taken-for-granted assumptions that structure their actions and world (Becker 1996). It is in the substance of the everyday that qualitative researchers gain understandings of process and power.

I sought to understand the power of discourses in this research project. Conducting in-depth interviews allowed access to the space of discourse. While I engaged beliefs from several theoretical frameworks, such as feminism with its concern for oppression of different categories of people, and post-modernism, which questions the voice and authority of the researcher and whether social facts exist, my research was mostly constructed around a post-structural account of power. In this analytic approach, subjects are understood as produced and disciplined through diffuse networks of power. Examining discourses, such as those of harm reduction and the disease model of addiction, in interviews with health care practitioners and people who inject drugs was a way to understand how health and the subject attached to it (i.e., people who inject drugs) are produced.

This chapter will proceed by offering a discussion of methodology and a discussion of ethics. In particular, the method of in-depth interviewing will be analyzed for the type of

knowledge and power relations it produces. Ethics will be discussed on both the macro and micro-scale, as well as in relation to “studying-up” and studying a vulnerable group. Finally, I will offer a summarized description of my research procedures from recruitment to data analysis, highlighting formative, as well as frustrating, moments. The chapter will conclude with a nod to reflexivity, though perhaps a critical one, through a discussion of my place within the research.

Instability and fluidity are central threads tying together much of the discussion to follow. My depictions of the power relations of interviews and the practice of reflexivity are threaded through with a refusal to offer fixed notions of certain types of people and certainties about the directional flows of power. In this sense, my discussion of methodology corresponds with my interest in post-structural understandings of power in that I see power as fluid, and thus not fixed within individuals. Rather, various modalities of power are manifested through technologies of action and inaction. In a Foucauldian sense, the interview is understood as a disciplinary technique of confession whereby the interviewee is enjoined to produce his or her “self” through articulating truths (Foucault 1978). I was unable to escape this form of power in that I used interviews as a data collection tool. However, an oppressive sort of power that elevates the researcher and creates status incongruities was not apparent in my fieldwork interactions. Power was not inscribed within individuals, but rather it was diffuse, interactional, and continually at work, even as I compose this chapter.

Power that functions through privileged and accepted discourses may produce subjectivities (such as the “injection drug user”), but this does not mean that my interviewees assumed a fixed positionality during our interviews. This is not to deny that some individuals may be more vulnerable to dehumanizing forms of power due to their experience of socially structured inequalities, but rather to recognize that the power dynamics of interviews cannot be

discussed with reference to simple unidirectional flows and fixed notions of certain subjectivities. Indeed, by engaging people who inject drugs in open discussions of health that did not center on drug use during in-depth interviews, I aimed to unsettle any fixed notions of an “injection drug user” subjectivity. It is the post-structural view that power is diffuse and continually circulating rather than possessed by certain individuals that guides my approach to understanding the power dynamics of research interviews.

#### PRODUCING KNOWLEDGE TOGETHER: ON IN-DEPTH INTERVIEWS

I chose to use in-depth interviews as a “search procedure” (Paget 1983) to help me understand the meanings attached to the concept of health for people who inject drugs. Interviews offer access to interior experiences and perspectives, as well as thoughts and feelings (Weiss 1995), all of which I felt were necessary to illuminate the questions that puzzled me. How did drug users understand their health? Did they believe themselves to be healthy? Were any discourses (e.g., harm reduction, disease) guiding their perspectives? The content of an interview is produced by what is puzzling the interviewer. The interviewer follows her perplexities as they arise in the conversation: “The questions asked and their sequencing presuppose and reflect a project. In-depth interviewing is a search procedure” (Paget 1983:78). In this way the interviewer is implicated in constructing, or at least co-constructing, the content of the interview.

As an interviewer, I did not take a neutral stance in hopes of “excavating” (Mason 2002) objective knowledge from the respondents. It is inevitable that the interviewer’s perspective will shape the interview, as well as the findings, and it is now widely accepted among qualitative researchers that interviews are “. . . active interactions between two (or more) people leading to negotiated, contextually based results” (Fontana and Frey 2005:698). Following the assertion that interviewers should not forbid themselves from all personal engagement during the

interview (Bourdieu 1996), the interviews I conducted evolved through the periodic insertion of my own thoughts and perspectives, and in some ways felt like a casual conversation (Bourdieu 1996). In this exchange I had with Dan, a 22-year-old who injects drugs, I inserted my opinion about the irresponsibility of his health care provider, a hospital emergency room. Dan is describing his struggle with receiving adequate medical care for diabetes:

Dan: Yeah, that's when my sugar goes completely too high. I black out. I can just die, and that's pretty much the only way they [the emergency room] would take me is if I was in DKA [diabetic ketoacidosis]. And I'd have to do three days, and I'd be out for four days, three days. My medical bills are ridiculous right now. If I get a regular job, I don't know what the hell I'm going to do, but they're just going to take all my money.

Kelly: Oh, man. That seems so wrong.

Dan: You know what I'm saying? Yeah, it's just the snowball that just. . .

Kelly: Yeah. Oh, wow. I just can't believe they wouldn't give you insulin to take with you.

Dan: I know. I'm like, "Just give me one pen, one Lantus, and I won't have to come."

"No, no. We can't do that." I'm like, "That's just crazy."

Kelly: Yep, that is crazy.

Dan: I was about to go under the counter and just take it.

With the addition of my perspective in this exchange, Dan further elaborated on his desperation for take-home insulin and his evaluation ("That's just crazy") of the actions of the hospital.

The internal context of the interview is also an agent in shaping the interview as it progresses. Paget (1983) explains that interviews are contextual in their organization in that, ". . . they respond to features of the ongoing interaction, to nuances of mood, and to the content of the

evolving conversation” (p. 69). As mood or topic shifts so too can the character of the interview. This is where creating, if possible, a comfortable flow and exchange for the interviewee is important, but this must be balanced with the recognition that in-depth interviews can be manipulative of the interviewee (Fontana and Frey 2003). Techniques that nurture rapport can lead interviewees to say things they may not actually want to disclose in a research interview (O’Connell Davidson 2008). This will be taken up in more detail in the section of this chapter on ethics.

Another way in which in-depth interviews are co-constructed is through the theoretical orientation the researcher brings to the interview. In fact, the mere choice of conducting interviews demonstrates a theoretical orientation that sees talk and text as central to ways of knowing the social world (Mason 2002). The central components of interviewing--asking, listening and interpreting--can be seen as theoretical projects in that they reveal assumptions about what is “. . . possible from asking questions and from listening to answers, and what kind of knowledge we hear an answer to be. . .,” all based around an implementation of the researcher’s theoretical orientations (Mason 2002: 225). As mentioned earlier, my interviews and my research project in general were guided by a post-structural theoretical orientation, which meant that my questions to drug users tried to get at their experience of power that aimed to govern their selves and bodies, and my questions to health care practitioners and IDU research experts sought to shed light on their roles in the implementation of this type of power. Due to my theoretical affiliation, I co-constructed the interview content by asking certain types of questions and interpreting answers in ways that aligned with my particular understanding of power.

The choice to use in-depth interviews as my fieldwork method was based on the belief that various discourses pertaining to drug use and health would be revealed through talk. By



asking interviewees questions that might reveal their understanding of what health means, I assumed (and correctly so) that interviewees would deploy a variety of discursive registers to explain their perceptions. I asked both questions that were abstract or general and those that delved into everyday activities believing that both types of questions would offer varying venues for the revelation of guiding discourses. The flexibility of interviews, along with the access they give to internal perspectives, and meanings, and depictions of everyday activities provided fertile ground for conducting the type of analysis I desired.

#### HOW SHOULD ONE BE/ACT?: ON ETHICAL PRACTICE

Often when research ethics are discussed, the conversation centers on the policies and procedures of Institutional Review Boards (IRB), as they are, at least superficially, the guardians of research ethics. While the structure and function of the activities of the IRB directly pertain to ethics, there is also a more fine-grained and contextual recognition and analysis of ethics that can and should occur in any research endeavor. A differentiation can be made between “procedural ethics,” or the set of ethical guidelines that are addressed in the creation of protocols for IRB applications, and “ethics in practice,” or the ethics that come to light as the research is carried out (Guillemin and Gillam 2004). While it has been suggested that the abstract principles of ethics embraced by IRBs—respect for persons, beneficence and justice--may not guarantee moral decision-making or moral action (Halse and Honey 2005), they can at least provide some guidance in the creation of the study protocol and “ethics in practice” (Guillemin and Gillam 2004). For example, these principles seek to protect the basic rights and safety of research participants from obvious forms of harm, and they offer an “ethics checklist” for researchers constructing their protocols (Guillemin and Gillam 2004:268).

Despite the potential usefulness of these abstract ethical principles, there are at least several ways in which the procedures of the IRB can interfere with the conduct of certain types of social science research. The requirement to define a particular research population, “. . . is an act of category construction with profound intellectual and moral implications” (Halse and Honey 2005: 2145). Often people do not fit neatly into pre-fabricated categories, or may fit within the category but reject the label of the category. At several points while recruiting research participants, the inadequacy of the recruitment categories I had provided to the IRB was revealed. For example, were people who injected methadone, a legal substance used for drug treatment, “injection drug users”? What about those who had recently injected but were trying to stop, who were in the act of withdrawing from this category?

The concept of informed consent is reliant on a notion of an autonomous liberal humanist subject who is able to make rational and independent decisions regardless of context. Further, the process of informed consent is premised on researchers being able to provide full and accurate information about the research (Halse and Honey 2005). However, there are many contingencies of research, and particularly qualitative research, that can lead to a wide variety of outcomes. Thus, it seems impossible to offer a full account of what may happen during the research. In the consent process for my research, I warned drug users that some of the questions I asked could make them feel embarrassed or otherwise upset, but I was unable to predict any other responses of which to warn participants. Perhaps, the interviews I conducted could initiate damaging emotional and psychological processes, leading participants to question themselves and become distrustful of medical care, for example. It is also not possible to be sure that research participants understood everything I told them during the consent process.

In creating a research protocol for an IRB application, the researcher must adopt a one-size-fits-all strategy for both introducing the study to participants and conducting it. This is despite the diversity of experiences among participants and the variety of ways in which the study might stir up difficult emotions (Halse and Honey 2005). The universalized, rational subject articulated in modern research ethics policy is also problematic because, “. . . it constructs the self as disembedded and disembodied, without sensibilities, history, or physicality” (Halse and Honey 2005: 2153). In essence, the requirements of the IRB application process flatten the multiplicity of research participants. In my research, the occupational label “health care practitioner” was used to define a category of people for recruitment. However, one’s occupation is only a piece of their felt-identity, and in fact, much of the content of my interviews with this group delved into personal views of drug use, stigmatization, and medical care. Some participants discussed personal experience with drugs or with friends who used drugs, which took them outside the terrain of the professional and into the personal. The two cannot be detached despite the implications of the identity categories required by IRB applications.

Much of my own experience with gaining IRB approval centered around the perceptions held toward drug users by individuals on the review board at my institution. This proved to be both fascinating and disheartening, in that I was subject to disparaging perceptions by a group of individuals whose experience working with people who use drugs was unknown to me. The personhood of the individuals I was planning to interview was flattened into a monolithic image of a socially deviant drug user. At the beginning of the process, I learned that my application would be subject to full-board review. In the end, I revised my application three times before it was approved. My first application was met with a memorandum outlining revisions that I

needed to make. Many of these had to do with clarity, but some clearly revealed concerns that seemed particular to a certain construction of drug users. For instance, I was disallowed from using email to communicate with potential study participants because this group was perceived to not have access to email. A concern was expressed about intoxicated participants, which came up again when I was required to attend a full-board IRB meeting a month later. The IRB members stated that an intoxicated person could not participate in the consent processes. However, people who inject drugs often inject heroin, and for those who use heroin on a regular basis, some amount of “intoxication” must be maintained to avoid the debilitating effects of opiate-withdrawal. Individuals who were in withdrawal would most likely not be participating in a research study, but would rather be spending their time finding ways to obtain heroin so they could address withdrawal symptoms. Unsure that articulating this nuance would be helpful, I simply complied with the request that no intoxicated individuals participate in the study.

Intoxication came up once again at the in-person full-board meeting I was required to attend. Showing a lack of knowledge about the environmental context of the research (New York City), one board member asked what I would do if an intoxicated person, who I had turned away from the study, attempted to drive a car. I knew from years of experience interviewing a large number of people who inject drugs in New York City, that this was quite unlikely as I had never seen this happen before. I addressed the concern by indicating that I would have the individual wait until he or she was no longer intoxicated. While I will agree that from an outsider perspective these concerns seemed valid, many of them were based around uninformed and thus unwarranted fears related to working with people who use drugs. In contrast, very little concern was shown for the other group of people I planned to interview—health care practitioners—who were vulnerable in other ways that went unacknowledged. Later, I added another group of

interviewees—experts and activists on injection drug users from the early days of the HIV/AIDS epidemic—and this amendment passed through the IRB with one minor revision. My experience with gaining IRB approval revealed perceptions of vulnerability that were sociologically interesting. While ostensibly aiming to pay particular attention to protections for potentially vulnerable research subjects, the concerns raised by the IRB reinforced hegemonic, and in some cases stigmatizing perspectives (e.g., inability to access email) of people who use drugs. Through a lack of expressed concern, perceptions about the invulnerability of health care practitioners and research experts were revealed. Additionally, this experience proved the contextuality of ethics. Unfamiliarity with the populations under study can lead to the anticipation of ethical concerns that may be irrelevant.

While the process of applying for IRB approval reveals ethical issues to be considered prior to commencement of research, once research begins, there are many other ethical issues to consider in the “doing” of research. One area that can become an ethical quagmire is the creation of rapport and intimacy with research participants. During interviews, participants may lose sight of the research orientation of the relationship and talk on a more intimate level. While these can be revelatory moments where the participant articulates ideas and thoughts important to the research, the interviewer may feel uncertain whether the participant is still aware of the nature of the interview, which brings up issues of informed consent (O’Connell Davidson 2008). In fact, some participants may mistake a good interview for a therapeutic situation and be more willing to open up emotionally<sup>2</sup> (Kirsch 2005; Walkerdine, Lucey and Melody 2002). In some feminist research, a close relationship of accountability is encouraged (Kezar 2003). However, this must

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<sup>2</sup> It has been found that there may be some therapeutic benefit to participation in qualitative research interviews (Hutchinson, Wilson, and Wilson 1994; Murray 2003). However, my concern here is with the ethics of consenting to exposure to these therapeutic processes.

be exercised with caution as researcher and participant priorities can diverge, and the relationship can edge close to exploitation (Kirsch 2005). Further, when research ends, participants may feel angry and betrayed (Kirsch 2005; Morrison, Gregory, and Thibodeau 2012). Kirsch (2005) suggests that researchers base their interactions with participants on an ethic of friendliness rather than friendship, as this close bond can imply more than the researcher is willing or able to give.

In my interactions and interviews with study participants who injected drugs, the group I considered to be most vulnerable, I tried to maintain a level of intimacy appropriate for a research study, while also seeking to avoid the impression that I was only using these participants for the information they could provide. This balance was a difficult one to maintain, but I attempted to do this by extending kindness and empathy during interviews, while avoiding commitments of time or other resources outside of the research relationship. On occasion, interviewees spoke in ways that seemed similar to how one might speak to a therapist. This included questioning their drug use and expressing dismay and frustration at their inability to stop. For example, nearing the end of my interview with William, a 46-year-old African American man, I asked him if there was anything else he'd like to add and he spoke about wanting to stop using drugs:

Right now I want to get out of all this shit. I want to get married. I want freakin' go back to my life again. I don't want to do that shit "wait aw damn you know I gotta go do this. I gotta do that." I don't wanna do that anymore. Of course, there's other people that they don't wanna keep doing the freakin same shit. And it's not the point to put three years in and then go start the bullshit again. I want now to just stop all this shit. Not for two years,

three years. I just don't want it anymore. I don't want anymore. It's not fun anymore. I don't enjoy myself. This is like the end of the rope. I don't want that anymore, you know.

William continued to speak about his desire to stop using drugs for several minutes. Our conversation eventually turned to the mysterious workings of addiction and the difficulties of changing one's behavior before the interview wound to a close.

I did not interrupt the interviewees when they began these types of introspections, but rather let them talk for some time. When they seemed to be winding down on this topic, I would try to ask a question that connected their thoughts to the research topics. In the few instances when this happened, the interviewees did not express feelings of betrayal or anger at my redirection, but rather thanked me for listening to them. During the interviews with health care practitioners and experts on the risk category "injection drug user," this type of talk did not occur. Most of these interviewees had conducted research themselves, and thus, likely had an understanding of the ethics and positionings of research relationships.

Reflexivity is an oft-discussed topic in the literature on qualitative methodology and ethics. There are perhaps as many definitions and ways to practice this concept as there are research topics in the social sciences. Macbeth (2001) asserts that, ". . . although this diversity assures us that any account of it can only be tendentious, it may still be useful to try to build one" (p. 35). At its root, reflexivity generally refers to a sense of awareness of the researcher's positionality, action, and thought alongside a concern for ethical practice. Reflexivity can be practiced throughout the research endeavor, but for clarity I will first discuss its use during the conduct of fieldwork, and in this case interviews, and then discuss reflexivity in the construction of knowledge and written work that is based on fieldwork.

As Guillemin and Gillam (2004) write, the goal of being reflexive is often related to “. . . improving the quality and validity of the research and recognizing the limitations of the knowledge that is produced. . .” which can improve the perceived rigor of the research (p. 275; Ball 1990). This is accomplished by recognizing the role of the researcher and her social and political positionings in the conduct and writing-up of research. However, Guillemin and Gillam (2004) suggest that reflexivity should not only be practiced as a way to produce rigor, but also as a way to ensure ethical practice throughout fieldwork. In this way, the researcher practices reflexivity with regard to the interpersonal aspects of research, as well as the ultimate purpose of the research, which may include advancement of the researcher’s career, addressing the participants’ self-defined needs, a more broad-based social justice goal, or a mix of these. This involves a constant process of critical scrutiny of both the researcher’s and the participants’ actions and thoughts throughout the research processes.

During the conduct of fieldwork, there are many areas in which the researcher can be reflexive. In preparing to conduct research, the researcher may become aware that the ethics approval process facilitates a hierarchical power relationship between researchers and participants by constructing the researcher as the objective knower and the subject as the object of knowledge. This works to construct the research subjects as other (Halse and Honey 2005: 2154-5). One way a reflexive awareness of this hierarchical construction can aid the researcher is in creating interview questions that do not position the interviewees as exotic or deviant. The researcher should also be aware that transferences, identifications, and fantasies do not disappear when she is engaged in research (Walkerdine et al. 2002). Besides “othering” the research participant, the interviewee may be enticed by emotion and desire to view the interviewee in certain ways, ask certain questions, and make particular assumptions. During the research



process, I certainly identified with some interviewees more than others, and in recognizing this I attempted to be aware of how this identification impacted the interview. This involved knowing that the questions I asked shaped the discourse (Presser 2004) and the answers I received projected “specific, contextually grounded and interactional content” (Paget 1983: 87-8). Being reflexive of the self and the research participant during the interactional moments of fieldwork can facilitate on-going and fine-grained ethical practice.

Reflexivity that occurs during the analysis and writing-up of fieldwork data often appears in two forms: self-referential reflexivity and textual reflexivity. Both techniques involve a “turning back upon” either the researcher and her social positionings or the text that she produces. Macbeth (2001) refers to the former as “positional reflexivity” and notes that it is centered around the agency of the researcher, pursues a foundational field of view, and is a “demarcation exercise that can warrant the value of an inquiry and the knowledge that it produces. . .” (p. 41). Thus, while the explicit goals of positional reflexivity are to remain vigilant against privilege or exploitative relationships, the implicit goals remain similar to the modernist project of producing a more “real” and rigorous, and thus authoritative representation of social experience. Skeggs (2002) notes that this type of reflexivity, or as she calls it “self-telling,” has historical roots in the act of confession and involves using the lives of others as a sort of “temporary possession” to aid the researcher in performing the self (p. 357-8). Both authors are concerned that this type of reflexivity has become almost obligatory when the researcher discusses her analysis and interpretations of the data.

One way in which researchers have attempted to deconstruct the authoritative emphasis placed on and assumed by the researcher is through reflexivity exercised while constructing text. Textual reflexivity refers to an explicit examination of the work of writing representations, and is

often exercised by disrupting claims to realist representations and textual coherence in the text itself (Macbeth 2001: 42-3). However, this act of decentering the singular voice of the author may ultimately serve to display the cultural capital that is necessary to be able to engage in textual play (Skeggs 2002: 363). Similarly, textual play “. . . is about the powerful showing how well they understand power by playing with it” (Skeggs 2002: 363). Thus, textual reflexivity may not ultimately display the deconstruction of authorial power, but rather reveal that the author has sufficient power within her disciplinary context to construct new forms of textual representation for an academic audience.

The critiques of these two types of reflexivity—positional and textual—seem to create a dead end for researchers who would like to engage in some form of reflection on power. Completely de-centering the researcher and her relational and authorial power from reflexive analyses may not be possible. But, I would like to suggest some potential considerations for engaging the act of reflexivity in other ways. Noticing other enactments of reflexivity while analyzing data may at least alleviate some of the emphasis on the researcher. This should involve recognition of the research participant’s own potential for being reflexive and for mobilizing a variety of social positionings during interactions with the researcher. While interviewing men who committed violent crimes, Presser (2004) noticed that the research interview became a context for the men to deconstruct their socially designated identities. In interviews and other fieldwork interactions, research participants may reflect on their social position vis-à-vis the researcher and the power relations contained therein. The researcher must be careful not to allow the perceived positionings of the research participants to sediment (Walkerdine et al. 2002), as they may shift in the course of an interview and as the interviewee reflects on his or her relationship to the researcher and the research topic. In advocating for non-violent

communication, Bourdieu (1999) advises the researcher to examine the objective of the inquiry as perceived by the research participant in an attempt to reduce distortions of the participant's beliefs and ideas. While it is neither possible nor desirable to impute the thoughts of the participant, recognition of his or her own potential for reflexivity and flexibility in self-presentation can guide the researcher away from a singular focus on her own reflexive ponderings. As mentioned previously, it may be preferable to practice reflexivity through reflecting back upon power and practice during the conduct of research (Skeggs 2002), rather than attempting to enact it post-hoc through confessional stories of the self and textual play.

### *Studying People who Use Drugs*

The use of qualitative methods to study drug users has been recognized as underscoring the humanity of these individuals along with signaling their value and giving them a personalized voice (Carlson, Siegal, and Falck 1995; Keane 2011; Page and Singer 2010). While early qualitative research on drug use sought to position it as social deviance (e.g., Dai 1937) and was mainly concerned with why people use drugs (e.g., Lindesmith 1947), research in the latter half of the 20<sup>th</sup> century examined drug use using a subcultural paradigm, and sought to understand the social and cultural components of drug use involvement rather than why individuals used drugs (Page and Singer 2010). Qualitative research on drug users until the appearance of AIDS was mostly interested in the micro-social worlds constructed by drug users, and thus did not recognize the wider social context that fosters drug use (Page and Singer 2010). In the late 1980s, the federal government began to fund ethnographic research on drug users to investigate the spread of HIV, which spawned another trajectory of drug user research that focuses on health risks related to drug use (Singer and Page 2014). The research of social scientists over the last 90 plus years has culminated in an image of the drug user as cultural other. As Singer and Page

(2014) note, three types of cultural others have been created: the drug user as cultural actor and knowledge seeker; the drug user as a deviant threat to society; and the drug user as a vulnerable person in need of unforced interventions (p. 182). If it were to be categorized, the image of the drug user produced by my research endeavor would likely fall into the third category, though rather than construct drug users as in need of health-related interventions, my research sought to have drug users self-define health and the problems they face with accessing needed health care. These accounts could lead to the creation of health-related interventions, but that is not my goal.

Among the methodological and ethical considerations mentioned by others who have conducted research with drug users is the notion that drug users function outside of mainstream norms and values (Carlson et al. 1985) and that researchers may need to exercise cultural relativism in order to remain open to the “difficult or shocking realities of drugs, sex, crime, and violence” (Bourgois and Schonberg 2009: 7). However, I found that the opposite occurred in my interviews with drug users. The respondents articulated what I would consider to be mainstream approaches to maintaining their health. They described attending regular medical appointments and seeking hospital care when necessary. The interviewees took vitamins, avoided sugar, did yoga, and sought other conventional ways to take care of their health. Most of them felt that there was some risk involved with injection drug use, but took measures to minimize the risks. The interviews seemed to afford the respondents the opportunity to construct a positive image of themselves in terms of health.

Though much is made in research methodology literature of power asymmetries in conducting research and their potential to cause violations of ethical principals (Page and Singer 2010), the power relations in the interviews I conducted developed in situ and depended on the character of the exchange between myself and the respondent (Smith 2005). As mentioned, the

research interviews allowed the drug users to present themselves in a positive light and, as Presser (2004) noted in her interviews with criminally violent men, the interviewees constructed identities that forestalled labeling as deviant. At times I felt as though the respondents were more in charge of the interview than I was and while this occasionally meant their talk diverged from the central interview topics, it demonstrated the power of which they were capable in this interview setting.

Early in my interview with David, a 55-year-old Puerto Rican man, the conversation turned towards his recent arrest and possible return to prison. He seemed anxious and spent some time describing the situation to me and explaining how the cops had set him up. The topic began when I asked him, as I did with all interviewees, if he had been incarcerated before. He responded affirmatively and explained: “Because I did sell drugs at the time to maintain my habit and to have money to get along and eat and live. And it’s cost me. It’s cost me dearly. I’m facing one right now.” David explained that an undercover officer approached him and “... asked me do I know where to get something. I told him, yes, let me make a phone call.” He continued: “So-and-so came out of the building and served them two bags of whatever, and all of a sudden the guy [the drug dealer] gets away, but they got me. And I’m sitting in front of my building.” The story then became a bit confusing as David explained: “It’s all a hoax. Really, it was. Because he originally stopped me for a robbery, then turned around and turned into a sale when I got to the precinct.” David then described how the police stopped him while he was sitting outside his apartment because he fit the description of a robbery suspect. David continued to talk about the situation for an extended period of time discussing such topics as police brutality, mandated drug treatment, stop-and-frisk policing, and mandatory sentencing laws. Sensing his anxiety and frustration, I did not attempt to re-direct the conversation until he seemed finished with the topic.

Though David's story was quite upsetting, it was sociologically interesting in that it revealed the intricacies of institutionalized discrimination in the criminal justice system. Eventually, I was able to ask him some questions about his health and experience with health care providers but he continued to reference his current entanglement with the criminal justice system. He clearly preferred to talk about this situation and I was happy to provide him with a listening ear.

Another instance in which an interviewee wielded some power over the interview happened early in my interview with Joshua, a 27-year-old white male. After responding to my question about how he came to live in New York City, Joshua turned the interview around on me. He began to ask me questions.

Joshua: Where are you from?

Kelly: I'm originally from Michigan but I've been in New York for a while.

Joshua: Upstate?

Kelly: Both. I've been in the city for about seven years and upstate for about three or four years.

Joshua: So that's where you live now?

Kelly: I live in the Hudson Valley. I'm a little...

Joshua: In between

Kelly: Yeah, in between, yeah, outside of the city.

Joshua: I was actually looking at jobs in the Hudson Valley for renewable energy. That's like a big focus, but it's kind of too far from the city.

Kelly: It is. Yeah.

- Joshua: Without a car, especially right now
- Kelly: Oh yeah, you'd need a car to work out there.
- Joshua: Anyway, sorry.
- Kelly: That's okay. Where do you live now?

While this reversal of interviewer-interviewee positionality was brief, Joshua's questions served to set a more conversational tone for the interview. Upon meeting Joshua, I recognized that we shared a similar racial and socioeconomic background. Perhaps also noticing this, Joshua seemed driven to curiosity about my background. His questioning early in our interview served to level the power differential.

One area over which the respondents could not exercise control was the representation of their voices in the research products. Of course, I did not take this power asymmetry lightly and worked to remain thoughtful and reflexive in the ways I portrayed the research participants in the text. This includes not editing or splicing together segments of speech or providing speech extracts without contextual description. While it is impossible to know exactly what the respondents meant at all times during their interviews, I could represent their words unedited and embedded within the context of our interaction. The same went for the health care practitioners and research experts I interviewed, though, as I will discuss, their social position varied from the drug using interviewees.

### *Studying Health Care Practitioners*

In conducting research interviews with health care practitioners, I was participating in what some social scientists refer to as "studying up" in that I was studying a group with a higher social status than myself and a group whose social status is generally held in high regard. Often, social science researchers do not choose to study those who are considered more socially elite,

which, unfortunately, leaves the upper reaches of the social system in the shade (Gusterson 1997). Emphasizing Laura Nader's 1969 call to "study up," Gusterson (1997) asserts its usefulness for examining operations of power, and thus democratizing access to knowledge about how structures of power function. One such structure of power is the health care system in the U.S., whose functions I sought to make more transparent through interviews with health care practitioners.

While the health care system is indeed quite powerful, the power relations I experienced in these interviews were less pronounced and felt than expected. Similar to the interviews with people who inject drugs, power was expressed relationally and interactionally, and depended on the particularities of the person I was interviewing and the discussion that took place. Taking a post-structural view of power, which viewed it as mobile and diffuse, Smith (2005) questioned whether interviewing a person identified as elite will necessarily lead to asymmetrical power relations. Taking into account the post-structural stance that power is not *possessed* by an individual, but rather practiced through certain modalities (such as seduction, manipulation, and authority), it is unclear if power in one realm can easily transfer to power within the interview setting (Smith 2005). Similarly, Rice (2010) experienced power in his interviews with elites involved in the construction of a shopping mall as a "relational effect of social interactions" (p. 70) and suggested that flexibility with one's social positioning can reduce any gaps between the social statuses of the researcher and the elite. In this way, the researcher can make efforts to present herself in such a way that the interviewee may see little if any status incongruity. In fact, upon reflection, the researcher may realize that she comes from a similar background of privilege as her respondents, and that as an academic she may be in a similar economic class (Kezar 2003; Ortner 2010). As a graduate student, I recognized that I was not in the same economic class as



the individuals I interviewed and did not have the same amount of social prestige. However, I recognized that I had the potential to soon be in similar social structural positions as my interviewees and that the interviewees might recognize this. Further, the health care practitioners did not all have the same professional status since some of them were nurse practitioners and one was a physician's assistant. The medical doctors were certainly more elite within this group, and the social statuses of the nurse practitioners and physician's assistant were closer to mine. I use the term "elite" fully recognizing that its meaning is contingent on the social background and worldview of the person using the term. From the perspective of the ultra-rich, medical doctors may not be considered elite. Likewise, from the perspective of the working poor, a medical doctor could be considered elite. I was not privy to other elements of the interviewees' lives beyond occupational role that may have increased or decreased their perceived social status.

Examined closely, there are several ways in which the researcher actually exercises power over the elite interview. Morris (2009) disputes the claim that researchers are powerless when interviewing elites, since they often control the questions asked during the interview, what is published, and the meanings contained therein. Interviewers may also be able to employ techniques of empowerment adopted from feminist research methodology to assist elites in transforming their views to begin a process of questioning power structures (Kezar 2003).

In the literature on interviewing elites, there is much concern expressed about gaining access to this often protected and private group of people (Gusterson 1997; Odendahl and Shaw 2002; Ortner 2010). Both Gusterson (1997) and Ortner (2010) experienced such difficulty in their research and both innovated strategies to compensate for their inability to conduct participant-observation. As I did not conduct participant-observation, this type of access was not an issue; however, I did experience some obstacles to access due to the health care practitioners'

busy and constantly changing schedules. Often interviews would need to be re-scheduled several times, and in one instance, a physician was not present at our agreed meeting time and place. Perhaps, these could be viewed as micro-expressions of power as it demonstrates the level of importance these participants gave to the research interview, though the health care practitioners seemed to have legitimately busy schedules and their work commitments undoubtedly took precedence over research interviews.

I found that in several of the interviews another type of access was denied to me—access to personal thoughts and perspectives. Kezer (2003) notes that elites often highlight the institutional perspective and bury their own personal views. Portions of the interviews I conducted tended to stay at a superficial level with the interviewee making statements about the approach to care their hospital or health care center offered. Sometimes it felt as though they were functioning as a public relations executive for their workplace by responding to questions about what they thought with answers that reflected the mission of their institution. Again, it could be considered a micro-expression of power to side-step a question about one's personal thoughts by responding with institutional rhetoric. Fortunately, these were rare occurrences, and most of the interviewees were forthcoming with their thoughts about drug use, health, and health care.

The interviews I conducted with drug use research experts proceeded similarly in terms of power relations and institutional rhetoric. Like my interviews with health care practitioners, the gap in social status between myself and the interviewee was present in the character of the interview, though the gap may not have been that wide. As drug use researchers in the fields of sociology, anthropology, and public health these interviewees seemed interested in helping me with my project to understand the history of the “inject drug user” risk category. In some ways,

the interview relationship felt similar to a mentor/mentee relationship. In this way, the interviews diverged from those with health care practitioners, as this group was interested in drug users, but approached this interest from a medical perspective and perhaps saw me as a disciplinary outsider whose interest in drug users overlapped with theirs in some ways.

## MY RESEARCH PRACTICE

As mentioned earlier, the main modality of data collection for this project was in-depth interviews that I conducted with three different groups of people. In the following sub-sections, I will discuss these groups of people, how I recruited them and carried out interviews, and finally how I analyzed the data. The recruitment and interview of study participants proceeded at a steady pace throughout 2012 and 2013, and all together, I completed 57 interviews with 57 unique individuals. Forty interviews were with people who inject drugs; thirteen with health care practitioners; and four with drug use research experts.

### *Who I Interviewed*

I was granted IRB approval to begin interviewing people who inject drugs and health care practitioners in late December 2011. Very quickly in early 2012, I connected with two health care practitioners through a local drug user organization and conducted interviews with them. Like eight other health care practitioners I would interview, these two practitioners provided primary care in affiliation with drug treatment. However, the care these two practitioners provided was in the context of a residential drug treatment program whereas the other health care practitioners either prescribed buprenorphine in the context of a primary care clinic, or methadone in a clinic where they also provided primary care to some clinic patients, or both. Thus, a majority of the health care practitioners I interviewed provided care for people who inject drugs because they work in affiliation with programs of drug treatment. Additionally,

seven of the thirteen health care practitioners devoted a portion of their professional time to various research endeavors broadly related to illness and disease, medicine, and substance use, which situates them in a field of knowledge consumption and production that undoubtedly shaped their perspectives and suggests they had thought extensively about the health of drug users.

Ten of the health care practitioners were medical doctors, two were nurse practitioners, and one was a physician's assistant. They all currently provide care at various types of facilities in three of New York City's boroughs—Manhattan, Brooklyn, and the Bronx. The types of facilities include a residential drug treatment program, a methadone clinic, primary care clinics within hospitals, free-standing primary care clinics, clinics within community-based organizations, and community health care clinics. Some of the health care practitioners also held administrative positions at their hospital or clinic and taught medical school courses if they were affiliated with a teaching hospital. This indicated that they had devoted time to reflecting on the provision of health care.

The other group I interviewed was low-income people who were currently injecting drugs. This proved to be a diverse group of individuals ranging in age from 21 to 59 and with differing access to resources. Some were homeless at the time of our interview and staying in shelters, 24-hour internet cafes<sup>3</sup>, or couch surfing. Others were stably housed in their own apartments. All resided in New York City or in a nearby city in New Jersey. In terms of race and ethnicity, 18 of these participants were white, 6 were African American, 14 were Latino, 1 was multi-racial, 1 was Arab, and 1 refused to state race or ethnicity. About half of the interviewees had received some type of health care in the past six months, ranging from hospitalization to a

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<sup>3</sup> It was an interesting discovery to hear that some of the interviewees paid a small sum of money to be allowed by the proprietor of an internet café to sit at a computer desk over night and sleep.

regularly scheduled visit with their primary care physician. Several of the interviewees had not received any medical care in the recent past, but said that they had connections to a doctor or clinic. Several had received a medical check-up at their methadone clinic or through their homeless shelter. Thirty-three of the participants were recruited from and interviewed at a harm reduction center and had access to medical and social services, as well as syringe exchange, through the center, though that does not guarantee they were accessing these services. The harm reduction centers did not provide drug treatment. They mainly provided education and basic necessities to their clients. The education received by clients of harm reduction centers usually comes in the form of pamphlets, one-on-one counseling sessions, groups or training activities. Recruiting people who inject drugs from these centers meant that these individuals had been privy to some form of harm reduction education on the prevention of infectious disease.

In early 2013, I received IRB approval via a protocol amendment to interview four researchers who specialize in research on drug users and had been conducting research when the “injection drug user” risk category came into being. The main affiliation of two interviewees was a university, while the other two were mainly affiliated with a research institute. Since all four of these research participants elected to disclose their identity—this option was available on their consent form—I have described their research backgrounds and current work in the appendix.

### *Recruitment*

In trying to locate and recruit participants, I used one strategy for recruiting people who inject drugs and another for the health care practitioners and research experts. To recruit people who use drugs, I hung fliers at a research study field site many injectors frequented and two harm reduction centers. Interested parties were asked to call my cell phone number. Several interviews were set up this way, but the majority of interviews were set up when word spread at

the harm reduction center that I was conducting interviews and interested individuals would approach me on site.

One tool that seemed to be helpful in recruiting people who inject drugs was monetary compensation, though this practice is not without its ethical concerns. Going into the research, I assumed, based on past experience, that clients of the harm reduction centers, as well as the research field site, were accustomed to receiving at least \$20 compensation for time spent in an interview. Monetary compensation raises concerns about voluntary participation since economically marginalized individuals may feel compelled to participate in the research. I am unsure if the participants felt this way. However, with the exception of two participants, I did not detect any reticence toward answering interview questions, and during the consent process I told each participant that they did not need to answer every question. Many of the interviewees seemed to enjoy telling me stories about their experiences and several thanked me for listening to them. With the two participants who gave short answers, I tried without success to build conversational rapport, but eventually gave up allowing the interview to end quickly.

Recruiting health care practitioners proved to be a much harder task. Initially, I attempted snowball sampling, but that only yielded one interview and then came to a standstill. A physician friend of mine tried to help recruit participants from her workplace, but that too fell through when her institution, in consultation with their legal department, disallowed hanging a recruitment flyer at their facilities. Finally, a colleague connected me to a physician researcher who provided me with links to two invaluable individuals. Ironically, neither of them were physicians, but they had both conducted qualitative interviews with health care practitioners in the past and were willing to connect me to potential interviewees. Over the next six months, I would correspond over email on a near daily basis with health care practitioners—sending them

information about my research, answering their questions, sending follow-up emails, and scheduling and re-scheduling interview times. I kept a chronicle of these recruitment efforts and below are notes from one attempt (which was ultimately successful) to recruit and interview a physician. Notably, this physician also held administrative responsibilities at his hospital, and thus had a professional assistant.

6/28/12

Emailed physician Phillip to see if he was interested in an interview.

7/16/12

Phillip responded to my June 28<sup>th</sup> email. He can do a “focused” 30 minute interview in the fall.

Heard from Phillip’s assistant about setting up the interview in late Sept. After a couple of emails we settle on Sept. 26.

9/19/12

Received an email from Phillip’s assistant asking if we can reschedule the interview for Oct. 2<sup>nd</sup>. I reply yes.

9/26/12

Received an email from Phillip’s assistant asking if we can reschedule the interview for Oct. 4<sup>th</sup>. I reply yes.

10/4/12

Interview Phillip. He was amiable and nice.

It was not uncommon for a month or two to elapse between my initial email and the actual interview. In all, I attempted to recruit 20 health care practitioners. Six did not respond to

multiple emails and one replied that he does not come in contact with injecting patients. Thirteen health care practitioners were successfully interviewed.

In the interest of equality, I also offered compensation to the health care practitioner participants in the form of a \$20 Amazon.com gift card. Knowing that I could not compensate them at the level they receive in their professional capacity<sup>4</sup>, I chose to offer the gift card as a token of my gratitude for their contribution to the study.

Recruitment of research experts was also conducted through the help of personal and professional connections. However, I personally knew two of the researchers I interviewed and encountered no difficulty recruiting them. The other two were recommended by colleagues. These interviews were shorter—averaging around 30 minutes.

### *Conducting Interviews*

The interviews I conducted with people who inject drugs took place in several different locations. The primary location was a private room at a harm reduction center. Six interviews were conducted in a private room at another research study field site, and two interviews took place at a donut shop at a table in the back corner. The interviews usually lasted about 45 minutes, but some went for over an hour. As mentioned, most interviewees were quite forthcoming with their responses to my questions. During the consent process, when I told them they did not need to answer every question, there were many who said something like: “You can ask me anything. I am a very open person.”

The interviews with health care practitioners took place in the offices of the participants with the exception of three individuals. One opted to do the interview in a café near his hospital,

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<sup>4</sup> I learned from one of the individuals, who connected me to health care practitioners and had conducted qualitative interviews with this group previously, that a compensation of \$200 per interview was used.



and two chose to be interviewed in their homes. Most of the interviews lasted around 50 minutes, with the exception of Phillip's "focused interview," which was 25 minutes. For the most part, the interviewees identified with my interest in the health and health care of people who inject drugs and offered thoughtful responses to my questions. The third interview I conducted, which was with Christine, the medical director of a methadone clinic, presented an interesting, but at the time anxiety-producing, resistance to the framing of my research. This exchange occurred near the beginning of the interview after I had just started to ask her questions about health care for people who inject drugs:

Christine: when I was looking over your stuff, I am sort of curious why this separation of people who inject drugs? I see this as a very academically derived group because from the bottom I don't see that as a very distinct group.

Kelly: When I first started it had to do with who I thought was stigmatized the most. And then it's sort of grown through talking to my advisor and my committee to looking at the creation of this public health, epidemiological population of injection drug users and how that sort of moves within biomedicine so that's going to be a piece of my research which I didn't put in my description which is looking at the history of that label.

Christine: Yeah. When you talk about a group of people who are stigmatized you probably want to talk about poor drug users. I mean there's huge overlap with those groups but...

A couple minutes later I ask again about people who inject:

Kelly: Do you see common characteristics among the people, the injectors that you do see?

Christine: I'm not even sure that I could sort out injectors from non-injectors. I can't describe my patient population. They all have a history of opiate dependence and most of them have probably injected at one point or another but I don't see injectors as a separate group.

Finally, after a series of questions about the identification of patients who inject and certain conversations she has when learning that patients inject, I still felt resistance to acknowledging injectors as a separate group. I decided to yield to her preference:

Kelly: Well I don't know, since you don't make that distinction... I'm glad that you're putting that out there. You're pushing it. So I want to steer the questions to, I guess to not talking about injection drug users as a specific subset but just talking more about active drug users.

Christine: That's easier for me. I mean most of them are injection drug users but I don't... I'd say like seventy thirty maybe. Seventy percent have injected sometime probably and thirty percent haven't. I just couldn't say like if I think of ten of my actively using patients, I'm not sure I could identify ones who are sniffing versus injecting and I mean I could think of some of them. I don't see a huge distinction between them.

These exchanges with Christine served as both a frustrating and revelatory moment in realizing that my specific research topic might seem irrelevant or incongruous to the experiences of the health care practitioners I would interview. I don't believe Christine was attempting to destabilize the interview as a way to assert her power, as one of my colleagues suggested, but rather she seemed to be trying to help me better understand her on-the-ground experience with providing care to drug users. This interaction caused me to reflect on my choice to investigate this particular group of drug user and add questions to my interview guide that asked health care

practitioners about the relevancy of this categorization to their work. No other health care practitioners questioned my focus on people who use drugs by injection and several noted the specificities of this particular type of drug use.

The interviews conducted with research experts occurred in the offices of the researchers. Through these interviews, I was hoping to learn more about the productive effects of the “injection drug user” risk category. All four interviewees didn’t quite understand this concept when I stated it plainly, which was a point of frustration for me. However, after concluding the interviews and upon further reflection, I realized that the interviewees provided useful insights into the practices and effects of governance over people who inject drugs. Their contributions offered observations of how this group is defined through its label and whether the group has self-awareness.

### *Data Analysis*

Data transcription and analysis took place during the same period of time when interviews were conducted and several months after interviews concluded. I used the qualitative data analysis software HyperResearch to organize and code the interviews. In analyzing data, I looked at whether and how descriptions of drug user health included references to harm reduction strategies or concerns, as well as the disease model of addiction. I found that references to harm reduction were made by most participants, but the health care practitioners were the only ones who spoke about drug use as a disease. In my analysis of the interviews conducted with experts on drug use research, I had questions in mind about the governance of drug users. None of my analyses were based in the exploratory and productive goals of “grounded theory,” but rather I approached the analysis of data with particular questions in mind.

However, I did conduct open coding of all interviews so that I could be aware of recurring topics and interests among the participants. These may prove to be useful in future writing endeavors.

#### ON BEING REFLEXIVE

As mentioned earlier, self-referential reflexivity is not without its criticisms. Among them are: concerns about the author's stable representation of self and other; the use of others as a type of possession that enables a "self-telling" (Skeggs 2002); a lack of awareness toward the produced nature of subjectivities, both the author's and the study participants' (Walkerdine et al. 2002); and collusion with the modernist goal to produce a more penetrating, rigorous, and foundational view (Macbeth 2001). However, despite these strong and warranted critiques, it still seems important to discuss where I fit within this project, though my position, assumptions, and perspectives were always shifting and contingent on context. Since I am the one who conducted and analyzed the interviews, and wrote manuscripts and other research products, I should make an accounting of my (shifting and contingent) positionings and beliefs. I do this as more of an ethical practice than as a way to signify that my research is more rigorous or "real" in its depiction of the health of people who inject drugs. That there are critiques of self-referential reflexivity does not permit the creation of an invisible author.

I entered the research field with certain assumptions about the people I would interview. I saw people who inject drugs as highly stigmatized, and thus often mistreated on an individual level and also at the level of social institutions. My sense from working with people who use illicit drugs for nearly five years prior to graduate school was that they felt great ambivalence about their drug use—receiving societal messages that they should stop, but feeling and knowing on some level that their drug use served a particular purpose in their life. This was *my* perspective—formed through and contingent on my past experiences. I intentionally adopted the

stance that drug use was neither wrong nor bad, but just something that people did. In this way, the mistreatment of drug users by health care practitioners was deeply troubling to me as was the apprehension drug users felt towards seeking care.

I firmly believed when I started fieldwork that an antagonistic relationship existed between drug users and health care practitioners. This was based on my prior work experience with drug users and the many informal conversations I had with them about their experiences with receiving or attempting to receive health care. I attributed this difficult relationship to the normative aims and disciplinary practices of health care. A part of my assumption proved to be incorrect—very few antagonistic doctor-patient relationships were described to me. The health care practitioners I interviewed seemed very understanding toward the plight of low-income drug users and were concerned with the quality of health care their patients received. In fact, they worried about their drug-using patients' interactions with other less sympathetic health care practitioners. Also disproving my assumption, many of the interviewees who inject drugs reported that they had a positive relationship with their health care provider, though they'd had bad experiences in the past. However, part of my assumption was at least partially correct—power was at play in the provision of health care to people who inject drugs and within constructed notions of health, though it was less noticeably disciplinary and more soft or pastoral in nature. This will be taken up in more detail in chapter four.

As mentioned, much of my orientation toward drug use and people who use illicit drugs was formed through several years of past experience working with drug users in New York City—first as a counselor at a methadone clinic and then as a research interviewer for a public health study on hepatitis C. In some ways, having lived a stable and privileged life as a middle class white person may have conditioned my interest in the outlaw and bohemian cultures

associated with drug use. My background may have also made harm reduction and syringe exchange more exciting or interesting. There is, indeed, a contingent of young, white, hip people involved in harm reduction programs and services. However, as my time as a harm reduction adherent and practitioner wore on, I became increasingly aware of the limited scope of intervention this approach offered. I was certainly interested in the health of drug users, but I felt there was a lot more going on than simply health. However, at the time, I didn't have the vocabulary to name it. Graduate school and sociology would subsequently assist in providing schematics for a broader social analysis.

My ability to tell this brief story linking my social background to my orientation toward the people I researched is a "self-telling" (Skeggs 2002) that relies on fixed notions of drug users, as well as the harm reduction movement. Neither the people nor the movement are stable and fixed, but in my mind, at various points in time, I produced generalizations about them that helped me understand how I got to be involved in this line of work and in this type of research. It is a story I told myself to help make meaning out of the trajectory of my interests. However, that story is about how I *became* interested in drug users and harm reduction. My enduring interest in this research field is less directly attached to romanticized notions of a drug use culture and has more to do with humanitarian concerns and an interest in the operations of power. An accumulation of sad and frustrating experiences with friends and colleagues who used drugs slowly worked to unsettle any notions of "cool" I had attached to drug use. As that happened, my studies and work in graduate school led me to understandings of power that ignited my interest and seemed to apply to the troubled relationship I perceived between drug users and health care. Thus, I shifted as my contexts shifted.

## CONCLUSION: ON BEING EVERYWHERE AND NOWHERE

Where does this flexible approach to research and power leave me? Has it allowed me to avoid recognizing power asymmetries? My hope, of course, is that it has not. During fieldwork, I aimed to avoid coercion and exploitation as any good researcher would. In some ways, entering fieldwork with fixed, preconceived notions of what the power relations should or could be, and what the people will be like in thought and action, can be profoundly disrespectful. Assumptions that remain fixed can interfere with relationships, as well as the careful collection of data. I found myself interested in qualitative methods because of their flexibility and responsiveness to context. Similarly, in-depth interviews allowed for fluidity and an organization unique to the context of the interview (Paget 1983). In attempting to mimic natural conversations, in-depth interviews permit an openness that can occasion a reconfiguration of power relations.

In my interview practice, my attempts at reflexivity, and the presentation of data, I aimed to avoid a fixing of the study participants into stable subjectivities, even as I described the production of subjectivity enacted by medical and public health governance. While IRB application procedures may require the researcher to construct a category that flattens the multiplicities of participants, this does not mean the research must be carried out with this assumption of flatness. Further, the three principles of ethics the IRB guardians—beneficence, justice, and respect for people—provide for no practical advice when dealing with the messiness of the field. Again, fixed notions are not helpful. Even the concept of “do no harm” can be difficult to implement when there are many pathways of action, and the harm they may produce is unknown. Being reflexive about self and other in these micro-ethical instances is helpful, though reflexivity is a slippery concept.

*Doing* reflexivity in fieldwork is generally recommended as preferential to merely being reflexive when composing research findings (Guillemin and Gillam 2004; Skeggs 2002). Positional reflexivity, where the author uses study participants in a “self-telling,” fixes at the same time as it produces the subjectivities of both researcher and researched (Skeggs 2002; Walkerdine et al. 2002). However, as I found, avoiding positional reflexivity due to these critiques serves to make the author invisible, which is not ethically sound. A reflexive accounting that recognizes the instability of subjectivity and the fluid (rather than fixed) operation of power works to address the critiques. This type of reflexive account resonates more soundly with my research experience. My assumptions shifted, my interview practices were fluid, power relations felt more interactional, and both my subjectivity and that of the interviewees could not be considered stable in any way. So, while this research project was surely conducted somewhere in the realm of people, power, discourse, and ideas, it is difficult to pinpoint the exact (fixed) location.



## Chapter 3

Who *is* the Injection Drug User?: The Intertwined Construction and Governance of an Emergent  
HIV/AIDS Risk Group

“Definitions of risk may serve to identify Self and Other, to apportion blame upon stigmatized minorities, or as a political weapon”.

Deborah Lupton (2013[1993]:489)

Previously considered a risk group for hepatitis B, the “intravenous drug abuser<sup>5</sup>” began to receive increasing interest from public health and medical researchers in the early 1980s. While researchers had long been interested in individuals who use illicit drugs and their cultural attributes and practices, those who inject their drugs came under particular focus at this time as a high rate of AIDS, as high as a 50% prevalence rate in some places (Des Jarlais et al. 1989), was documented among this group. Identified as an AIDS risk group by epidemiologists, the figure of the “intravenous drug abuser” was subsequently linked to various traits through numerous research studies and corresponding publications, and then submitted to behavior change interventions emanating from the state, as well as communities of people who use drugs. As public health researchers, as well as those of other disciplines, notably ethnographers with anthropology and sociology backgrounds, labored to understand how and why AIDS, and then

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<sup>5</sup> A note about language: There have been several terms used in the scientific literature to label this risk group. The initial term that predominated was “intravenous drug abuser,” which was then changed in the late 1980s to “intravenous drug user” and very soon after to “injection drug user.” None of these changes were across the board; for example, some still use “intravenous drug user.” Recently, there has been a push among people who conduct research on injection drug use to use the term “people who inject drugs” because it represents people-centered language. In agreement with this change, I have attempted to use this language in my own writings, including this chapter. However, when writing about older research that used older terms, I use the terms employed by the authors and put them in quotes. Any inconsistency is a result of my own reticence to use older language.

later HIV, was spreading through drug using communities, they also actively constructed the meanings attached to a category of people who had not been so clearly defined previously. Since the social process of constructing this category was supported by the modernist rationalities of science, it was understood as a necessity, an obvious tool in the fight against AIDS. The path taken in constructing the figure of the person who injects drugs was determined in part by science, but also through acts of interpretation and morally-shaded concern. Much of this research can be linked to the desire to govern a newly emerged category of people who inspired concern and fear in the midst of a moral panic surrounding the AIDS epidemic. This chapter will in part focus on representations in research articles early in the AIDS epidemic (from 1984 to 1988) that built the “injection drug user” (née “intravenous drug abuser”) and their connection to acts of governance over certain individuals and groups. The implementation of behavior change interventions aimed at this group, as well as efforts towards self-care, will also be examined as acts of governance.

This analysis shows how this risk category was created as an act of governmentality by a diffuse set of actors laboring under a concern for managing a population and the individuals it contains. The Foucauldian concept of governmentality aids in understanding how power is exercised at both the level of the population and the level of the individual. In governmentality, the sphere of the social is constituted by two types of power—policing at the population level and pastoral care at the level of the individual. These form the, “... double itinerary of a power that moves *between* managing social relations and governing individual conduct” (Orr 2010: 549). The on-going construction of the figure of the person who injects drugs involves an intersection of these two types of power, as efforts are made to regulate the population and individuals are activated to participate in self-care.

The Foucauldian concept of bio-politics, which is a form of policing power that focuses on health and vitality, also guides this analysis as it seeks to understand how and why a category was created to manage the health of the population. As Foucault (1984) writes, beginning in the 17<sup>th</sup> century, the exercise of power was reconfigured in the West such that it became "... bent on generating forces, making them grow, and ordering them, rather than . . . dedicated to impeding them, making them submit, or destroying them" (p. 259). This type of power is interested in the propagation of life, in managing life so that it can flourish. The fact of living enters the power/knowledge nexus, such that power over life is maintained through the production of knowledge of life processes, health, and disease. Foucault (1984) states, "... one would have to speak of *bio-power* to designate what brought life and its mechanisms into the realm of explicit calculations and made knowledge-power an agent of transformation of human life" (p. 265). The management of life through calculations reveals a historic shift away from reliance on faith and religion as authors of transformation.

Regarding the construction of the injection drug user, as knowledge was produced about this type of drug user, more power could be exerted over this group to change their behaviors and on a deeper level, their subjectivity. Going a step further, the mere creation of this category and its attribution to certain individuals signifies a powerful process of differentiation whereby the individual is produced as distinct and deviant from an elusive "norm." In examining Foucault's genealogy of the modern individual as subject, Dreyfus and Rabinow (1982) write: "Foucault's thesis is that sexuality was invented as an instrument-effect in the spread of bio-power" (p. 168). The invention of the injection drug user is both a way to serve the ongoing processes of bio-power and an effect of it. While there is no doubt about the importance of stemming the spread of HIV among people who use drugs, a biopolitical lens offers the analysis of the creation of this

risk category a way to examine the governmental, political, and managerial power infused in the activities of the science of public health and the population it created.

An individualizing form of power theorized by Foucault also guides this analysis, as the figure of the person who injects drugs was not merely considered or analyzed at the level of population, but also on the individual level. Foucault's notion of "technologies of the self" aids in understanding how power operates through permitting, "... individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality" (Foucault 1988: 18). Through pastoral acts of power, individuals understand themselves as certain types of subjects and manage themselves according to guidance provided by diffuse networks of power. Practices of self-care work to determine who the person is: "As there are different forms of care, there are different forms of self" (Foucault 1988: 22). Behavior change interventions aimed at people who inject drugs often engage individuals in their own self-care and management, while at the same time constructing their subject position or "who they are."

Pastoral power with its emphasis on self-care has an affinity with a neoliberal rationality of governance and its production of the self-activated, entrepreneurial subject. Provocations of self-care resonate with a neoliberal rationality which "... involves creating a sphere of freedom for subjects so that they are able to exercise a regulated autonomy" (Petersen 1997: 194). Neoliberal governance demands self-development within the context of the devolution of public welfare, which effectively "privatize[s] social inequalities" (Orr 2010:550). Pastoral and neoliberal forms of power become most relevant to those who inject drugs when considering self-advocacy and self-care movements that began in the mid-to-late 1980s.

The analysis in this chapter is informed by an understanding of science as socially and culturally constructed. Simultaneous to the public health construction of the risk group of people who inject was the construction by the scientific community of AIDS and HIV, the disease and the virus. In her analysis of the battles fought over the scientific discovery and naming of the virus associated with AIDS (which eventually was called HIV), Treichler (1992) showed how scientists constructed the reality of the virus, showing that what is considered “real” is often the result of conflict between competing perspectives. In summarizing part of her argument as to how science is culturally constructed, Treichler (1992) states: “The point is that these data always engage with an already constructed perceptual and interpretive apparatus, albeit one designed to mitigate or erase its own effects (e.g., scientific method)” (p. 72-3). As with data collected on people who inject drugs, the findings must be understood as filtered through “perceptual and interpretive” apparatuses that have been constructed to understand results in ways that fit with prevailing logics. As Rosenberg (1989) asserts, the sociological study of epidemics offers a “cross-sectional perspective” that reveals the “continuing interaction among incident, perception, interpretation, and response” (p. 3). Understanding that science is a constructive process allows social and cultural analyses of the creation of “facts” or “populations” to reveal the workings of power, as well as the constructed-ness of “reality” (Knorr-Cetina 1981; Latour 1987).

To trace the construction and correspondent governance of the “injection drug user” in the scientific community, I reviewed the course of scientific publications about people who inject drugs from the early 1980s onward, looking at the meanings and concerns attached to this group. I carefully examined several highly-cited publications that appeared between 1984 and 1988 to get at what this group was coming to mean for public health researchers and how they proposed

to act upon it. Additionally, I interviewed four prominent public health researchers of drug use and AIDS/HIV in the New York City area to get their perspective on the construction of this risk category. Those interviews revealed insights about group awareness among people who inject drugs and the motivations behind transitions in the language used for the risk group label.

### *The New Public Health*

The creation of this risk category must be understood in the context of the prevailing paradigm in public health at the time. According to Petersen and Lupton (1996), the new public health emerged in the mid-1970s as new knowledges and practices that focused on health status, particularly that of the “population” and aspects of “lifestyle” conducive to ill health, began to proliferate (p. 15). The new public health has a broad reach since it takes as its foci the categories of “population” and “environment” in their widest sense, which allows it to stretch into psychological, social, and physical elements (Petersen and Lupton 1996:ix). Arriving at a time of economic and cultural neo-liberalism, which emphasizes individual freedom yet self-responsibility, the new public health regulates at a distance by providing norms by which individuals are monitored and classified. In this way, it aims to persuade people to conform voluntarily to the goals of the state and other agencies (Petersen and Lupton 1996).

The field of epidemiology, as a modernist and rational method employed by the apparatus of the new public health, aims to identify, define, and manage public health “problems.” In doing so, epidemiology creates categories by which people are classified, which in turn, shapes the data collection. Petersen and Lupton (1996) quote Bloor (1995) to explain the self-fulfilling nature of category creation: “The ways of seeing that are endorsed by the adoption of particular classificatory schemes become themselves the basis for the everyday interpretative acts of those who compile and construct the statistical tables” (p. 40). In attempting to organize and contain

disorder, epidemiology creates categories such as “injection drug user.” This act of category creation installs a particular field of visibility, as well as certain practices of seeing and interpreting that self-perpetuate as data is presented and new data is collected. Commenting on the method of scientific classification mobilized by the field of epidemiology during the early years of the AIDS epidemic, Oppenheimer (1988) writes that it “defined the questions raised and thus answered.” Further, the ceaseless measurement, standardization, and comparison used by epidemiology to control disorder also works to contain disorder by clearly identifying social groups as being at-risk. In turn, such groups become “... reservoirs for shared anxieties and dreads on the part of majority groups, who are presented as members of ‘the public’ who require protection from ‘contaminating others’” (Petersen and Lupton 1996:56). A concern for containing AIDS/HIV within the community of people who inject drugs, and thus not allowing it to escape from that group and infect others, is apparent in popular scientific literature and will be shown later in this chapter. Understanding current practices and activities of the new public health, such as its regulation-at-a-distance and reliance on epidemiological measurement and categorization, offers context for recognizing the construction of the “injection drug user” risk group in the public health imaginary of the 1980s. Re-visioning this group as a socially constructed category in 1980 offers a penetrating reflection, in the mode of a Foucauldian-style genealogy, on the constructive acts of power, as it literally brings certain subjects into being on both a discursive and material level.

### *Risk Groups*

The epidemiological concept of “risk group” has been vital to predominant understandings of HIV/AIDS transmission from the early days of the epidemic onward.

The popularization of the concept of AIDS risk groups was made possible by efforts initiated early-on by the Centers for Disease Control (CDC) to identify subgroups at risk for AIDS. The CDC feared that since homosexual and bisexual males were such a large proportion of AIDS cases, dynamics of transmission in this group would overshadow those of other groups unless the data were examined separately (Glick Schiller, Crystal, and Lewellen 1994; citing Centers for Disease Control 1989). The CDC constructed a highly-criticized hierarchy of exposure categories that was used when AIDS cases were reported to local registries. This strategy served to obscure modes of exposure by assuming that if homosexual sex or injection drug use were reported, then that was the mode of transmission. There was no consideration for the HIV status of the person's partner(s) in sex and drug use, nor, if the person had injected drugs, whether he/she shared needles (Glick Schiller et al. 1994; citing Schoepf 1991). Glick Schiller et al. (1994) assert that: "The end result of the logic of classification utilized by the CDC was that, in the United States and industrialized nations, anyone who was gay or who used intravenous drugs became identified as a member of a risk group, whether or not he or she engaged in behavior that transmitted HIV" (p. 1338). Further, the CDC classification system obscured the fact that semen and blood transmit the virus—not sexual orientation and the use of drugs (Glick Schiller et al. 1994). Since prior to 1984 no microbe had been isolated as the etiologic cause of AIDS, and thus being part of an AIDS risk group was equated with being a carrier of the disease (Oppenheimer 1988).

Another concern with the creation of AIDS risk groups is that they have led to the fabrication of what are believed to be pathologic subcultures. In trying to understand the transmission of AIDS among people who used injection drugs, the federal government funded ethnographic study of this risk group after a significant push from the social science community



to do so. The cultural analysis of this group resulted in the production of language and imagery that further exoticized, stereotyped, and isolated an already highly stigmatized sector of society (Kane and Mason 1992) and produced the notion that HIV risk is confined to only marginalized sectors of the U.S. population (Glick Schiller et al. 1994). Noting the social processes of differentiation associated with the concept of an epidemic, Berlant (2010) states: "... we learned most recently from AIDS, after all, that the epidemic concept is not a neutral description, but always a contribution to ongoing mechanisms of social distinction. Who's degenerate, who's competent, and who's out of and in control?" (p. 31). In fact moral attribution has historically been a component of a society's attempt to understand the randomness of an epidemic. In analyzing the episodic quality of epidemics, Rosenberg (1989) found that: "Men and women have often expressed moral convictions as they have sought to explain and rationalize epidemics, but such values have ordinarily been articulated in terms of those mundane biological processes that ordinarily result in sickness or health" (p. 5). The concept of an epidemic renders the expression of moral values, which may be articulated through social differentiation, the appearance of natural-ness.

Problematically, culture was represented in early research on people who inject drugs as a natural descriptor, such as age or sex, by which populations could be divided into bounded subgroups, which facilitated the partition and marginalization of this group (Glick Schiller et al. 1994). The categorization by risk group also served to obscure the within-group diversity, which was found by Glick Schiller et al. (1994) to be much greater than the differences between members of the risk group and individuals outside of it. By focusing on the behavioral practices and so-called culture of this group, researchers failed to account for the production of risk by the law, poverty, and social stigmatization (Kane and Mason 1992). The AIDS risk group led to the

manufacture of a subculture that was found at fault for its pathologic practices and further pushed to the margins. Later in this chapter, I will discuss a rift between researchers over the attribution of cultural traits to the IDU risk group.

Ironically, it was through recognition by the CDC that people who inject drugs were also at risk for AIDS, that the lifestyle model of analysis, which hinged on the moralistic notion of promiscuity, was dropped in favor of the hepatitis B analogy (Oppenheimer 1988). Under the hepatitis B analogy the transmission of AIDS was re-understood as related to a biological agent whose vector was blood and/or its constituents. However, lifestyle factors could still be incorporated into explanations for transmission, though to a lesser degree (Oppenheimer 1988).

#### ACTS OF CONSTRUCTION AND GOVERNANCE

My aim in this section is to closely follow the figure of the “intravenous drug user” through the early days of the AIDS epidemic from 1984 to 1988, and then give an overview of the continuing social construction and governance of this figure from 1989 to the present. I will accomplish this by conducting an analysis of five acts of construction and governance represented in popular research publications that focus on injection drug use, as well as literature that addresses the progression of the HIV/AIDS epidemic and interviews with prominent public health researchers of drug use. I’ve identified five groupings of constructive and governmental acts that loosely flow chronologically, but are not completely mutually exclusive: 1.) suspicion and concerns; 2.) surveillance and differentiation; 3.) behavior change and self-activation; 4.) sociological intervention; and 5.) the expansion of power. As Rosenberg (1989) asserts, the negotiated public responses to epidemics have historically provided social scientists with insight into social values at particular times, as well as structures of authority and belief. Following the construction of this risk group offers the opportunity to glimpse popular values and beliefs, and

their connection to new technologies of managing public health as revealed through responses to the AIDS epidemic.

Notably, there are historical patterns to how epidemics and their social response proceed. Rosenberg (1989) likens the progression of epidemics to acts of a play owing to the fact that he sees epidemics as taking on the quality of a pageant, "... mobilizing communities to act out proprietary rituals that incorporate and reaffirm fundamental social values and modes of understanding" (p. 2). This resonates with the understanding discussed earlier that the practices and assertions of science, public health science included, reveal hegemonic styles of interpretation, as well as social values. The "proprietary rituals" mentioned by Rosenberg can be understood as the epidemiological response to AIDS and the way research on IDUs proceeded. These both reveal dominant structures of thought and feeling (Williams 1977) that created and facilitated the social and public response to AIDS.

Recently, Des Jarlais, Arasteh, and Friedman (2011) published a brief historical account of HIV among people who use drugs at Beth Israel Medical Center in New York City over the previous 25 years. Their historicization relied on a different method of organization that hinged on disease prevalence and transmission rates. In tracing the epidemic among "injection drug users" from the mid-1970s through the early 2000s, they believe the epidemic can best be described in four successive stages—introduction and rapid transmission (1978-1983), stabilization of HIV prevalence at high levels (mid-80s through mid-90s), decline in incidence and prevalence following the arrival of syringe exchange programs (mid-90s through early-to-mid-2000s), and a phase where sexual transmission is more important than injecting-related transmission among IDUs (mid-2000s to the present) (Des Jarlais et al. 2011: 131). As this chapter follows the public health literature on HIV/AIDS and people who inject drugs, this

construction of history will be engaged along with other research articles by Des Jarlais and Friedman since they both were and are influential researchers in this relatively small field of knowledge production.

*Suspicious and Concerns (late 1970s-1985)*

Several years before the CDC officially released its 1981 report on what was to become known as the AIDS epidemic, substance abuse researcher Don Des Jarlais and his colleagues at the New York State Division of Substance Abuse Services, including a group of former drug users called the Street Research Unit who monitored drug use and sales for the state, noticed an increase in pneumonia deaths among people who use drugs (Des Jarlais 2009). People who use drugs had long been the subject of social science and public health research, and those who inject drugs (then referred to as “intravenous drug abusers” or “intravenous drug users”) had been traditionally considered a “subculture” within anthropological and sociological research (Des Jarlais, Friedman, and Strug 1986; Singer 2012). Much of the early sociological and anthropological literature on drug use was not focused on or organized around certain ways of administering drugs, but rather tended to focus on a particular drug or simply on “addicts” (e.g., Agar 1973; Becker 1963; Feldman 1976; Preble and Casey 1976). A more explicit focus on those who inject drugs is an artifact of the AIDS epidemic.

Using its risk group schematic, the CDC reported the first cases of AIDS among people who inject drugs in late 1981. The risk group organizational principle introduced more fully by the CDC in 1983 (Oppenheimer 1988) served to make order out of the disorder generated by this new disease. It seems to have achieved a fixed stability at this time as much, if not all, of the literature to follow utilizes it. This risk categorization continues to be used today in research literature reminding us that when supported by hegemonic systems of rationalization, which

themselves may be undergirded by “stories,” there can be a “hardening of the categories” (Haraway 1997:139; citing Watson-Verran 1994). Samuel (Sam) Friedman<sup>6</sup>, a long-time researcher at the National Development and Research Institutes (NDRI), attested: “When I started, when I got my job [in 1983] we were studying that group. It was already all set up.” By about 1983, there was indication that people who use drugs knew about this new disease and had some sense that it was spread through needles. Prior to AIDS, those who injected drugs had known that hepatitis B could be spread through sharing needles, and thus they extrapolated this to the new ailment going around, which many referred to as “walking pneumonia” (Des Jarlais 2009; Des Jarlais, Friedman, and Hopkins 1985). Well before AIDS, researchers showed that those who injected cohered as a group within drug using culture and may have formed something of a subculture, which included communicating with each other about illness (Des Jarlais et al. 1986).

In 1984 and 1985, the virus that causes AIDS, then referred to by two names as the result of conflict in the scientific community—lymphadenopathy-associated virus and human T-cell lymphotropic virus type III (LAV/HTLV-III)—had been isolated and the anti-body test developed. This led to the discovery that at least half of the injection drug users in New York City were infected with the virus (Des Jarlais et al. 2011). Prior to this discovery, epidemiologists who were studying AIDS had not researched drug users because they believed there was a relatively small number of research subjects available (Oppenheimer 1988). This was proved incorrect by the anti-body test. Researchers were also reluctant to study drug users before 1984 due to a feeling also reflected in the attitudes of society at large, “that addicts are of less social consequence than other patients” (Oppenheimer 1988; citing Schultz 1987).

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<sup>6</sup> See Appendix for professional profiles of the four researchers interviewed for this chapter.

In medical, social science, and public health academic literature on AIDS, this risk group began to cohere around 1984 and was identified as “intravenous drug users,” a label that had been previously used in medical literature documenting particular medical conditions among this group. One of the more popular research articles that focused on AIDS and people who use drugs in 1984 came from a group of researchers affiliated with the New York University School of Medicine, and also included Des Jarlais and Friedman as authors. Michael Marmor, Ph.D., an epidemiologist was first author of the article, which was published in the first volume of the *Journal of Substance Abuse Treatment*<sup>7</sup>. In correspondence with the journal title, the article focused on “drug abusers,” which is emblematic of both the current language in use and the moral attribution of people who use drugs at that time. The article proposes the suspicion that AIDS is spread among drug abusers “presumably” by the transmission of the virus via sharing needles, works (drug injection equipment such as cookers), and drug-containing solutions (Marmor et al. 1984:237). The article also plays a role in the initiation of a refrain heard in many research articles to follow: that AIDS can be spread from IV drug abusers through sex and perinatal transmission. This claim constructs the person who injects drugs as a vector in the spread of AIDS and also points to the necessity of containing the virus within this group.

Another article published in 1984 by Harold M. Ginzburg, a psychiatrist and an associate director in the Division of Clinical Research at the National Institute of Drug Abuse (NIDA), uses the term “intravenous drug user” and worries about the “... occasional recreational drug user who shares a needle and syringe when he or she self-administers cocaine or amphetamines at a party on the weekend” (1984:206). In fact, Ginzburg (1984) voices a variety of concerns with respect to “intravenous drug users” and AIDS ranging from their possible infection of drug

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<sup>7</sup> The shared timing of the first volume of this journal and the appearance of “intravenous drug users” in research literature on AIDS appears to be coincidental.

treatment program staff to their lack of organized advocacy to the diversity of this group impeding prevention efforts. Voicing another concern, Ginzberg (1984) states: “Because the drug-abusing community is poorly defined and services to it are typically provided by a potpourri of resources, containment of AIDS among this group becomes a serious public health issue” (p. 207). Similar to Marmor and his colleagues (1984), people who inject drugs are described as drug-abusing, which again reveals the moralistic shading of the risk group. The issue of containment is also raised, which positions the “intravenous drug user” as a threatening figure that must be bounded. Finally, similar to Marmor and colleagues (1984), Ginzberg (1984) makes a preliminary claim about the significance of sharing needles in the transmission of AIDS, which shows that researchers were not yet completely convinced that sharing needles was a mode of transmission.

Containment was raised again in an article published in 1985 by Des Jarlais, Friedman, and Hopkins in the *Annals of Internal Medicine*. The authors state that “intravenous drug users” (the label used in this article) are a “bridge” for the transmission of AIDS to other groups, most notably children and heterosexual partners (p. 98). As two socially-sanctioned groups, children and heterosexuals are positioned as the innocent victims of the socially-maligned “intravenous drug user.” Furthermore, this claim enacts a partition between the “intravenous drug user” and heterosexuals and children, effectively keeping this type of drug user distinct from those two (supposedly) non-infectious groups. However, Des Jarlais, Friedman, and Hopkins (1985) show concern for the plight of the person who injects drug and say as much: “Public health control of the AIDS epidemic must include control within the intravenous drug use group, because of both the large numbers of intravenous drug users at risk and the possibility of outward spread to nondrug users” (p. 756). Notably, this article explicitly shows concern for people who inject

drugs and works actively to dispel negative stereotypes about them, which in turn works to construct who this drug user is. Firstly, the authors worry that “intravenous drug users” may be impeded from recognizing AIDS as a health risk because it is difficult to distinguish between AIDS as the cause of death and other causes of death in this group. IV-drug users may experience AIDS-related symptoms simply from the travails of drug use, and thus may not recognize that they have the early signs of AIDS. Secondly, Des Jarlais, Friedman, and Hopkins (1985) use research they conducted through the Street Research Unit to show that “intravenous drug users” are capable of changing their behavior and concerned about their health. Des Jarlais and Friedman repeat this assertion elsewhere (Friedman, Des Jarlais, and Sotheran 1986; Des Jarlais 2009) and in doing so reveal an effort to counteract de-humanizing assumptions about people who inject drugs and to reformulate the predominant image of this group within research circles. Through their policy oriented research, Des Jarlais and Friedman endeavor to educate readers about the relevant characteristics and behaviors of IV-drug users and advocate for their protection from AIDS.

The research articles during this time of concern and suspicion show the early stirrings of governmentality as the researchers and authors begin to suspect that the sharing of needles transmits the new virus, and thus reveal nascent ideas about pathways of intervention. Further, the researchers begin to enact a boundary around this group of individuals by expressing the need to contain the virus. Ginzberg (1984) issues a call for a more precise construction of the risk group when he says that it is “poorly defined” (p. 207). A clearer picture of the parameters and characteristics of this risk group will facilitate efforts to manage its members’ behaviors. To the mounting concerns over how to implement prevention programs, Des Jarlais, Friedman, and



Hopkins (1985) add that “intravenous drug users” seem to be conducive to and capable of changing their behavior in the name of health.

*Surveillance and Differentiation (1986 and onward)*

For the figure of the “intravenous drug user,” 1986 brought the publication of research articles based on ethnographic surveillance of cultural attributes of this group. As Campbell and Shaw (2008) write: “Ethnographic drug research has been a central discourse through which the construction of identity categories has metamorphosed into the IDU subject position” (p. 707). Friedman and Des Jarlais, along with collaborators, published two articles, which aimed to describe the culture of intravenous drug use in order to understand why and in what contexts needles were shared. Friedman, Des Jarlais, and Sotheran (1986) described the characteristics of this “subculture” as a way to propose effective methods of health education for this group. They explicitly state that “IV drug users” (the term they use) are not ensconced in a pathological culture, but rather one that provides them with rewards. They describe the attributes of this subculture as mistrust, violence, oral communication, and difficulties in reading and writing (Friedman, Des Jarlais, and Sotheran 1986: 385). Further, needle sharing is deeply embedded in this culture and serves social bonding and economic functions (Friedman et al. 1986). An article published by Des Jarlais, Friedman, and Strug (1986) in an edited collection on the social dimensions of AIDS delves further into explanations for sharing needles. They see it as a ritualistic part of the initiation into drug injection, a necessity and way of demonstrating trust between sexual partners or friends (i.e., running partners), and an economic and utilitarian exchange in shooting galleries where drugs can be injected with less fear of police interruption. It appears that this early exploration of “sharing,” a behavior not well-understood, was primarily based on interview material rather than direct observation (Page and Singer 2010:72).

Both articles point out that the entrenchment of these cultural attributes and practices of “intravenous drug users” is such that behavioral change among this group will be difficult. For instance, refusing to share needles could endanger personal relationships that people who use drugs need to survive (Des Jarlais, Friedman, and Strug 1986; Friedman et al. 1986). The cultural traits, though deemed not pathological by the authors, are practices that are widely stigmatized (Stoller 1998). Further, by showing the IV drug user culture as generative of risk, the authors present a degree of hopelessness for change and fail to recognize that external social and economic factors shape risky behavior (Clatts 1994; Schiller Glick, Crystal, and Lewellen 1994). In fact, cultural representations of needle sharing as ritualistic bonding among people who inject drugs were used at least as a partial excuse by the federal government for not supporting needle exchange or distribution programs (Stoller 1998:98). Stoller reports: “It seems that people at the CDC believed (or said they believed) that even if you gave junkies clean needles they would still share” (p. 98).

Showing a crack in the on-going scientific construction of the association between drug use and AIDS, an article appeared in 1986 that questioned the hegemonic focus on needle sharing as the main risk factor for AIDS. Brown et al. (1986) hypothesized that the overall physical experience of drug abuse (not just injection drug use, but all types of “abuse”) could cause immunologic aberrancies that put one at increased risk for developing AIDS. In fact, in the late 1980s and early 1990s, controversy arose over the attribution of HIV to AIDS. A prominent molecular biologist at the University of California at Berkeley and a member of the National Academy of Sciences, Peter Duesberg, asserted that HIV was one of many viral infections of AIDS patients, rather than the cause of AIDS. Instead, Duesberg hypothesized that the AIDS epidemic was attributable to long-term consumption of recreational drugs, as well as the toxic

effects of AZT (Epstein 1996; citing Duesberg 1987). This focus on the drug user lifestyle is emblematic of new public health approaches that highlight the association between lifestyle and ill-health (Petersen and Lupton 1996). With their lack of specificity, the hypotheses of Brown et al. (1986) and Duesberg (1987) reveal a wholesale stigmatization of people who use drugs rather than the more targeted approach of researchers who constructed representations of the culture of needle sharing.

However, these articles all work to differentiate and then malign the lifestyle and culture of drug users by directly connecting it to the acquisition of AIDS. Through surveillance of intravenous drug users, Des Jarlais, Friedman, Strug, and Sotheran make claims about the peculiarities of the culture they enact, a culture that in many cases runs counter to the logics of mainstream culture. Specifying that it is the culture, or in the case of Brown et al. (1986) the lifestyle of drug use, that promotes transmission of the virus opens a surface upon which interventions can spread, a surface upon which power can play.

Although on-going throughout the 1980s and 1990s, and thus concurrent with other acts of construction and governance, changes made to the language used in the risk category label exhibit an emphasis on precise differentiation of this emerging public health population. All of the researchers interviewed acknowledged transitions in terminology for naming this risk group, but placed differing levels and kinds of significance on the terminology. As Sam and Brian Edlin, a physician-researcher at NDRI who conducts research on hepatitis C and people who inject drugs, explain the initial name for the group involved the term abuse. Brian: "... when I was in my medical training [in the early '80s] we used the term IVDA, which stood for intravenous drug abuser." Sam: "When I came in '83 everyone was talking about, to the extent they talked about it at all, was intravenous substance abusers, sometimes abbreviated IVSA, or

intravenous drug abusers; always abuser, abuser, abuser.” Noticing this convention when he began working with Don Des Jarlais in 1983, Sam felt compelled to push toward changing the term to “intravenous drug user” or IVDU. He explains how he did this: “So when I first got here and was working on papers Don would write or some of our colleagues on the project, I’d keep writing notes saying, ‘We can’t use that terminology. No one thinks of themselves as an abuser. It’s totally misleading in every respect because it’s the injection that’s the risk. It’s got nothing to do with use or abuse.’” Both Brian and Sherry Deren, a researcher of injection drug use at New York University, noted that when NIDA put out its large funding initiative to support research into drug injection and HIV/AIDS, the federal institute used the term “injection drug user.” Sherry explained: “I think that’s part of what defines it because people start using that in writing their proposals and in writing their papers.” When Brian arrived at the CDC in 1989, they were in the process of changing the term from IVDA to IVDU. He explained,

... from the epidemiologic and public health standpoint, in other words the CDC standpoint, we were interested in talking about behavior. We were not interested in judging or characterizing behavior. We weren’t even interested in treating addiction. We were a public health agency and we were interested in doing epidemiology. So epidemiologists want to use terms that are as neutral and descriptive and precise as possible. So these were people who were using drugs whether they were abusing or not was baggage we didn’t want to bring into the terminology that we use. So it would be intravenous drug *user*.

The concern for neutrality also appeared in Sam’s description of the transition from abuser to user, though he sites different origins: “That comes out of my radical past. That came out of simple concepts and crude mainline sociology that in some ways I disagree with, which is value

neutrality.” Sam put his past training in sociology, as well as his radical beliefs, into practice by fighting for the term “user,” which has a more neutral signification.

All of the researchers brought up precision or accuracy as a reason for the transition from “*intravenous* drug user” to “*injection* drug user.” Injectors were not always shooting substances directly into their veins. In explaining this transition, Brian said it was due in part to the recognition that people on the west coast were skin popping (or shooting under the skin rather than into a vein) black tar heroin.

De-stigmatization also played and continues to play a role in the language transitions that accompany this risk category from the 1980s until now. By de-stigmatizing or neutralizing the label, prevention efforts could be made more palatable to recipients, as well as attain scientific accuracy. When discussing the early use of the term “intravenous drug abuser,” Sam stated: “It’s both stigmatizing and inaccurate scientifically because it’s not what we’re talking about and as a prevention tool, totally puts people off, so how can you use it?” As Brian stated earlier, the abuse of drugs was not being studied as a factor contributing to HIV transmission so it was “inaccurate scientifically” to use that term. Further, as Sam explained, using the term abuser when interacting with people who inject drugs as part of prevention efforts “totally puts people off.”

These risk group language games were played in the name of de-stigmatization, neutrality, and accuracy and serve to further differentiate the group of individuals who were the target of HIV/AIDS prevention campaigns. Precise differentiation constructs subject positions that are both ready for and malleable to governance.

#### *Behavior Change and Self-Activation (1987-1988)*

On March 12<sup>th</sup> of 1987 the first meeting of the AIDS Coalition to Unleash Power (ACT-UP) took place. This activist group was, at least initially, dominated by the concerns of middle-

class gay men, as that group had been hit very hard by AIDS and had the resources to form a powerful coalition (Patton 1990). That same year, Friedman, Des Jarlais, Sotheran, Garber, Cohen, and Smith (1987) published what was to become a very popular article that examined the possibilities for self-organization among “intravenous drug users” (the term they used). They compared the developing efforts among “intravenous drug users” to inject more safely to the more widespread attempts by the gay community to protect themselves from HIV, asserting that the gay community had achieved more risk-reduction behavior change than “intravenous drug users.” Finding that “intravenous drug users” are more likely to protect themselves (i.e., refuse to share needles) if their friends and acquaintances do, Friedman et al. (1987) suggested that collective self-organization could develop peer support for risk reduction. However, they noted serious obstacles to this self-organization on the individual, group, and societal levels. On the individual level, addiction exhausts time and energy, and poverty limits access to resources. On the group level, the obstacles involve the predatory social relationships of the drug market, which result in mistrust and a lack of solidarity. On the societal level, the obstacles are legal repression and stigma, including a hostile press and public. Despite this, Friedman et al. (1987) reported that a group of people who formerly used drugs had formed in New York. Calling themselves the Association for Drug Abuse Prevention and Treatment, or ADAPT, this group, which was non-judgmental toward people actively using drugs, worked to address the problems of AIDS among people who use drugs.

Friedman et al.’s (1987) article presented a further delineated picture of the “intravenous drug user” as concerned about his/her health. In this new rendering, the “intravenous drug user” may also be civically-minded, or at least the members of ADAPT were. Adhering to neoliberal cultural rationalities, many of the practices of the new public health have to do with a widespread

tendency to establish links between personal goals and “the public good” (Petersen 1997: 203). The obstacles to self-organization presented, while appealing to the reality of coalition formation, also work to form the image of the “intravenous drug user.” However, more salient at this moment in time may have been a shift in the discourse that revealed support for the efforts of people who use drugs to protect themselves from infection (Stoler 1998:100). Under the new public health, as well as neoliberal rationalities, health promoters, such as Friedman and colleagues, see themselves as working from a distance to forge collaborative ventures and promote community action (Petersen 1997). By supporting and collaborating with current and former drug users, researchers could spur self-governance among this group. Through the interplay of research activities and grassroots actions, the image of the activist “intravenous drug user” was beginning to form.

Around this time, syringe exchange programs were beginning to legally open in the cities of Tacoma, Washington in 1988, San Francisco also in 1988, Portland, Oregon in 1989, and New York City in 1992 after the brief appearance of a legal syringe exchange in 1988 (Lane et al. 1993). These exchanges were being organized by the voluntary efforts of people who currently and formerly injected drugs, activists, researchers, and other advocates. In representations of the figure of the “injection drug user” in research publications, as well as reports and news coverage of the newly opened syringe exchanges, the emerging discourse of the “injection drug user” as an active participant in self-care and advocacy appeared (Stoller 1998). People who inject drugs were forming legally sanctioned organizations to protect themselves. In this mode of activity, they were not docile bodies being molded through outside disciplinary forces, but rather a group that had organized itself and provided the means for their own behavioral change.

On the subject of group awareness and the formation of a community among people who inject drugs during this time of self-activation, some disagreement emerged among the researchers interviewed. Ric Curtis, a Professor of Anthropology at John Jay College of Criminal Justice who conducts research on drug users, felt that researchers had no impact on the formation of this group. He states: "I don't think the presence of the researchers led to any more or any less community among the community of injectors. I don't think our presence would have made that much difference, to tell you the truth." Furthermore, Ric is doubtful as to the existence of any significant amount of self-identification among people who inject:

I don't think anybody necessarily wants to have their primary identity as that of an injecting drug user. I mean, who wants to self-identify as that? "I'm a man first," you know what I'm saying? So no one would ever identify in that fashion first and foremost as an injection drug user unless they were looking for something specifically related to that. Like, "I'm an injection drug user. Can I get that free bag of dope that you're offering?"

Ric further explained that drug dealers might advertise their product by giving a free bag of dope to an injector who is more "the real deal" than a sniffer, because this person would subsequently advertise the product to other users. In this instance, a person who injects drugs might identify as such, but otherwise he or she would not want to take on this identity. Ric's observation that people will identify as an "injection drug user" in very limited circumstances casts doubt over claims about self-organization among people who inject drugs.

However, Sam's take on group awareness and self-organization was quite different. Discussing his activist work beginning in the mid-1980s with self-organization among people who use drugs, Sam showed that there was group awareness:



Meanwhile in terms of the self-concept of drug users and drug user organizing, that has a long history, some of it before I came on the scene. There was the NAMA group, National Association of Methadone Advocates, and also an early version of ADAPT (Association for Drug Abuse Prevention and Treatment). It all started before I came around. Now, in '85 a group of us kind of re-created ADAPT to focus on AIDS. And through various AIDS meetings and harm reduction meetings, once they started to happen, and syringe exchange conventions, we had meetings to set up U.S. users groups in coalition. Now, it was slow, disorganized. Part of the problem was some of the U.S. user groups had to hide the fact that they were users groups because they were publicly out as other things. This was high tide in the war on drugs so it created some difficulties.

We had meetings, various kinds of other meetings in the U.S. trying to organize them.

In Sam's depiction, people who use drug were making attempts to organize themselves along with the help of other advocates, such as Sam, revealing their group awareness and showing that this risk group category did not only exist in the minds of researchers, but also, materialized in activist efforts to address the spread of AIDS.

Around the same time as the beginnings of self-organization among people who inject drugs, the federal government provided wide-scale funding to support research that investigated HIV among people who inject drugs, using a variety of research methods, including ethnography, surveys, and intervention trials. While the National Institutes of Health (NIH) had supported four research centers in 1986, between 1987 and 1988, forty-one projects in sixty-three different sites were funded. A study model was designed called the National AIDS Demonstration Research (NADR) project, which involved initial research by ethnographers to establish contact with networks of "injection drug users" (the term used by federal funders) and

then assignment of willing research participants into enhanced or standard-of-care risk reduction interventions. The findings of this research were mixed, with some support for the enhanced intervention (Page and Singer 2010). Mostly, this research was fixated on why people who inject drugs share needles and how to prevent them from doing so.

Popular publications that came out in 1988 focused on behavior change, particularly in terms of needle use, among people who inject drugs. Des Jarlais and Friedman (1988) published an article that proposed a theoretical framework to be used in designing new AIDS prevention programs for “intravenous drug users” (the term they used). The components of this framework involved the attachment of new cognitive and emotional meanings to sharing needles, making available the means of behavior change, such as through the provision of clean needles, bleach, and drug treatment, and reinforcement of new behavior patterns. After examining several other research studies, Becker and Joseph (1988) show that, contrary to the common stereotype, “intravenous drug users” (the term they use) are changing their behaviors, but caution that this group doesn’t trust public health authorities.

The publications in 1988 show a new effort being put forth to examine the intricacies of behavior change among people who inject drugs. This group was now being viewed in terms of its malleability, as researchers began to prepare a major project, NADR, aimed at exacting behavior change. Reflecting on his own participation as a researcher in NIH-funded AIDS prevention research, Clatts (1994) suggested that this research became an exercise in behavior modification theory and had more to do with social control than the prevention of disease. Further, Clatts (1994) saw this research as fitting the subject to the prevention technology, rather than the other way around. That this type of interventionist research occurred concurrently with the self-organizational and self-care efforts of people who inject drugs reveals the “double

itinerary of power” functioning on the population and individual (i.e., self-care) level within operations of governmentality (Orr 2010: 549).

*Sociological Interventions (1994)*

As mentioned previously, the practice of sharing needles was represented as firmly embedded within the culture of people who inject drugs and served social, as well as economic, needs. People who inject drugs purportedly shared needles with close friends and lovers as a way to forge bonds and express trust, and the managers of shooting galleries allowed customers to inject with available (often previously used) needles for a fee. In the early-to-mid nineties, this assertion about injection drug use culture was questioned by the ethnographer Stephen Koester, who was working for a NADR project in Denver. The reliance on a vague and simplistic notion of needle sharing was being questioned by researchers who sought to understand the social context, as well as the micro-practices of sharing (Page and Singer 2010). Thus, researchers were beginning to unpack the reasons for and practices of sharing with the aim of moving away from any simplistic notion of this practice.

Koester (1994) troubled the previous, culture-bound depiction of sharing through his ethnographic research in Denver, which revealed that syringe sharing took place largely because access to new syringes was blocked by legal restriction. Koester (1994) specifically noted that cultural or psychological explanations could not be relied upon to understand needle-sharing practices. The illegality of syringe possession further works against carrying needles on one’s person since many people who inject drugs have outstanding warrants that may be called-up if they were to be stopped by the police for needle possession. Koester’s work represented a shift from individual and group-level explanations for needle-sharing to an analysis that examined the law and criminal justice practices.

Similarly, Clatts (1994) questioned the notion that a universal culture of needle sharing existed that crossed boundaries of time and place. He asserted: “. . . I have never talked to a drug injector who wants to share needles” (1994: 94). Rather, it is the larger social and economic circumstance that put most people at risk for AIDS, and further much of the suffering caused by AIDS is connected to the social rather than medical response to the virus. Clatts (1994) wrote: “I maintain that the anguish and suffering that I have witnessed over the last ten years is not caused by a virus. Rather, it is generated by people and is what we do to make more out of an affliction than the merely medical, and to make something other of the afflicted than merely sufferers of disease” (p. 93-4). The construction by researchers of the pathological subculture of injection drug use positioned those who inject drugs in ways that increased rather than soothed their suffering.

These sociological interventions provoked much needed reflection and criticism with respect to individualizing behavioral change interventions that had been standard practice. They focused attention on social structural circumstances that made risk reduction among people who inject drugs difficult, as well as the harm that had been done by constructing this group as pathological in a variety of ways. While the analysis presented by Koester (1994) was formative for future research and structural interventions, it cannot be understood outside of the operations of power. Structural adjustments, such as removing legal prohibitions on carrying syringes, allow for more autonomy, and thus more choices for individuals. Increasing freedom, which is a key aim of neoliberal rationalities of governance, places individuals in the position to make choices that are in accord with cultural norms and social institutions (Reith 2004). Through this governance-at-a-distance, freedom is expanded, but expectations of appropriate thought and behavior remain intact and function to carry out this veiled form of governance.

*Expansion of Power (1990s-present)*

In the early and mid-90s, another concern regarding the health of people who inject drugs began to appear in the literature—hepatitis C. Prior to AIDS, infection with hepatitis B had been a widespread health concern for people who injected drugs, and a research interest for those who studied this group. In fact, those who injected had discerned that hepatitis B was spread through sharing needles and had made some efforts to avoid this behavior (Des Jarlais 2009). Unlike hepatitis B, there is no vaccine for the hepatitis C virus (HCV), and it has and continues to run rampant among people who inject drugs, though syringe exchanges have helped stem the tide to some degree (Hagan et al. 1995; Edlin 2011). HCV is spread primarily through blood-to-blood contact, and thus there is not the concern of people who inject drugs infecting innocents through sexual contact, though sexual transmission does happen in rare instances. The federal government has provided relatively little funding to investigate this virus, despite the fact that five times as many people are infected with HCV as HIV in the United States (Edlin 2011). There is concern that if this health concern is left unaddressed by research and social programs, people who inject drugs and are infected with chronic HCV will be a significant cost to our public health care system. The estimated costs are in the tens of billions (Edlin 2011; citing Pyenson et al. 2009). Hepatitis C has become part of the public health identity of the risk group along with the worries, economic and humanitarian, that come attached to the high prevalence of this infection. Additionally, people infected with chronic hepatitis C, many of whom inject drugs, are positioned to cost society billions upon billions of dollars in the near future.

Finally, in an interesting twist, public health researchers began to speak about the non-injection drug user or NIDU in the early 2000s (e.g., Neaigus et al. 2001; Gyarmathy et al. 2002). This corresponds to stage four of the chronology of injection drug users and HIV

constructed by Des Jarlais, Arasteh, and Friedman (2011). At this time, the research gaze turns to HIV transmission among people who use drugs, but do not inject. Thus, sexual transmission of HIV between drug users becomes the concern. As Des Jarlais, Arasteh, and Friedman (2011) report, HIV prevalence among heroin and cocaine users who have never injected is around the same level as HIV prevalence among people who inject (citing Des Jarlais et al. 2007). In light of this, Des Jarlais, Arasteh, and Friedman (2011) recommend a re-organization of HIV risk groups, such that heroin and cocaine users--whether they inject or not--are considered a single population. They note that there are many transitions between injecting and non-injecting drug use, and that heroin and cocaine users may change behavior over time (Des Jarlais et al. 2011). This development reveals that a “hardening of the categories” (Haraway 1997:139) may not always be complete or enduring. Perhaps, what could be called a softening of the category is evident in the appearance of the NIDU in research literature.

A breakdown in the immutability of the risk categorization “injection drug user” was evident in one of my research interviews with a health care practitioner. When I began asking Christine, a medical doctor who directs a methadone clinic and provides primary care to drug users, questions about her injection drug using patients, she stated: “I am sort of curious why this separation of people who inject drugs? I see this as a very academically derived group because from the bottom I don't see that as a very distinct group.” She continued: “I'm not even sure that I could sort out injectors from non-injectors.” Probing further, I questioned whether she asked her patients about injection, and if that in turn triggered any certain types of medical discussions. She replied: “Well because all of our patients are at such high risk for HIV and hepatitis, everybody gets screened...” This resonates with the expansion of risk group categorization

proposed by Des Jarlais, Arasteh, and Friedman (2011) whereby all users of cocaine and heroin are considered to be equally at risk for HIV transmission.

Both of these developments—the increasing recognition of HCV risk and the appearance of the NIDU—offer an expanded field of intervention upon which power can play. The revelation that hepatitis C is highly prevalent among people who inject drugs indicates that governance specific to this virus is needed. Now that syringe exchanges and the possession of needles is legal in some localities, people who inject drugs must participate in self-surveillance and care to avoid hepatitis C. The re-organization of HIV risk groups suggested by Des Jarlais, Arasteh, and Friedman (2011) widens the risk group to include drug users who do not inject (NIDUs), and thus subjects new bodies to governance practices that had been reserved for people who inject drugs. Christine enacts this breakdown in the IDU risk categorization by screening all of her patients—whether or not they inject—for HIV and hepatitis.

Another change in the power play of governmentality over people who inject drugs is the recent push to begin calling this group “people who inject drugs” (PWID) rather than the previous term “injection drug users.” Using people centered language can be considered symbolic of the individualizing tendencies of neoliberalism, where governance is exacted at the personal level. Three of the researchers interviewed, Sam, Brian, and Sherry, favored this shift in language because it was humanizing and more respectful. Sherry described her interest in this term:

And then the last year or so, now they are PWID and I actually incorporated that. I’m writing a proposal and that’s the term I use. And that’s certainly not commonly used at all but they are people who inject drugs obviously and I think that it’s just sort of a more respectful way of describing them. They’re not just known as injection drug users.

They're people and they inject drugs and they also do other things. I don't actually know how that change came about but a couple of my colleagues started incorporating it in their work and I've decided to do that as well.

Brian also explained that he had incorporated the new term, which he referred to as "person-centered language" into almost all if not all of his work. He had also written a letter to the *American Journal of Public Health* advocating the journal adopt the term when the authors of an article he was reviewing for the journal were hesitant to switch from injection drug user to people who inject drugs, which the journal responded to "enthusiastically."

Sam applauded the nascent terminology change, but recognized that some apprehension existed:

In the last few years there's been a push for person who injects drugs, although I have to tell you, some of the people really don't like it even though in some ways they invented it because it's abbreviated PWID. I said this is what's going to happen. The "people who" is absolutely essential and that's something which came out of chiefly the users groups themselves.

Similar to person with AIDS or PWA, PWID acknowledges the person first and then the behavior or illness of interest. The researchers see this new term as a further step towards de-stigmatizing people who inject drugs, though it comes with some reservations in connection with the way it sounds when spoken. While this term may be seen as suggestive of a neoliberal emphasis on the individual and personal responsibility, for the researchers, it represented a move toward more respect and a fuller recognition of one's humanity.



## CONCLUSION

“... the ways in which these categorizations are made, and which categories come to have effects in the world, are never neutral”

David Valentine (2007:5)

While the researchers interviewed for this chapter may have felt that the adoption of the “injection drug user” label provided a more neutral identification, the constructive process that generated knowledge on this risk category reveals a host of concerns and attributions that malign this group at the same time as they facilitate the opening of a space for governing power.

Through the early days of AIDs, when concerns about containment of the virus and a lack of knowledge about the people at risk dominated, until the present state involving expansion and specification of this risk group, a range of operations of power at the population and individual level have simultaneously constructed and governed this particular type of drug user. Producing knowledge about this group, as occurred in the period of surveillance and differentiation, is simultaneously an act of governance as it determines what personal characteristics and behaviors will be acted upon and in what ways. Descriptive information generated about “intravenous drug users” in this period discursively manufactured governable subjects. These subjects were then managed through behavioral change interventions, and governed-at-a-distance through support and facilitation of self-activation. Through self-organization and the proliferation of syringe exchanges, the activist “injection drug user” participated in self-care and self-governance.

Sociological interventions into the production of knowledge about this risk group supported a more free and autonomous “injection drug user” who could self-manage in an environment with minimally restricted access to new syringes. Prior to these interventions, knowledge generated through public health research had focused on the pathological culture of injection drug use and

ignored the structural constraints that made risk reduction difficult or impossible for those who injected drugs. By freeing “injection drug users” from these constraints (such as legal prohibitions against needle possession), they could participate in self-care as neoliberal autonomous decision-makers. Finally, the specification and expansion of the risk category by the appearance of hepatitis C and the figure of the NIDU allowed for both new and expanded surfaces upon which governance could be enacted.

A re-visioning of the construction of this risk group category through the lens of governmentality allows for a reflection on the productivity of power. The person who injects drugs was constructed and re-constructed throughout the last three decades, and this had effects on the levels of research, discourse, identity, and practice. However, this entire process was enveloped within a general humanitarian concern for a vulnerable group of people. As the research publications and the interviews with researchers show, an interest in protecting and improving health was coupled with a concern for de-stigmatizing a group that participated in illegal activities and was labeled socially deviant. Acts of “caring for” individuals can be understood as forms of governance (Deverteuil and Wilton 2009), whereby power works through enactments of care and protection and the promise of well-being. Laboring under a desire to install policy and practice to reduce the transmission of HIV/AIDS, public health researchers mobilized epidemiological organizational principles and ethnographic modes of understanding to manage the disorder caused by disease and fear.

An analysis of the frameworks that were mobilized to understand and organize the spread of HIV/AIDS, such as the notorious CDC hierarchy of infection, and the practices they engendered, such as behavior change interventions, casts light on the dominance of particular social values. This genealogical analysis of a risk categorization reveals that the use of

epidemiology and other public health modes of analysis to understand the spread of HIV/AIDS, led to the creation of a subject position and an identity category. Using the individual person as the unit of analysis rather than the virus aligns with cultural logics of neoliberalism that place responsibility for the monitoring of risk and illness on the individual. The way HIV/AIDS was studied and organized affirms the social value of individualism, and more specifically, the belief that individuals can be governed through education that urges behavior change.

This dissertation research project cannot escape the claim that it too constructs the figure of the person who injects drugs by utilizing the subject position to conduct analyses of power and health. After all, sociology as a practice of knowledge production is deeply intertwined with “the social” as a field invented by governmentality to enact certain rationalities and produce power effects (Orr 2010). Ironically, by using the Foucauldian concept of “governmentality” as an analytic tool, the re-visioning of the construction of this risk group offered here can perhaps lead to a “method for making up and re-making again what’s real” (Orr 2010: 554). Telling the history of epidemiological risk categories with an understanding that they are produced by power, that they are power-effects, can un-do what may be seen as “real” for those involved in public health research and for those upon whom the label has been bestowed. This opens a space for a shift towards focusing on acts of power rather than the individuals who are produced through their effects, as well as a shift towards disrupting settled accounts of the identity of the person that injects drugs. This is important when we consider that representations of this group in scientific literature may be used by policy makers, as well as the media, to craft opinions and recommendations on policy and law, which have material effects on individuals and work to construct and reinforce the “real” existence of this group.

## Chapter 4

### Contingencies of the Will: Uses of Harm Reduction and the Disease Model of Addiction Among Health Care Practitioners

For health care practitioners, understanding the relationship between health and drug use for patients who use drugs is complicated by at least two conflicting yet overlapping frameworks from which to draw. The harm reduction approach offers practitioners a picture of drug users at risk for infectious disease and other harms associated with drug use, but willing and able to protect their health given the right tools, such as new syringes and risk information (Fraser 2004; O'Malley 1999). The disease model of addiction, which is firmly embedded within established medical knowledge, positions drug users as pathologic and excessive consumers. This chapter will show how these two approaches to defining and intervening upon the health of drug injecting patients take shape and overlap in the medical practices and discourses of a sample of health care providers in New York City by examining qualitative interviews conducted with them in 2012. Despite its philosophical differences with the medical model of care, which largely hinge on the attribution of autonomy (Heller, McCoy and Cunningham 2004), a harm reduction approach to care was embraced by all in this group. This did not prevent them from also holding a disease concept of addiction, and, in fact, allowed some interviewees to articulate rationales *for* the disease concept. Harm reduction principles were evident in descriptions of the disease model of addiction offered by several health care practitioners. In the discourses of the health care practitioners, an affinity emerged between the “objective” medicalized discourse of addiction as disease and the non-judgmental approach of harm reduction. Placing commitments to harm reduction alongside the discourse of disease, including that which drew in neuroscience, this

chapter offers a window into the ongoing and occasionally conjoint constructions of both harm reduction philosophy and the disease model of addiction in the context of health care. In offering this window, this chapter shows how differential technologies of power manifest in the context of primary care.

Harm reduction has been analyzed through the lens of governmentality, wherein drug-taking individuals express their regulated autonomy through technologies of the self that accord with ideologies and calculations of risk emanating from diffuse sets of institutions, experts, and other health promotion organizations (Campbell and Shaw 2008; Fischer et al. 2004; McLean 2011; O'Malley 1999). In contrast, notions of addiction as disease, which denote excessive and troubled patterns of consumption associated with a lack of autonomy, remove the option of self-governance and place responsibility for care in the hands of addiction experts and health care professionals. The absence of will symbolized by addiction as a disease offers the gateway through which health care practitioners can bring in ideological commitments associated with harm reduction, such as the de-stigmatization of drug use. However, harm reduction in practice and discourse places great emphasis on drug user autonomy (Denning 2001). It has been posited that discourses of self-governance or personal responsibility sow the seeds for contradictory discourses of excessive consumption such as addiction (Reith 2004), but the health care practitioners articulated no great conflict between the seeming opposition between the facilitation of autonomy found in harm reduction discourse and the refusal of autonomy expressed by discourses of addiction. Rather, both approaches to the health care of people who use drugs could be deployed and in some ways intertwined, though they addressed the will of the drug user in distinct and contingent ways.

In tracing inscriptions of the will of the drug user as it was expressed in contingent discursive contexts the findings of this chapter offer an examination of the incorporation of harm reduction, broadly defined, into the medical practices of the interviewees, as well as an examination of how the health care practitioners articulated various constructions of the disease model of addiction drawing in harm reduction principles.

Any analysis of the disease model of addiction must recognize that it is a social construction linked to historical conditions, cultural standards of normative behavior, and advances in biotechnology (Campbell 2010; Kaye 2012a; Keane 2003; Reinerman 2005). To contextualize this, a discussion of the medicalization of addiction and various critiques of the disease model of addiction is offered. In scrutinizing the inclusion of harm reduction philosophy in the construction of addiction as disease, points of conflict between the medical approach to providing care and that of harm reduction will be discussed. Given the recognition of drug user autonomy rooted in the philosophy of harm reduction, it is remarkable that health care practitioners are incorporating elements of it into their practices of medicine.

The practice of medicine has been studied as a site of disciplinary power where authoritative judgments are bestowed by credentialed health care providers onto docile patients who play the “sick role” (Foucault 1979; 2007b; Lupton 1994; Parsons 1951; Szott 2014). Incorporating a discourse, such as harm reduction, which mobilizes a form of power that works to bolster the will of the individual toward self-care, into the disciplinary context of medical care presents contradiction in terms of individual autonomy. However, this contradiction does not preclude the ability of these two forms of power to work together in a single setting. This chapter explores the implications of the co-presence of technologies of power noting how one type of power may beget another.

*Harm Reduction Philosophy*

I think that most doctors don't use it [harm reduction]. I think that the health care system works under a different philosophy. People talk about it because it's kind of sexy and they don't know exactly what they're talking about.

Monica, M.D.

As Monica, one of the health care practitioners I interviewed, explained, the health care system in the United States operates under a framework that differs from the philosophy of harm reduction in significant ways. Further, she intimates that while health care practitioners might give lip service to harm reduction, their knowledge of it is superficial, and therefore their practice of it inadequate. Examining the philosophical framework of harm reduction reveals that it runs counter to the hegemonic practices and philosophy of medical care. This may be why Monica disparages the knowledge level of people working in our health care system. If they knew what harm reduction was really about, they'd realize they were not practicing it, since it looks quite different than the way care is provided in mainstream medical contexts.

The philosophy behind harm reduction is seen as revolutionizing the way we respond to human problems, namely addiction and AIDS, and as a middle-road alternative to the moral model (as exhibited by the War on Drugs) and the disease model of addiction. In contrast to harm reduction, both of these models tend to support abstinence as the primary goal. Harm reduction is rooted in a "bottom-up" approach based on drug user advocacy and accepts alternatives to abstinence that reduce harm (Marlatt 1996: 779). An amoral or neutral stance toward drug use is often adopted, despite the difficulty of enacting this approach (Keane 2003). In contrast to criminal and medical approaches to managing drug users, harm reduction

recognizes and respects drug user autonomy, though this autonomy may be regulated by risk calculations (O'Malley 1999) and the neo-liberal logic of individual responsibility (Fraser 2004).

While there have been calls for the use of the harm reduction approach in medical settings, its successful inclusion is quite rare (Rachlis et al. 2009; Strike et al. 2014). In an article well-known to the harm reduction social movement community in New York City<sup>8</sup>, Heller et al. (2004) list philosophical clashes between harm reduction and medical models in several domains of practice and care. The authors themselves encountered these clashes while working to develop a collaborative relationship between a harm reduction center in the South Bronx and a local hospital. Many of the clashes stem from differences in where authority lies and who creates knowledge. Heller et al. (2004) see harm reduction as centered on the autonomy of the drug user, and thus valuing of self-knowledge and individual choice. Medicine, on the other hand, places the locus of authority in the physician and his or her discrete and stable medical knowledge. Another difference lies in the theoretical framework for understanding drug use, where harm reduction uses a model (referred to as “drug, set, and setting” (Zinberg 1984)) that encompasses pharmacology, psychology, and macro- and micro-level social setting to aid drug users in assessing the benefits and harms of their drug use, as well as finding strategies for changing risky practices. This model emerged from research Zinberg (1984) conducted on a group of heroin users who presented evidence of “controlled use,” thus substantiating a long-standing harm reduction assertion that there can be “functional users.” Another theoretical framework presented by a central proponent of harm reduction psychotherapy involves addressing “the continuum of drug use and the particular harms that are associated with different drug use styles” (Denning

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<sup>8</sup> Throughout my field work, as I interacted with the staff at harm reduction centers and also during interviews with health care practitioners, I was referred to this article. It was clear that this is a well-known and well-regarded piece among those interested in the health care of drug users.



2001:24). This approach draws attention to the potential for certain types of harm rather than focusing on the perceived necessity of abstinence.

In the field of medicine, the disease model is employed to understand drug use. Active drug use is given a formal psychiatric diagnosis--in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), it is called “substance use disorder,” (American Psychiatric Association 2013) and patients who use drugs are referred for drug treatment that usually requires abstinence (Heller et al. 2004: 37). While the DSM-5 diagnosis of “substance use disorder” takes into account pharmacology, psychology, and social context (though in a more limited way), it is the authoritative way in which the diagnosis is applied that differentiates it from the “drug, set, and setting” model or that of harm reduction psychotherapy. The diagnosis is not used as a way to guide drug users towards self-assessment of the various components of their drug use practices and to find places where adjustment might decrease riskiness. Rather, it is applied in a definitive manner backed by the authority of medical knowledge, and serves as the initiation point for a pathway to abstinence-based treatment. This accords with the belief that the will of the drug user has been compromised through drug use and its restoration is dependent on complete abstinence. In recognition of the autonomy of the individual who uses drugs, harm reduction practitioners simply provide a way (“drug, set, and setting”) to understand drug use and information about the health risks it poses.

In the United States, one of the key stewards of harm reduction, the Harm Reduction Coalition, which is an educational and policy advocacy organization, sets out eight principles that define their construction of the approach. Notably, the first principle states that harm reduction: “Accepts, for better and or worse, that licit and illicit drug use is part of our world and chooses to work to minimize its harmful effects rather than simply ignore or condemn them”

(Harm Reduction Coalition). The fourth principle states that harm reduction: “Calls for the non-judgmental, non-coercive provision of services to people who use drugs. . .” (Harm Reduction Coalition). This principle alludes to an amoral stance towards drug use in calling for a non-judgmental approach. While Keane (2003) asserts the identity of harm reduction is best articulated as pragmatic rhetoric and flexible practices, the principles set down by the key harm reduction organization in the United States alludes to ideals of acceptance and non-judgment. Both constructions of harm reduction conflict with the established model of medical care in the U.S., in that medicine approaches the provision of care with a stable and discrete, rather than flexible, set of knowledge, which gives way to standardized treatment prescriptions (drug treatment requiring abstinence) that leave little room for patient autonomy and symbolically denounce the use of drugs.

#### *Critiques of Addiction as Disease*

Defining addiction as a disease is a product of a larger social process of medicalization that has expanded the jurisdictional domain of medicine into areas formerly considered social problems. Earlier formulations of the concept of medicalization focused on the definitional activities of the social process. Conrad (2005) explains: “The essence of medicalization became the definitional issue: defining a problem in medical terms, usually as an illness or disorder, or using a medical intervention to treat it” (p. 3). The medicalization of a problem also results in new forms of medical social control, which works, “. . . to secure adherence to social norms—specifically, by using medical means to minimize, eliminate, or normalize deviant behavior” (Conrad and Schneider 1992: 242). A clear example, and one which Conrad and Schneider (1992) explore, is the use of methadone administered in a clinic setting to normalize the deviant behavior of illicit opiate use. Besides addiction, other social problems that have been re-defined

as medical conditions are obesity, child abuse, and hyperactivity. Zola ([1972] 2013) similarly warned of the expanding presence of medicine in our social world. Medicalization is an “insidious and often undramatic process” that affects much of our daily living ([1972] 2013: 497). He asserts: “the labels ‘healthy’ and ‘ill’ are becoming relevant to more and more parts of human existence” ([1972] 2013: 497). In fact, anything that can be found to affect the workings of the body and to a lesser extent the mind can be labeled an illness (Zola [1972] 2013: 501). Zola ([1972] 2013) points to drug addiction as an example of the process of medicalization stating: “It was once considered a human foible and weakness” (pp. 501-2). When something becomes labeled as an illness, the issue is not whether to deal with it, but how and when to deal with it. This pushes aside the fundamental question of what freedoms an individual should have over her body (Zola [1972] 2013: 504).

The forces behind medicalization that propelled its wide expansion in the late 20<sup>th</sup> and early 21<sup>st</sup> centuries are many. Previously, social scientists took a social constructionist approach that positioned moral entrepreneurs, professional dominance, and claims-making as the engines of medicalization (Conrad 2005). Zola ([1972] 2013) asserted that medicalization was due to our increasingly complex technological and bureaucratic system, which had led us to reluctantly rely on experts. More recent theorization sees the drivers of medicalization as commercial and market interests, biotechnology, managed care, and consumers themselves (Conrad 2005). The process of biomedicalization as theorized by Clarke et al. (2010) denotes the co-constructive relationships between medicine, biotechnology, risk and surveillance, late capitalism, and privatization. Explaining the difference between medicalization and biomedicalization, Clark et al. (2010) state: “Medicalization practices typically emphasize exercising *control over* medical phenomena--diseases, illnesses, injuries, bodily malfunctions. In contrast, biomedicalization

practices emphasize *transformations* of such medical phenomena and of bodies, largely through sooner-rather-than-later technoscientific interventions not only for treatment but also increasingly for enhancement" (p. 2). Similar to Zola's perspective, the theory of biomedicalization notes the increased focus on the maintenance of health, as opposed to the earlier medical foci of illness and injury (Clarke et al. 2003: 162). Under this regime of health, new identities are forged based on personal relationships to health and embodied health risks (Clarke et al. 2010). Further, Clarke et al. (2003) point to a reorientation of the medical gaze, such that bodies are viewed at the molecular and genetic level based on the medical assumption that, "... it is 'better' (faster and more effective though likely not cheaper) to redesign and reconstitute the problematic body than to diagnose and treat specific problems in the body" (pp. 175-6). Viewing the brains of addicts through magnetic resonance imaging, as well as research that searches for genetic components of addiction, are two such examples of the reoriented gaze of medicine. These new forms and practices of technoscience offer high-tech formats for interpreting addiction as a neurobiological disease, and thus further sediment notions of biological determinism.

While the study and treatment of addiction has certainly been re-shaped by the transformative social processes of biomedicalization, defining addiction as a disease is a process that began over two hundred years ago with the emergence of a new paradigm that defined addiction as a central problem of drug use and diagnosed it as a disease, or disease-like (Levine 1978). Members of the temperance movement argued that habitual drunkenness was a disease and a natural consequence of moderate alcohol use. These claims underscored the necessity of outlawing alcohol since it was thought that even drinking in moderate amounts could lead to the disease of addiction. The temperance movement found the source of addiction in the drug itself,

while post-prohibition thought located the source in the individual body (Levine 1978). The beginnings of this individualized notion of the disease of addiction can be seen in the prohibition-era federally-funded research of Lawrence Kolb, which concluded that psychopathology and personality disorders were the root causes of addiction (Courtwright 2010: 139). The disease concept of addiction gained further traction with the 1935 opening of the Addiction Research Center, a congressionally mandated narcotics farm that sought to investigate physiological components of addiction (Campbell 2007). Methadone maintenance treatment, which was developed in the 1960s as a system of clinics, further medicalized addiction by using a so-called medication to aid addicts in stabilizing their lives and their relationship to opiates. The idea behind methadone treatment was partially based on the belief that opiate addicts created a permanent biochemical change in their physiology (Conrad and Schneider 1992: 135). Vincent Dole and Marie Nyswander, two U.S. physicians who developed and advocated the use of methadone for the treatment of opiate addiction, believed that opiate addiction was a metabolic disorder. Methadone clinics were embraced by the Nixon administration as a cure for the heroin epidemic. Even though the public raised concern over potential diversion of methadone, the clinics stayed in place in part because they served as a mechanism of social control (Conrad and Schneider 1992: 140). The multitude of rules enacted at clinics mean that the patients' lives are highly regulated and surveilled, and there is little room for resistance since patients need regular access to methadone to avoid using illicit opiates. The current approach to understanding addiction focuses on the brain, and its chemical activity and receptor behavior, as a way to explain addiction. Campbell (2010) asserts: "Placing addiction in the brain—effectively displacing it from the social body—has been the culmination of a long social process by which

addiction was redefined as a CRBD [Chronic Relapsing Brain Disease] in the mid-1990s” (p. 90).

In fact, simply defining addiction as a disease was the culmination of a long social process enveloped in particular and changing historical and cultural contexts. As Reinerman (2005) shows: “... addiction-as-disease did not emerge from the natural accumulation of scientific discoveries; its ubiquity is a different species of social accomplishment” (p. 308). Societal institutions such as government-funded research institutes, policy think tanks, and the treatment industry have been instrumental in crafting and cementing the notion of addiction as a disease. One such example is the National Council on Alcoholism (NCA), which was specifically formed in the 1940s by Marty Mann, a public relations executive and former “drunk,” and Dr. E.M. Jellinek at Yale. They joined together to create an organization whose purpose was, “... to popularize the disease concept by putting it on a scientific footing” (Reinerman 2005: 313). Reinerman (2005) specifically notes the chronology of the NCA’s endeavor: “... science was not the source of the concept but a resource for promoting it” (p. 313). Similarly, the current emphasis on neurological explanations of addiction must be put in relation to historical efforts to understand the physiology of addiction and the rise of various technoscientific advances. Campbell (2010) provides a summary of the conditions of possibility that allowed the conception of addiction as a CRBD to emerge:

... visualization of opiate receptors; discovery of the role of endogenous opioids, which unseated the once easier distinction between ‘natural’ and ‘artificial’ rewards; importation of the concept of the ‘brain reward system’; invention of brain imaging technologies (Dumit, 2002); and evolution of technosocial structures within which federally funded research could be conducted and disseminated (p. 96).

While some of the activities listed by Campbell are attributable to basic science, such as the discovery of endogenous opioids, other conditions of possibility relate to advances in technology and structures that support research. Though it may be framed as the natural and logical progression of science, the application of neuroscience to the study of addiction is strongly tied to advances in technoscience and institutional structures (Campbell 2010; Hammer et al. 2013; Vrecko 2010). Neuroscience in the 1990s produced “an expansion of the biological” allowing addiction to be seen in the brain, and undermining previous distinctions between physical and psychological drug dependence (Keane and Hamill 2010: 55-6). Further, neuroimaging research on addiction has resulted in new ways of envisioning the relationships between brain images, “brain types” and perceptions of individualized disease (Dingel, Karkazis and Koenig 2011). Tiger (2013) sums up the use of technology to forward certain types of claims about addiction: “Brain scans and medical diagnoses tell us little about the values of sobriety and abstinence from drugs, but they are products of these values” (p. 35).

The often-unacknowledged interpretive work involved in scientific research is, of course, present in the study of addiction. Campbell (2010) notes: “The capacity to make claims stick depends not only upon what happens in the magnet [meaning MRI scans], but also on the interpretive work—from signal processing to literature reviews—that occupies this culture of science” (p. 90). The production of viable scientific claims involves interpretative work, which can be complicated by the cultural meanings attached to addiction. Through her interviews with drug court advocates who deployed disease model discourse, Tiger (2013) noticed that: “Loopholes and gaps in the ‘science of addiction’ allow for moral and personal considerations to guide the construction and presentation of the science” (2013: 35). Tiger found that while advocates of drug courts were armed with the latest scientific findings on addiction, “... many

appealed to their personal experience with addiction as the source of their knowledge” (p. 35).

Laboring under the rubric of addiction as disease, scientists and drug treatment adjudicators alike use their interpretive skills to support and further the medicalization of drug use.

The medicalization of addiction, including the disease model of addiction, continues the cultural work of instilling meaning within the concept of addiction. Normative judgment with regard to human behavior and the intake of substances inheres within these cultural meanings. Despite its scientific sheen, a medical framing of addiction still has social normalization and improvement as its goal (Keane 2002). As Keane (2002) explains: “It is this therapeutic impulse, the will to improve the body and the self of the individual, which unites the medical ‘scientific’ study of addiction and the burgeoning popular literature of addiction and recovery” (p. 5). Medical discourse constructs parameters of addictive desire that work to judge behavior as diseased or healthy, and in doing so operationalizes a variety of profoundly normative hierarchical dichotomies such as natural/chemical, internal/external and order/disorder (Keane 2002: 6). Diseases, and particularly addiction, are initially recognized through violations of culturally created behavioral norms. Disease is seen in the body when an individual fails to accomplish certain tasks (Kaye 2012a: 36). The practice of attributing addiction to certain individuals works to reveal which types of tasks and behaviors our culture values. Thus, addiction’s formulation as a disease reveals the maintenance of socially constructed notions of health and self-control as paramount social values.

Addiction was produced and continues to be re-produced as a disease in a particular cultural context. For as Keane (2002) explains: “...addiction is not a universal feature of human existence, but a historically and culturally specific way of understanding, classifying and regulating particular problems of individual conduct. It is tied to modernity, medical rationality



and a particular notion of the unique and autonomous individual” (p. 6). These features of our culture are the conditions of possibility for addiction as we know it. A concept of addiction is produced because these features have the capacity to individualize failure, make it knowable, and label it a disease. Recognizing that biology, as well as culture, play a role in our current construct of addiction, Kaye (2012a) conceptualizes addiction as *biocultural* explaining that this does not deny the usefulness of biological information or even biological intervention. Rather: “... it seeks to re-situate these material possibilities in relation to cultural and political realms that socially materialize the biological and bring it ‘to matter’” (Kaye 2012a: 43). Thus, it is the cultural that makes the biological matter.

Working from the stance that addiction exists as a problematic condition that is present in society on the individual and community level, other social scientists have pointed out that there are social and cultural factors, rather than simply biological ones, associated with addiction. Problematizing the National Institute on Drug Abuse’s (NIDA) focus on the neuroscience of addiction, Courtwright (2010) points out that the prevalence and incidence of drug abuse is largely determined by demographic variables, such as migration and family stability, and social forces, such as pharmaceutical marketing strategies and bohemian fashion to name a few. Knowing that there are social patterns of drug abuse raises questions about focusing on individual biological pathology (Courtwright 2010: 140). The study of addiction as an individualized biological disease oversimplifies its causes and removes it from its social environment (Dingel et al. 2011; Levine 1978). There is concern that resources will be funneled to pharmaceutical responses to addiction and away from prevention or response efforts that take into account social contexts (Dingel et al. 2011).

Looking more broadly at the social management of addiction reveals that the complete medicalization of addiction has not occurred (Campbell 2013; Courtwright 2010; Meurk et al. 2013; Tiger 2013). The societal response to drug addiction is not solely medical, as many people who use drugs are managed through the criminal justice system for their addiction (Gowan and Whetstone 2012; Kaye 2012b; Tiger 2013). The incomplete-ness of medicalization is also evident at the level of addiction treatment, where the 12-step model predominates (Gowan and Whetstone 2012; Tiger 2013). While the 12-step model may refer to addiction as a disease, it does not involve or allow pharmaceutical treatment, but instead relies on behavioral and personality change. Tracking the rise of drug courts in the U.S., Tiger (2013) found that their advocates draw on medical theories of addiction to advocate for enhanced criminal justice and by doing so they are contributing to the medicalization of addiction in a particular way. Drug courts, which coerce those convicted of drug-related crimes into drug treatment programs, represent an approach in-between medicalization and de-medicalization. This approach is constituted by "... the appropriation of medicalization that simultaneously emphasizes the veracity of the disease model while de-emphasizing the hold the medical system should have on curing the problem" (Tiger 2013: 87). Drug court participants are sent to treatment programs that emphasize behavioral change and thus, "... fit within the progression of punitive interventions that aim to cure deviance and promote conformity" (Tiger 2013: 87). Criminal justice approaches, including coercive therapeutics, such as mandated drug treatment imply a loss of will among drug users who must be forced into disciplinary treatment settings.

Similarly, Courtwright (2010) finds that the medicalization of addiction is incomplete and resisted from several sources, including medical personnel, social scientists, police, and political actors. These groups have not wholeheartedly embraced the medicalization of addiction for a

variety of reasons. Despite strong support for medicalization in their field, medical personnel have not used their substantial powers to fight the prison-oriented war on drugs because they have little in the way to offer as therapeutic treatment for addiction<sup>9</sup>. The medical profession is: “Stuck in therapeutic limbo, with pathological insight but little ability to cure the underlying pathology...” (Courtwright 2010: 143). While NIDA continues to march forward with its emphasis on the neurobiology of addiction, criminalization is still standard practice. For example, in New York City in 2010, the police department made 50,300 arrests for marijuana possession, which is more than for any other offense and one out of seven arrests in New York City (Levine and Siegel 2011). Statewide in 2011, 137,000 drug arrests were made, which is approximately 24 percent of all arrests in New York State. This puts the per capita drug arrest rate at 703.6 arrests per 100,000 New Yorkers, which is among the highest rates of drug-related arrests per capita nationwide (New York State Division of Criminal Justice Services 2012 and Federal Bureau of Investigation 2011; as cited in Pugh et al. 2013: 13). Further, drug offenses are the leading causes of new commitments to New York State prisons, accounting for about 25 percent of all commitments (Pugh et al. 2013: 13). Arrest and imprisonment related to drugs is a sizeable sector within New York’s criminal justice system at both the city and state levels. It could be said that the criminalization of drug use in New York State is thriving.

The continued criminalization of drug use raises questions about the status of addiction as a disease. Why would someone with a disease be sent to prison for attending to their medical condition? NIDA cleared up any confusion around the status of addiction in its 2007 (revised in 2010) publication *Drugs, Brains and Behavior: The Science of Addiction* which states that:

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<sup>9</sup> At present medical personnel only have the ability, using a small number of pharmaceuticals, to treat drug addiction—not cure it—with maintenance medications, such as methadone and buprenorphine, and a medication, naltrexone, that blocks the euphoric effects of opiates.

“Addiction is defined as a chronic, relapsing brain disease that is characterized by compulsive drug seeking and use despite harmful consequences.” The report explains how addiction changes the structure and function of the brain and has long lasting neurobiological effects. Further, scientists estimate that genetic factors account for between 40 and 60% of a person’s vulnerability to addiction (NIDA 2007). This formulation of addiction is known as the NIDA paradigm and remains hegemonic in many addiction research circles (Dingel et al. 2011). Since the 1990s in the United States, the disease of addiction has been a neurological disease, which aligns with trends of the technoscientization of biomedicine “. . . where interventions for treatment and enhancement are progressively more reliant on sciences and technologies, are conceived in those terms and are ever more promptly applied” (Clarke et al. 2010: 2). However, the NIDA paradigm and its “molecularization” and “geneticization” (Clarke et al. 2010) does not track with notions of regulated agency apparent in discourses and practices of harm reduction. Rather it embeds addiction deeper within the body, and thus intensifies the erasure of will.

As this chapter contends, there is flexibility with the disease concept of addiction, such that it can be used in conjunction with principles of harm reduction, which regulate rather than deny autonomy. Through researching drug courts, Tiger (2013) concluded that: “Addiction’s flexibility as a biomedical category is evidenced by the fact that it is characterized both as a disease, cured through individually tailored treatment, and a moral failing, punished through a variety of coercive sanctions” (p. 77). The investigation here of the uses of the disease model by health care practitioners notices another type of flexible usage that allows contingent recognition of the will of the drug user.

*The Health Care Practitioners*

While all of the health care practitioners practice primary care, they do so in a variety of settings and several also provide drug treatment using the pharmacotherapies buprenorphine and methadone. Additionally, seven of the thirteen health care practitioners devote a portion of their professional time to various research endeavors broadly related to illness and disease, medicine and substance use, which situates them in a field of knowledge consumption and production that undoubtedly shapes their perspectives and suggests they had thought extensively about the health of drug users. Among the health care practitioners who prescribed buprenorphine to treat opiate dependence, the dominance of the disease model was nearly complete, though practitioners who did not prescribe buprenorphine also used the model. Since buprenorphine is a medical approach to treating addiction, it logically follows that the practitioners who prescribe it would deploy the disease model in the interviews. The use of harm reduction was claimed by all of the health care practitioners, though they articulated its meaning and usage in differing ways.

While all of the health care practitioners provide care for low-income drug users and many of them work in clinics situated in economically marginalized neighborhoods like the South Bronx, they may not necessarily represent the typical doctor encountered by a low-income person who injects drugs. A particular community of health care practitioners who had purposefully chosen the career track of working with underserved populations was tapped into during the recruitment process. Further, a majority of interviewees specifically sought to serve people who use drugs. While low-income individuals who inject drugs might encounter these health care practitioners, there is a whole other world of practitioners, who did not choose to focus their careers on the care of marginalized populations, and who drug users might encounter in their quests for health care. The health care practitioners interviewed were particularly sympathetic to the plight of drug users and made efforts to treat them respectfully. However,

having worked with a variety of drug using patients, they also expressed exasperated familiarity with patterns of difficult behavior they ascribed to drug users, though often this was done with a sympathetic tone.

## FINDINGS

### *Practices of harm reduction*

Looking at the ways the health care practitioners described their harm reduction practices reveals their understanding of where harm reduction can fit within biomedical practice. While some of the uses of harm reduction strictly addressed the risks of injection drug use, other practices sought to retain people who use drugs in care or treatment. Harm reduction implemented in the context of methadone or buprenorphine treatment took on particular attributes that aligned with the goals of treating a chronic disease. While the inclusion of harm reduction in a medical context might seem contradictory given the philosophical clashes between the differing models of care, the health care practitioners did not articulate any dissonance in their own practice.

Many of the health care practitioners, whether they provided care in the context of drug treatment or only provided primary care, reported that they incorporated assessments and education around opiate and needle use practices in their care for patients who inject drugs. Julia, a medical doctor who works in a primary care clinic in the Bronx, said that she knows some of her patients use drugs, but she was not sure if they currently injected them. When asked to speak about her experiences providing care to patients who were actively injecting drugs, she reflected on the time she spent several years ago caring for drug users at a syringe exchange. She explained her incorporation of harm reduction into her practices of care:

What I would try to do when I was talking to my patients about whatever medical

problem they had is try to talk to them, if they were coming in because they were having infections and abscesses. I would talk to them about appropriate skin care and wound care and ways to not make themselves sick when they were injecting. And so rather than being like, “You should really just stop injecting drugs all together,” it makes a lot more sense to be like, “If you’re going to inject, you use alcohol [swabs on the injection site] before--not after,” which is a common thing. I had a lot of my patients be like, “well I always rub with alcohol after I shoot.” I’m like, “no, no, no, before you shoot you have to clean it.” If I’m aware where they’re getting their water for cooking, and all of these things. So I can talk to them a little bit about that, and that tends to be useful... So that’s sort of the way that I use harm reduction principles as a practitioner...

Julia spent time educating her patients about wound care and safer injection techniques, if they were seeing her for infections and abscesses, instead of simply telling them to stop injecting drugs. This reflects the core tenet of harm reduction to avoid exhortations to abstinence and accept that “. . . licit and illicit drug use is part of our world. . . and that some ways of using drugs are clearly safer than others” (Harm Reduction Coalition).

One of the common refrains of harm reduction discourse is to meet drug users “where they’re at,” meaning to accept the current drug use practices of individuals without judgment. The Harm Reduction Coalition’s *Principles of Harm Reduction* defines the harm reduction approach in part as incorporating, “. . . a spectrum of strategies from safer use, to managed use, to abstinence to meet drug users ‘where they’re at,’ addressing conditions of use along with the use itself.” This refrain was found among the health care practitioners’ inclusion of harm reduction in their medical practices, though with slightly different meanings. Andrew, a physician who provides primary care for drug users, and methadone and buprenorphine patients

under the auspices of a well-respected hospital, framed this approach as a way to guide drug users towards treatment:

I think that's also one of the things for people who are actively using, if you get them into medical care, develop a relationship with them and you are non-judgmental about their use and are like, "Okay, what can we do to make you healthier and much safer when you're using?" and you build that level of trust, I think it's easier to make that progression to like, "Okay, let's try buprenorphine or methadone or some sort of treatment." But you have to get them to trust you and be willing to do that. I think that also helps engage this population but you have to be willing to not do "STOP USING!" sort of thing. You have to be willing to meet them where they are and help them where they are. A closed door can stop them.

For Andrew, meeting drug users "where they're at" contributes to their engagement with health care and potentially leads them towards seeking drug treatment. Though harm reduction is centered around reducing the riskiness of drug use and not forcing abstinence on drug users, Andrew employs its message of meeting drug users where they're at as a strategy that may eventually lead to consideration of drug treatment.

Doctors who provided pharmaceutically-mediated addiction treatment, whether methadone or buprenorphine, incorporated practices of harm reduction into their approach towards providing addiction treatment by refusing to terminate their patients' treatment if they continued to use licit and illicit substances. The federal government, through its agency the Substance Abuse and Mental Health Services Administration (SAMHSA), provides clinical guidelines for the use of buprenorphine in the treatment of opioid addiction. In a section on "unstable patients," these best practices guidelines recommend that doctors discontinue



buprenorphine treatment after eight weeks with patients who continue to use opiates or use other illicit substances (Center for Substance Abuse Treatment). The health care practitioners who went against this recommendation cited this as a practice of harm reduction. Nisha is a medical doctor who directs inpatient HIV services, sees patients in an ambulatory HIV clinic, and created and directs a buprenorphine drug treatment program at a public hospital located in a low-income area. She explained that in creating the buprenorphine program at her hospital, she and her colleagues had to determine a policy regarding allowable substance use during treatment with buprenorphine. Asked to describe their approach, she stated:

It's like they say, things can't be perfect. In an ideal world, there would be no problems with addiction and everybody would be able to be abstinent, but that's not the reality, so I have patients who are dependent on alcohol and heroin and are injecting heroin, and if I can get them off the heroin and give them Suboxone, then if they're still drinking, I'm not going to withhold treatment for the heroin addiction, because then they have two problems instead of the one. I'm definitely a proponent of the harm reduction model.

Other health care practitioners enacted harm reduction in the context of drug treatment by allowing the continued use of any drug, including opiates, despite receiving treatment that specifically targets opiate addiction. Monica, a primary care doctor and buprenorphine prescriber who works at a community health care clinic, said:

I provide drug treatment and people relapse and people still use drugs. It's part of the conversation and I try to figure out new goals for treatment. I certainly don't kick people out because they use drugs because they've come to me because they use drugs. So I think a lot of it is trying to understand what people's goals are and try to work with them on their goals.

Monica's approach of refiguring goals is also an enactment of the "meet them where they're at" approach, in that she recognizes that people relapse and continue to use drugs, and she meets them at that stage to rework goals.

The use of what the health care practitioners themselves termed harm reduction was consistent throughout the interviews, with each practitioner revealing what harm reduction meant in their context of care. Whether it was education around injection techniques or refusing to terminate patients for continued opiate use, the health care practitioners made attempts to reduce the harms associated with injecting and oriented themselves to the acceptance of some drug use. Two overlapping philosophical principles of harm reduction were apparent in the care these practitioners provided—the "meet them where they're at" approach and the acceptance of some drug use. Both principles are supportive of a regulated autonomy for people who use drugs by acknowledging the choice to take drugs, but also constructing space for interventions into the modes of drug use. The health care practitioners demonstrated recognition of their patients' choice to use drugs, while offering expert advice and treatment. By allowing the continued use of substances, both Monica and Nisha provided their patients with space to self-govern while they continued treatment in the disciplinary context of medicine. As noted by Andrew, the freedom allotted patients by harm reduction clinical policies may facilitate stronger ties to medical care.

### *The Uses of Disease*

One way the health care practitioners envisioned the health of drug using patients was by defining drug use, addiction, and dependence as a disease. The health care practitioners deployed both the disease model and neuroscience to explain drug addiction and dependence, sometimes simultaneously and other times independently. Several of the health care practitioners who asserted their belief in the disease model also remarked that this model could be strategically

deployed to reduce the stigma of addiction for less sympathetic audiences of colleagues.

Attempts by health care practitioners to remove blame and reduce stigma through use of the disease model coincide with principles of acceptance and non-judgment found in constructions of harm reduction.

Andrew, the primary care physician mentioned earlier, articulated a clear explanation of how he understands addiction. He framed his explanation by saying that this is how he teaches addiction to medical students:

There are several models that people believe in about addiction. I firmly believe in the biological model, that it is like any other sort of disease. In this case you lack the natural production of endorphins when it's heroin or opiates. So I explain it to people like it's diabetes. Like your body can no longer make insulin, you have a sort of dependence, you need medication, you need help to do that. If you treat it like any other disease, it makes it easier to understand that it is actually a chemical imbalance. There's a lack of a chemical in your body and that explains why you have cravings or why you sort of have those feelings and it's not just your psychological will or psychological decision. There's nothing wrong with you anymore than there's something wrong with someone who has diabetes.

In describing his understanding of opiate addiction, Andrew states that he believes opiate addiction is *like* a disease. His explanation is neurochemical and, as found among other health care practitioners, Andrew describes addiction as similar to diabetes in that the body cannot produce a certain chemical (insulin or endorphins) that it needs. In Andrew's explanation, the assignment of a chemical imbalance to the drug using body releases it from governance over its own psychological will.

Julia, who was mentioned earlier, provides a similar explanation, though she specifically refers to chronic drug use as a disease. Additionally, she's more explicit about the effects of drug use on the brain:

When I think about like chronic use, so sort of leaving aside casual pot smokers, and chronic drug use as a medical problem, it's a disease. That's what I've been taught and it's clearly the case from working with drug users, clearly a disease, not a choice. It's just not people deciding to do this for kicks. My understanding of the physiological effects on the brain is that when people use drugs their brain and body chemistry changes and then they become physically addicted but also psychologically different. Their brains respond differently to the drugs than people who haven't used the drugs. Dealing with it as a problem requires a medical model the way that we deal with diabetes. It's a chronic disease. It's not something that tends to be quick and then be over.

Julia directly associates the disease of "chronic use" with the will of drug users when she says drug use is "clearly a disease, not a choice," pointing out the lack of agency inherent in constructions of disease.

Within both Julia and Andrew's explanations of addiction, the lack of "psychological will" or "choice" is evident, and works to remove responsibility for drug use from the patient. In describing the use of harm reduction in their medical practices, both Julia and Andrew expressed the importance of avoiding exhortations of abstinence when caring for drug using patients. Deploying a formulation of the disease model, which releases the drug user from control over the usage of drugs, means that drug use can now be accepted and moral judgment avoided—two core principles of harm reduction. As proponents of harm reduction, Julia and Andrew can practice their commitments to harm reduction through the use of the disease model by a

contingent negation of the will.

Demonstrating self-reflexivity and an activist approach, Andrew explained that deploying a biological model of addiction can work to destigmatize drug use. He stated: “And it's the same model when I'm teaching residents and med students that is what I try to focus on as well to minimize all the stigma, the judgment that goes into it.” Andrew’s use of this model allows his commitment to the destigmatization of drug use to come through in his medical educational endeavors.

Another primary care physician who prescribes buprenorphine, Elizabeth, described how she uses certain language to discuss drug use with her colleagues in order to reduce stigma. Elizabeth provides care in a primary care clinic and an HIV clinic at a public hospital. She also supervises what she refers to as a “harm reduction program” in the HIV clinic, which provides patients with access to an on-site substance abuse counselor. This statement came in the midst of a discussion during my interview with Elizabeth about the ways disease itself can be stigmatizing: “. . . when I talk to my medical colleagues about it [drug use], I do emphasize what we know about the neurochemical aspects of substance use disorders because it’s a language that they understand. . . . And I think it is de-stigmatizing for them.” Elizabeth is interested in de-stigmatizing drug use for her colleagues, and thus deploys neurochemical vernacular when talking to them. Elizabeth’s deliberate and strategic use of a biological explanation aims to increase the acceptance and reduce the judgment surrounding illicit drug use among her medical colleagues.

Elizabeth also offered a nuanced description of when, in providing health care to drug users, it’s appropriate to use the disease model and when a harm reduction approach is more relevant. Her differentiated use of the two models reveals a contingent recognition of

autonomy—in some contexts the will of the drug user is relevant, while in others it is not. She explained:

If I was counseling someone in a harm reduction program, I'm not sure I'd spend my time on the disease model or think of them in that way necessarily. But where it's most meaningful to me is in the primary care context. There are people with unhealthy or risky patterns of use who do not have a substance use disorder, who do not have maybe the disease of dependence, whether abuse is a disease or not, I truly don't know, but who don't have dependence. I think dependence is something that is palpable and evidence-based and distinguishes the level of treatment or the level of intervention that it might take for that person to make changes in their substance use. So in that context, I think it [the disease model] works. But for the full spectrum, I'm not sure that it does.

For Elizabeth the disease model does not have a place when counseling someone at a harm reduction program, someone who may have “risky patterns of use.” Where it does belong, according to Elizabeth, is in determining the “level of intervention” needed to change the patient's substance use. Elizabeth describes the palpable presence of opioid dependence and refers to it as a disease. While discussing the disease model and harm reduction, Elizabeth also noted that she feels she does not need to adopt a harm reduction perspective when treating patients for addiction: “So I think that from my perspective, I buy it [harm reduction], but I don't feel like I need to employ it in every case. If a patient is seeing me for [drug] treatment in clinic, then that's my perspective towards them.” Using a contextual approach, Elizabeth reserves the disease concept for patients she is treating with buprenorphine and uses harm reduction to counsel those with risky patterns of drug use. Both types of patients, the diseased patient and the

risky drug user, will be met with interventions, the levels of which differ along with the gradations of autonomy.

As Elizabeth, Andrew, and Julia show use of the disease model is deliberate and strategic, while at the same time, what disease means and where it should and can be applied is flexible. Though mobilizing it in different ways, all three physicians maintain their usage of the concept of disease to describe addiction (Andrew), chronic use (Julia) or drug dependence (Elizabeth). Flexibility in meaning and usage allows the disease concept to maintain its relevance through continuous re-constructions. Through deploying the model, some health care practitioners can bring their ideological commitment to the de-stigmatization of drug use into the medical context. This opens the question or concern of whether harm reduction logics are being usurped by the power of the medical field. Similar to the encroachment of medical jurisdiction emphasized by theorizations of medicalization (Conrad and Schneider 1992; Zola [1972] 2013), the disease concept of addiction, as articulated by the health care practitioners, is incorporating ideas from harm reduction. Here, it is important to point out that the interviewees were a self-selected group of health care practitioners particularly sympathetic toward drug users and interested in their well-being.

## CONCLUSION

In revealing rectifications and recuperations of the disease model of addiction among health care practitioners who embrace and practice harm reduction, this analysis notices a conflicted, as well as contingent, mobilization of drug user autonomy. The health care practitioners activated harm reduction in their medical practice by educating their patients about safer drug use practices and accepting on-going drug use without judgment. When practicing harm reduction, the health care practitioners implicitly acknowledged their patients' autonomy in

decision making about taking drugs. In discussing their use of the disease model of addiction, the health care practitioners noted that addiction negated “psychological will” (as voiced by Andrew) and “choice” (as voiced by Julia), and that it required a certain level of medical intervention. These depictions allowed the health care practitioners to deploy ideological principles of acceptance and non-judgment associated with harm reduction philosophy. The disease model was used by the health care practitioners to excuse drug users from responsibility over their use of drugs and to de-stigmatize drug use when speaking to medical colleagues. The lack of will in these constructions of addiction as disease served as the mechanism through which harm reduction’s ideological principles could be made visible.

The use of models of care that simultaneously recognize and negate the will of people who use drugs is indicative of the operation of two technologies of power—pastoral and disciplinary. Both Foucauldian constructs, pastoral power denotes the devolution of care to the individual, such that technologies of the self, such as personal risk reduction and psychological therapeutics, are voluntarily practiced at the level of the individual (Orr 2010). Disciplinary power marks the reformation of docile bodies through internalized institutional power (Foucault 1979). With the recognition that “addiction treatment has become a primary site for the reeducation and reform of poor people,” the connection between addiction and “old-fashioned” disciplinary institutions becomes clearer (Gowan 2013). As institutions are expressions of regimes of power (Foucault 2007a), addiction treatment programs are expressions of disciplinary power directed at the docile body whose will must be reconfigured. The attenuation of will constructed by notions of addiction as disease is the discursive technique that lends reason to disciplinary technologies of power. The resultant institutions of disciplinary power in the form of drug treatment facilities have been found to transform the biomedical diagnosis of addiction into



a moment for moral and cultural reinvention (Gowan and Whetstone 2012). These facilities are often linked to the state through funding sources, such as Medicaid reimbursements, and the criminal justice system when it mandates drug treatment. This reveals a link between the state and biomedicine whereby a medical diagnosis may lead to state sanctioned re-socialization.

Medical settings, such as primary care clinics, can also be understood as sites of disciplinary power where patients are evaluated by reference to norms and subject to attempts at reformation. The deployment of discourses that support self-governance, such as that of harm reduction, in a medical setting may be used as a strategy to further engage patients in medical care. Thus, pastoral power may work to facilitate attachments to disciplinary institutions.

The analysis in this chapter reveals that within biomedicine drug users may be subject to two forms of normalizing power—one enacted through self-care and the other through disciplinary reformation. While drug users have been drawn into the wide nets cast by diffuse channels of power that govern through encouragement of self-care, such as that exhibited by harm reduction, they are still subject to forms of power recognized as disciplinary. The continued obliteration of the will enacted by the construct of addiction assures this.

## Chapter 5

A Broader Sensibility: Examining Narratives of Risk and Illness toward Expanding the Mission  
of the Harm Reduction Movement

“These days my health concern is not to contract HIV”

Dorian, white, age 40

“Health-wise, I feel good except for right now I have this thing called sciatica.”

Ricardo, Latino, age 42

Asking economically marginalized people who inject drugs about their health resulted in a wide variety of responses ranging from psychiatric concerns to worries over the genetic predisposition of disease to managing diabetes. As evidenced by the quotes from Dorian and Ricardo above, health concerns were occasionally related to injection drug use and other times they were not. Discussing health with the drug users I interviewed resulted in two types of narratives--those of risk and those of illness. The interviewees tended to speak of risk in two ways. Some spoke utilizing the discourse of harm reduction--describing their desire to avoid infectious diseases, such as HIV and hepatitis C, and their desire to avoid overdose. These individuals talked about needle usage or prescribed ways of avoiding opiate overdose, for instance. Other risk narratives centered on such worries as genetic predisposition for disease and obesity, and thus did not involve harm reduction discourse. The narratives of illness voiced by the interviewees were often stories of survival in conditions of absolute poverty. They, too, did not include allusions to the risks of drug use, but rather focused on immediate health needs. This chapter will explore how both types of narrative operate to mobilize certain types of selves

within low-income drug injectors' discussions of health and what the implications are for societal efforts toward addressing the health and well-being of people who use drugs. Since all but eight of the interviews I conducted with people who inject drugs were carried out onsite at harm reduction centers, and six of those eight interviews were conducted at a research field site that provides harm reduction education, it is important to discuss the implications of my findings for the harm reduction movement, especially since it is frontline in addressing the health concerns of drug users.

Rather than focusing on the overall health of drug users, harm reduction in the U.S. has evolved such that technical interventions on needle use and drug consumption remain its primary focus. Most historical accounts of harm reduction place its origins in the *Junkiebond* of the Netherlands, which functioned as a type of trade union, "to improve the housing and the general situation of the addict" (Marlatt 1996: 784; cited in Wijngaart 1991: 39). Through a series of politicized and contextually influenced transitions, harm reduction in the U.S. became an institutionalized, technical response to the proximate harms of drug use. The transmission of HIV/AIDS was initially the harm focused upon by the movement, but the movement has since expanded its focus to the transmission of hepatitis C and overdose prevention. In Northern European countries, Canada, and Australia, harm reduction has also become institutionalized within a public health framework (Keane 2003; Marlatt 1996), and thus in terms of drug use, remains largely focused on technical rather than social interventions. Notably, many of these countries have sanctioned more politically radical harm reduction practices such as prescribed heroin and supervised injection spaces. While these may lessen the vulnerability of drug users to arrest and the health risks of injection drug use, they still leave individuals vulnerable to the ravages of social and economic marginality. However, there exists a sizable contingent of

academics abroad writing critically against this direction (e.g., Fischer et al. 2004; Fraser 2004; Moore and Fraser 2006; Roe 2005; Smith 2012).

Harm reduction discourse was peppered throughout most of my interviews with people who inject drugs, but when describing health concerns most interviewees discussed situations and worries that did not align with the current focus of harm reduction's pro-health interventions. While it may be impossible to restore harm reduction to its earlier iteration as a movement broadly aimed at improving the lives of drug users, remembering the roots of harm reduction, namely the *Junkiebond*, can influence future efforts toward recognizing a broader range of concerns among marginalized people.

This chapter will show how the narratives of risk and narratives of illness voiced by the drug users I interviewed reveal two ways in which individuals construct themselves as personally and ethically responsible subjects. Narrative analysis has long been used in sociological studies of the illness experience to reveal the meanings and knowledge produced by the sufferer. Illness narratives draw attention to the lived experience of illness as a field of knowledge that works along with medical knowledge to socially construct illness and health (Bell 2000). Studying narratives of illness, "... draws attention away from medical settings and medical perspectives on disease and toward the nonmedical settings and nonmedical perspectives of everyday life" (Bell 2000: 184). Specifically important to the analysis here, illness narratives in many cases exhibit a "narrative reconstruction," in which "... disturbance and suffering are brought under some form of meaningful control" (Bury and Monaghan 2013: 82). Furthermore, illness narratives may function as moral narratives that offer "... ways of presenting the self as virtuous in comparison with others" (Bury and Monaghan 2013: 83). In this way the illness narratives offered by interviewees presented windows into the construction of the self in relation to ideas of personal

responsibility and ethicality often in settings of poverty.

Similar to narratives of illness, narratives of risk reveal the meaning individuals attribute to particular risks they encounter and also offer opportunity for the construction of responsible and ethical selves. Some of the narratives of risk found in this research were linked to the agenda of the harm reduction movement in the U.S. That is, the health risks mentioned offered a conceptualization of health that is fully recognizable to and supported by the harm reduction movement. The concept of health addressed by harm reduction as it appears in the U.S. is linked to risk and particularly the proximate risks, such as HIV and hepatitis C, associated with drug use.

### *Risk*

In fact, risk has become a dominant way in which health is measured in the U.S. A calculus of risk factors has come to stand in for health in biomedical and epidemiologic contexts. It is not that the treatment of injuries or diseases has lost priority to the anticipation of ill health, but rather that risk factor calculations on the individual and aggregate level play a large role in shaping our current understandings of health. The whole of modern medicine has seen a shift in which the calculation of health risks has come to replace the individualized interview between practitioner and client (Castel 1991: 281). As Castel sees it: "The new strategies [of risk calculation] dissolve the notion of a *subject* or a concrete individual, and put in place a combinatorial of *factors*, the factors of risk" (1991: 281). On the individual level, this means that health is determined by quantitative and qualitative measures of risk for future ill health. In the biomedical context, this tabulation of risks comes to stand in for one's level of health. On the population level, health is ascertained through surveillance and calculated based on risk. As Clarke et al. (2003) find, something else is borne of this process of surveillance and calculation--

more specificity and standardization. They state: “Risk and surveillance mutually construct one another: Risks are calculated and assessed in order to rationalize surveillance, and through surveillance risks are conceptualized and standardized into ever more precise calculations and algorithms” (2003: 172; citing Howson 1998; Lupton 1995, 1999). Through mutual reinforcement, risk and surveillance beget more risk and surveillance, and our conceptualization of health becomes more refined by an increased specificity of risk.

As an individual, to be healthy means to have a relatively low level of risk factors or to be successfully managing the risk factors one is presumed to have. Through the identification of health risks, individuals are enjoined to self-manage and pursue an increasingly out-of-reach notion of health. As Petersen (1997) sees it, risk plays a crucial role in ‘neo-liberal’ societies by, “... distancing experts from direct intervention into personal lives, while employing the agency of the subjects in their own self-regulation (‘risk management’)” (p. 203). For those on the losing end of socially structured inequality, such as low-income people who inject drugs, the imperative of self-management can translate into blame for the effects, health or otherwise, of poverty and discrimination. People who inject drugs are, of course, recipients of, and participants in, the proliferation of risks and their synonymous association with current notions of health. Harm reduction-based, public health interventions employ the agency of drug users in their own governance, and thus facilitate practices of risk management.

The atomizing emphasis of pastoral power is in effect when people who inject drugs claim personal responsibility for managing their health risks and chronic illnesses. Governed by discourses of risk, as well as political ideologies that organize structures of public assistance, these individuals often must expend a tremendous amount of energy and determination to maintain their health within conditions of social and economic marginality. Gowan (2012/2013)

explains: “The great risks collectivized by the welfare states—unemployment, poverty, sickness, and death—shift to the domain of individual responsibility and self-care, rewarded and punished with conditional cash benefits and deductions.” Governmentality is still relevant for those who express their health concerns in terms of illness rather than risk because they are subject to the governing of the welfare state.

In this chapter, I will first examine the narratives of risk, which were inflected with harm reduction discourse. It is important to recognize that harm reduction has shaped the ways *some* drug users talk about their health and their selves though these instances were limited in scope and number. Then, I will discuss the other narratives of risk I encountered, which revealed the non-drug use related health concerns of low-income people who inject drugs. Next, I will present narratives of illness, which were also unrelated to drug use, and offer a way to understand the link between health and structural inequality. These are representative of the health concerns I heard most often from the drug injectors I interviewed. They present health concerns that fell outside of the harm-reduction-as-public-health-intervention paradigm. However, all of the narratives I heard contained elements of a concern for personal responsibility toward managing health and illness, and thus allowed interviewees to construct responsible and ethical selves in the face of harrowing conditions of poverty and social stigmatization as drug users. Interviewees were able to construct themselves as “good” citizens through the help of harm reduction discourse, as well as narratives of pro-health endeavors. Their constructions support Metzl’s (2010) claim that more than being a desired state, health is also a “prescribed state” and an “ideological position” (pp. 1-2).

## FINDINGS

### *Narratives of Risk*

In this section of the chapter, I will examine the limited ways the discourse disseminated by harm reduction has impacted interviewees' understandings of their health and ultimately their selves. In this section, all references to "harm reduction" are to its existence as a public health intervention rather than its historical configuration as a broader social justice movement. The behavioral practices advocated by harm reduction allow drug users to reduce the riskiness of their drug use, and thus promote a healthier way to use drugs. This claim toward healthiness has reshaped the conceptual contours of bodily health in some limited ways for the targets of these interventions—people who inject drugs.

Since all but two of the interviews were conducted in settings where harm reduction was promoted, it is perhaps unsurprising that this type of discourse emerged in the interviews. Some of the typical messages that adorned posters on office walls asked if individuals had been tested for HIV or hepatitis C and enjoined injectors to only use a needle one time. One poster at the research field site read "It's All About the Blood. Prevent Hepatitis C" and showed pictures of injection equipment contaminated with blood. Another poster simply said, "Naloxone Saves Lives" referring to the antidote for opiate overdose that individuals can be trained to administer, and is distributed from harm reduction centers. At harm reduction centers, as well as at the research field site, participants receive structured and unstructured education on harm reduction matters through interactions with staff. As my interviews show, the messages that circulate in these settings are internalized by injectors with varying motives for their deployment. Even the two interviewees—Dwight and Victor—who were not interviewed in locations that promoted harm reduction, spoke about their health and their selves in terms of infectious disease and



needle sharing, showing that they had encountered harm reduction messages at some point. Their narratives of risk will be discussed below.

Two themes emerged in the ways harm reduction discourse appeared within risk narratives found among the forty interviews conducted with economically marginalized people who inject drugs. First, infectious disease and overdose were mentioned as a health risk for several interviewees, above and beyond other health problems, reflecting two of the main goals of harm reduction—to reduce the spread of blood-borne pathogens like HIV and hepatitis C and to prevent opiate overdose. Second, in some narratives of risk adherence to harm reduction practices was put forth by interviewees to position themselves as responsible, ethical drug users. Thus, harm reduction as a practice was able to link the avoidance of risk through certain behavioral practices to ethical and responsible subjecthood for some of the interviewees. Injectors who self-govern to decrease risk for themselves and others were able to construct ethical selves through the use of harm reduction discourse. These narratives reveal how the shift to individual risk as a way to define health results in the application of ethics on the individual level rather than the social structural level. In a turn typical of neoliberalism, the emphasis is on crafting the individual as ethical rather than focusing on improving the ethics of social structures and institutions.

Before discussing the deployment of harm reduction discourse by the interviewees in this study, it is important to point out that several researchers have found that when interrogated about their injection practices, as people who inject drugs often are when participating in public health research or receiving harm reduction services<sup>10</sup>, they will repeat the tenets of safer

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<sup>10</sup> There is often a blurring of the line between academic researchers and social workers since researchers often provide material and educational resources while collecting "data." Likewise,

injection communicated in health promotion material and by community health outreach workers (Bourgois and Schonberg 2009; Campbell and Shaw 2008; Fraser 2004). Drug users know how to answer the questions of social science and public health researchers about needle use practices, and will repeat pre-packaged claims of bleach use and refusal to share needles.

Campbell and Shaw (2008) assert that: "Repeated invocations have multiple aims, including the dismissal of moralistic claims issuing from the public health domain, shielding users from further 'intervention,' and establishing ethical harmony between participant and researcher" (p. 696). In their ethnography of homeless injectors in San Francisco, Bourgois and Schonberg (2009) also found that their subjects would assert their public health worthiness by repeating standard HIV prevention instructions despite the structural and environmental obstacles to following them. A lack of consistency between what is told to researchers and actual behaviors was noted among Campbell and Shaw's (2008) study participants highlighting the Foucauldian notion of "incitement to discourse" which denotes the results of disciplinary power flowing through the act of confession or here, the research interview.

Bourgois and Schonberg (2009) discussed how counselors seeking to prevent the spread of hepatitis C engendered resistance among the long-term street-based addicts when they exhorted them to take personal responsibility for damaging their bodies. They write: "The interaction reaffirmed the 'hope-to-die-with-my-boots-on' righteous dopefiend subjectivity among the Edgewater homeless. Being willfully and oppositionally self-destructive feels like an empowering alternative to conceiving of oneself as a sick failure who lacks self-control" (2009: 109). The men in Bourgois and Schonberg's ethnography were effectively coached on what to say in terms of their injection practices, but chose to resist this disciplining. Thus, there can be

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social workers may also ask research-like questions to gather "data" about their client base, in addition to providing material and educational resources.

inconsistency between what drug users say to community health workers and researchers about their injection practices and the actual behaviors in which they participate, as well as outright resistance to the normative standards of health imposed by these interlopers. At other times, as Campbell and Shaw (2008) and Fraser (2004) found, drug users may feel compelled to repeat the public health messages they've received in order to appear ethical and responsible, and to ward off further interrogation into their drug use practices.

These investigations into the deployment of harm reduction discourse are instructive for understanding the ways injectors responded to the health-related questions asked in my research study. The possibility that interviewees in this study are incited to discourse, as Campbell and Shaw (2008) describe, must be recognized, though it may be impossible to know from the interviews alone what exactly is happening in terms of discourse and "true" beliefs. As Bourgois and Schonberg (2009) show, sometimes discipline is resisted and self-destructive behavior is openly discussed, and at other times, as shown by Campbell and Shaw (2008) and Fraser (2004), drug users may adopt the language and logics of public health interventions. In terms of making sense of the discourse used by people who inject drugs, it is important to recognize that even if they are simply repeating harm reduction messages they've heard elsewhere, they are still reproducing the messages in a way that makes sense to them, which makes these utterances indicative of the interviewees' thoughts and feelings. It is sociologically interesting to understand what I heard from my interviewees as both representative of what they thought I wanted to hear, as well as simply what they were thinking in that context and at that time. The thoughts and ideas of the interviewees presented here should be read with this tension in mind.

*Infectious disease and overdose.* One way that I understood harm reduction interventions to impact the interviewees' relationship to health was through the specter of two infectious

diseases—HIV/AIDS and hepatitis C—within the narratives of risk. One of the more telling questions I asked during interviews examined the main health concerns of the interviewees. The immediate response to this question of Dorian, a 40-year-old white bike messenger, provides an example of the mental proximity of harm reduction discourse for some of the interviewees. Dorian answered this inquiry right away with a concern about risk, although he may not have completely understood the question.

Kelly:           These days what are your main health concerns?

Dorian:          These days my health concern is not to contract HIV. I have... say that again?

Kelly:           (repeats the question)

Dorian:          I had hepatitis C since I have been 18 years old. I've been diagnosed with it. I am an exposure victim, not a carrier.

Dorian went on to describe his liver biopsy and non-existent viral load using technical language.

I was exposed to the virus and developed an antibody for it. It did not integrate into my liver because I had the biopsy done even though the biopsy is not 100%. I had the [screening] done on the biopsy looking for liver particles, looking for the DNA of the viral particles, which none were found. I haven't done it since then but I also have no elevated enzymes, no elevated liver levels, none of that, no viral load in my blood stream. I test positive for antibodies but [for the actual virus] I come up negative.

Through his use of biomedical language, such as viral particles, enzymes and viral load, Dorian demonstrates that he's taken personal responsibility for monitoring his liver health by learning about hepatitis C and the tests that are conducted to diagnose it. He has also made efforts to manage his health by submitting to such tests.

Dorian defines his health concerns through and with two of the key drug user health problems addressed by harm reduction interventions—HIV and hepatitis C. He is also able, through his discussion of hepatitis C, to express the responsibility he has exercised in addressing this potential health concern.

Another example of the deployment of harm reduction discourse while defining one's health concerns occurred during my interview with Yusuf, a 24 year-old homeless Arab man. When I asked him about his health concerns and whether he had any worries about his health, he replied: "Yeah. I don't use other people's syringes. I could get hep C or AIDS or HIV like that. That's my main concern. Or overdose." Yusuf's immediate reference to syringe use, hepatitis C, and HIV/AIDS shows how close at hand harm reduction discourse can be for some people who inject drugs when they talk about health. Yusuf links his understanding of his own health to the risks of syringe use, and thus harm reduction educational messages about syringe use resonate with his main health concerns as stated. Further, Yusuf is able to show that he is a responsible drug injector by mentioning harm reduction's three main targets of intervention and how he avoids at least two of them by not using other people's syringes.

My interview with Dwight, a 53-year-old African-American man, was one of two interviews that took place in a setting unrelated to harm reduction. I met with him at a donut shop. As soon as I began to ask the questions pertaining to health in the interview guide, he proclaimed his HIV status. The exchange went like this:

Kelly: Ok let's talk about your health. This is a study about health so how do you feel these days? How's your health?

Dwight: It's fair. I have no AIDS. No AIDS.

Kelly: No HIV or?

Dwight: No HIV. Let me show you something. [retrieves a folded document from his wallet] I took an AIDS test over here... No hepatitis, no anything.

Kelly: That's great.

Dwight: Male, African male... I took it ten, twelve, two thousand eleven and it's been dated by these people. Ok, non-reactive and anything else non-reactive.

To my surprise and without even asking, Dwight revealed his HIV negative status and produced documentation to, perhaps, prove to me that he was actually HIV negative. Dwight's image of health is undoubtedly shaped by his HIV status and materialized through the document stating it. When I asked if he was nervous when he took this HIV test, Dwight said that he was and explained:

I used behind a girl, a beautiful girl, drop dead gorgeous. You would never think that she was infected but she wasn't. She's loaded with money. She works on Wall Street. Those are the people I've dealt with. Very picky. I'm very picky. I'm telling you the truth. I'm not going to lie to you.

Even though Dwight shared a needle, which could be construed as an irresponsible act, he presents himself as responsible in that he shared with a wealthy, beautiful girl. Dwight's emphasis on HIV status and this instance of syringe sharing demonstrates how his construction of healthiness includes both the risk of HIV infection and his own syringe use.

Across these three interviewees—Dorian, Yusuf and Dwight—infectious disease is a prime concern rising above any other ailments they were concerned about or experiencing. For these men harm reduction public health interventions address their foremost health concerns and the practices promoted by its interventions can be utilized by this group to address their health concerns as they see them.

Another focus of harm reduction interventions among drug users is the prevention of drug overdose. While overdose was mentioned by several people who inject drugs during their interviews, only one, Ashley, a 22-year-old biracial homeless woman, mentioned it first as her primary health concern. When I asked Ashley what her health concerns are, she responded:

Just like dying. Overdosing. Everybody I know is dying--three people in the last month. They just can't get right out of some place after a year and go back to doing a whole bundle. People go to sleep and they don't wake up. I'm just scared. I don't really sleep. I'm scared.

When Ashley refers to people getting out of “some place,” she is referring to a drug treatment program. One of the most dangerous times for people who frequently use opiates is right after release from a drug treatment program. Following days or months of abstinence, one’s tolerance for opiates decreases. If a person decides to use, he or she may misjudge dosage and take too much, leading to an overdose. Ashley expressed her great fear of this risk of opiate use as her main health concern. The harm reduction movement has focused great effort on educating drug users about overdose prevention, and Ashley’s main health concern aligns with this educational program.

As found in the research on harm reduction interventions mentioned above, it could be that these interventions have successfully coached some drug users in the framing of their own health concerns around infectious disease or overdose. While mere interviews cannot show if harm reduction interventions have taught Dorian, Yusuf, Dwight, and Ashley how to prioritize their health concerns, it is presumable that this sustained, wide-reaching biopolitical campaign has served to shape self-understandings of health for some drug users and given them the tools for presenting themselves as responsible citizens.

*Ethical subjects.* Beyond producing a notion of health, the use of harm reduction discourse within risk narratives allowed the interviewees to present themselves as ethical subjects of the governing provided by harm reduction public health interventions. Interviewees presented themselves as upstanding subjects of harm reduction by affirming their strong resistance to sharing syringes and by reporting the use of proper injection techniques. For some, this meant producing an ethical subjectivity by reference to the ways they maintained their health. Marco, a 30-year-old Puerto Rican handyman, furnishes an example of the connection of harm reduction practices to the maintenance of health, and in turn, their connection to a normative judgment. While discussing his surprise at not “having anything,” meaning HIV or hepatitis C, after being tested upon his entry into the prison system, he stated: “I never shot up with nobody. I never shared needles or intercourse when it comes down to sex... In those ways I’ve been good.” Marco attributes being “good” to following two central proscriptions of harm reduction educational interventions—sharing needles and unprotected sex. It is interesting to note that Marco was surprised the he didn’t “have anything” despite obeying harm reduction proscriptions. This is a testament to the fear instilled in drug users by harm reduction teachings.

Some of the interviewees also presented themselves as ethical subjects of harm reduction by discussing their refusal to give others their used syringes. During a conversation about avoiding abscesses from injection, Rebecca, a 34-year-old Latina, stated:

I am like very cautious and stuff. I am. People will be asking me, “Do you have a syringe? Can I use...? No.” Even though I’ve used it already and I’m going to throw it away, I still don’t feel comfortable. God forbid something happens. I’m going to feel like crap.

Through this statement, Rebecca explains the level of caution she uses with respect to syringe



sharing. The caution she takes extends outward to others, over whose safety she takes caution. While in the end, it appears that Rebecca is exercising this degree of caution because she does not want to “feel like crap,” she is also making a claim about her personal ethics. Making this ethical claim is only possible through the use of harm reduction discourse on the sharing of syringes.

Victor, a 41-year-old Latino security guard with a lengthy history of incarceration, explains his personal ethics using harm reduction discourse on needle sharing. Interestingly, Victor’s interview was the other interview that took place in a location unrelated to harm reduction. During a discussion of the meaning of harm reduction, Victor proclaims: “I don’t share needles. Never. No, never. If I want to use something, I go and buy it.” I asked if he purchases his needles from a pharmacy and he replies: “Yeah, I buy it. That’s how I get everything. Everything is clean. I will never share nothing with nobody. Never. Never did. I won’t do that.” Victor’s emphatic reply and his clear statement of unwillingness to share needles is evidence of the personal ethic he has developed around syringe use. He seems to have a rule about needle sharing that he upholds with emphatic strength. Victor is clear in presenting himself as having strong personal ethics with regard to syringe use, ethics that are able to be spoken because of harm reduction discourse.

Another way an ethical self was crafted was through the discussion of injection techniques. Harm reduction interventions spend considerable time and resources advocating for certain injection practices, such as always using clean needles, cleaning the injection site, and being precise when finding a vein, among many other practices. Alicia, a 48-year-old Latina, presents an example of the link between ethical subjecthood and proper injection technique. When asked if it’s possible to inject drugs in a healthy way, she replies: “Well yeah, properly.

Like me I do it just when I need it.” I asked her to clarify what she means by properly and she replies: “Using proper new needles, disinfecting the area, cleaning it out and taking your time.” Alicia insists upon the propriety of certain injection techniques, namely those that are taught through harm reduction educational interventions. By including that she injects “properly,” Alicia makes a claim about herself as an injector. She is able to present herself as an ethical injector through the use of harm reduction discourse. Harm reduction enables ethical subjectivity, and does this through its claims to protect public and personal health.

*Other risks.* When asked about their main health concerns, several interviewees mentioned risks to their health that were unrelated to HIV/AIDS, hepatitis C, and overdose, and furthermore, were not directly linked by the interviewees to drug use. The framing of health concerns as risks unrelated to HIV/AIDS, hepatitis C, or overdose merit mention here because they reveal the use of risk in conceptualizing health. By discussing their health in terms of risk, the interviewees constructed responsible selves through demonstrating that they were monitoring health risks. The assessment of health through the lens of risk, as mentioned before, has become a way to govern individuals by requiring them to actively participate in processes of on-going self-care. Low-income people who inject drugs have not been exempt from this societal shift in the assessment of health. To give a sampling of the types of risks mentioned by these interviewees, I will describe the risk narratives voiced by several of the interviewees when I asked: “What are your main health concerns these days?”

Two interviewees mentioned genetic risk. Linda, a 56-year-old Latina who is stably employed as a waitress said: “My main health concern is I’m always worried because cancer is such a high risk in my family.” Linda went on to explain that she would like to be scanned for cancer and was trying to figure out where to get this done. Brian, a 47-year-old white homeless

man said: “I would question my heart, because my dad died of heart complications. I have two brothers who died of heart complications.” Unlike Linda, Brian did not mention taking any steps to monitor this risk, though articulating his main health concern through the language of risk is telling.

Other interviewees expressed concern for the health risks posed by smoking cigarettes. Helen, a 40-year-old white woman, mentioned this concern along with another one: “My main health concerns are smoking and what’s going on now with me because I’ve been smoking for so many years and the weight.” She went on to say: “I’ve noticed I’m wheezing. I’m a little short of breath.” Helen showed that she was monitoring her health. Also concerned about smoking, Angela, a 29-year-old white woman, stated: “My main health concerns? I want to quit smoking. I have asthma too. What I think about the most health-wise, what I think about the most is that you are killing yourself. I think about really quitting smoking...” At several points in the interview Angela conveyed frustration at herself for not participating in prescribed self-care practices. At one point she proclaimed: “I feel like I know how to stay healthy and why don’t I do it? You know what I mean? I don’t know how to say it. I can hear the words but...” Angela is aware of the responsibility she should exercise in taking care of her health but she feels unable to align her behavior with her thoughts. Perhaps, if she could say it in a certain way, she might truly “hear” the necessity of self-care and take action. Angela felt stuck in an internal struggle: “That’s why it’s frustrating because I know that I should be doing this when I’m doing this. It’s been a battle, a struggle in my head between myself.” She does one thing, even though she knows she should be doing another. Angela feels the call to responsabilization within herself as a struggle between maintaining her present behavior (e.g., smoking) and acting in accordance with the ideology of health (Metzl 2010).

When discussing her health concerns Helen also mentioned her weight. She articulated a concern for how it presently made her feel, as well as for the future health issues it could cause: “I don’t have any health issues yet. I’ve only had it [the extra weight] on me for a couple of years. It’s just how I feel. It’s unhealthy. It slows you down a little. I don’t know if that’s worse.” Helen was uncertain what was worse in terms of her weight--the risk it poses or its present effect. As far as who or what is responsible for her weight gain, Helen was divided: “It [her weight] was always just regular like that and I guess you can say life changes. I went on methadone and I really... a lot of people don’t want to admit it but it slows your metabolism, and you’re trying to substitute food for the drug, and it’s a catch 22.” Despite the measured blame that is due methadone treatment, Helen recognized that she substituted food for her drug of choice—heroin. By articulating her concern over weight, Helen produced a responsible self who is self-monitoring in the context of a treatment for heroin use that may itself pose a risk for the health problems associated with obesity.

Eric, a 53-year-old white man, who was homeless at the time of our interview, was also concerned about his weight and simply stated: “weight” when I asked: “What are your main health concerns?” Not finishing his sentences but still conveying a point, he explained: “Weight is a very... I’m thinking of going and having my stomach...” I asked if he wanted to say stapled and he replied affirmatively. Later in the interview, Eric revealed that he had been speaking with his primary care physician about this surgery. Eric wanted to take action about his weight: “I’m 300 pounds plus. That is not healthy for a man of my age. No, something has got to be done about this weight.” Eric explained that at least part of the responsibility for his obesity lie with the practices of organizations that address hunger: “I have to eat in soup kitchens where they serve just a lot of starch to fill you up. The main issue there is hunger. Okay, what they do is they

feed you a plate of spaghetti with mashed potatoes and bread.” Despite Eric’s limited ability to determine the food he will eat, he takes responsibility for addressing the outcome of eating the starchy foods available at soup kitchens by pursuing bariatric surgery. As with the other interviewees who put forth risk narratives, Eric produces himself as a responsible subject by expressing concern over his health risks, demonstrating that he is monitoring his health, and considering ways to address risk.

### *Narratives of Illness*

Many of the health concerns expressed by interviewees were not articulated in terms of risk but rather had to do with chronic illnesses. While telling the stories of their illnesses, interviewees did not often make mention of their drug use, and the chronic conditions they dealt with did not appear linked to drug use. Through telling these stories, the interviewees showed the efforts they made to address their conditions or in some instances expressed worry over their inability to address their conditions. These individuals took responsibility for their chronic illnesses despite living in socially and economically marginal positions that made caring for illness quite difficult.

In terms of evidence-based, risk-reduction techniques, harm reduction has shown much success as a public health intervention in stemming the spread of HIV, but if my interviews are any example, health is still poor among low-income drug injectors. Besides health problems the drug users I interviewed also experienced housing instability, which in some instances worsened or created health problems. This section will examine three illness narratives that vividly reveal the link between poverty and health and further, show that the interviewees maintained personal responsibility over their health despite extremely difficult circumstances. Offering space in this chapter for the illness narratives of the interviewees and their intersection with socially

structured disadvantage reveals that individual-level interventions may be inadequate to address the health concerns of socially marginal populations.

Dan, a 22-year-old white homeless man, unraveled an incredible story of survival as our interview progressed that not only reveals the negative health impacts of poverty but also how our health care system can work to create them. In explaining how he came to reside in New York City, he is originally from Long Island, Dan also described how he became homeless;

Well, I was living with my girlfriend, and I had three jobs. I had custody of my brother. She had a kid too, and we ended up breaking up, and everything was in her name. So I was living out of my truck for a little while. I was working. I was doing fine. I was taking care of my brother. Somebody stole my truck. Yeah, so I lost all my jobs and just became homeless, and it was just pretty much downhill from there. Yeah, I lost custody of my brother. I mean my aunt has him. He's okay, but I just kind of ended up out here [in New York City]. It's actually a lot easier to hustle out here. It's a lot easier to be homeless out here than it is on Long Island.

At the time of our interview Dan had been living in a shelter in Brooklyn for about a month. Prior to that, he was living on the street. He described this experience:

Yeah. The winter was... Thank God it's getting warmer because there was a lot of nights where I just woke up thanking God that I woke up. There were a lot of nights I was drenched. Yeah, yeah. It didn't kill me, so it made me stronger. That's the way you've got to take it.

Dan showed a remarkably positive attitude throughout the interview, only revealing any amount of upset when discussing his health. Before getting to this, it is important to point out that the harm reduction center where this interview took place played something of a role in Dan's life.

He explained: “I thought it was a place for homeless people because everybody that I knew came here, and I’m like, ‘Oh, why is everybody coming here?’ And I started volunteering, and I’ve used needles, so it worked out... It’s like a hangout.” The syringe exchange services of this harm reduction center occupy a minor position in Dan’s characterization of his introduction to this so-called hang-out. It “worked out” for him to become a participant and volunteer because he injects drugs. However, Dan didn’t identify the harm reduction center as a place that addresses his injection drug use but rather, as a place for homeless people like him to hang out. Dan’s prioritized needs have more to do with his homelessness than his injection drug use. However, it is his injection drug use that allowed him to gain entrance to this harm reduction center, which he seems to use for purposes of hanging out with his social network and to pass time volunteering.

During our interview, it was clear that diabetes shaped Dan’s life, as well as how he understood his health. He had previously found employment in the food service industry and described this work environment as helpful for addressing his diabetes. In describing his interest in food service, Dan remarked: “I’m a diabetic. So I’ve got to eat every hour and a half to keep... So it was just easier that way.” When I asked, as I did with every interviewee, what his main health concerns were, Dan said: “My main health concerns? Pretty much just my diabetes.” Notably, he did not mention the health risks associated with injection drug use though going through his drug use history revealed weekly injection of heroin, as well as the use of crack and prescription painkillers. When I asked him how he managed his diabetes while living on the street a story of desperation and frustration with Medicaid sanction and hospital bureaucratic rules emerged. He described it:

Well, it was difficult in the beginning because I didn’t have as much hustles and able to make as much money. So I wasn’t doing so good in the beginning, and my Medicaid got

cut off because I accidentally set up a case out here [in NYC] while I had a case in Long Island. They cut it off for six months. I almost died like four or five times. I was in the hospital every week because I didn't have my insulin. I can't go three days without my Lantus<sup>11</sup>. I take two different types, and I can't. I just – I get sick beyond all means. I got no energy because what the insulin does is it literally makes energy in your body, so if you don't have insulin, you don't have energy. So I couldn't even make money if I tried. I was a wreck.

Kelly: Because you didn't have Medicaid, they wouldn't give you insulin?

Dan: So I would have to go into the hospital in DKA, diabetic ketoacidosis. That's when my sugar goes completely too high. I black out. I can just die, and that's pretty much the only way they would take me is if I was in DKA. And I'd have to do three days, and I'd be out for four days, three days. I mean, I... my medical bills are ridiculous right now. I mean, if I get a regular job, I don't know what the hell I'm going to do, but they're just going to take all my money. It's just the snowball that just...

Kelly: I just can't believe they wouldn't give you insulin to take with you.

Dan: I know. I'm like, "Just give me one pen, one Lantus, and I won't have to come." "No, no. We can't do that." I'm like, "That's just crazy." I was about to go under the counter and just take it.

Poverty, Medicaid sanctions and hospital policy worked against Dan in acquiring the medication he needed to treat his diabetes. To receive his medication, Dan was compelled to push his diabetes to acute levels and seek treatment in the emergency room where he was not allowed to take medication with him. Faced with this dire situation, Dan's primary focus is rightly placed on

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<sup>11</sup> Lantus is a long-acting insulin that is taken once a day as a form of diabetes treatment. It comes in the form of a pen that uses a small, thin needle to inject the medication.



his diabetes though he did show some minor concern for contracting HIV. When asked his usual reasons for visiting the doctor, which he does about two times a month now that he has health insurance, he replied: “My sugar.” Then, he continued: “To make sure everything is in check, to make sure my A1C’s<sup>12</sup> good. Just general... I take HIV tests like every three months, other tests...” Though Dan was concerned about contracting HIV and has himself tested while at the doctor, his diabetes is the motivating force for making the doctor’s visit. Dan gets an HIV test because as he explained: “Everybody should do it. Just you never know. You never know if you’re going to find a hundred dollar bill. You don’t know if you’re going to find out you have AIDS.” Though he admitted to doing “a couple stupid things,” meaning things that increased his risk for contracting HIV, Dan presented HIV tests as something good that everyone should do, rather than a test he should get because he’s taken some risks. Visiting the doctor for his diabetes offers access to HIV testing rather than the other way around. Dan’s prioritized need is treatment for his diabetes, which could be addressed through consistent access to health insurance.

John, a 56-year-old Puerto Rican homeless man, presents an illness narrative that also links health to poverty. Additionally, John’s narrative reveals the worry and anxiety felt when one is unable to take personal responsibility for their health even though their circumstances make it near impossible. Though residing in transitional housing at the time of our interview, John was homeless and living on the street the year prior. After losing his job of 12 years in the maintenance department of an apartment complex, John began living on the streets. He attributed the year he lived on the streets directly to the loss of his job. Now that he is off the streets and working part-time as a peer educator at the harm reduction center where the interview took place, he’s been able to focus on his myriad health concerns. When I asked him what his main health

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<sup>12</sup> The A1C test measures average blood glucose control for the past 2 to 3 months.

concerns are these days, he replied: “My health is my main concern right now. I do have health issues... You know, I was homeless. I didn’t have no insurance. I had nothing.” John listed his health concerns as “an aneurysm, kidney stones, COPD [chronic obstructive pulmonary disease] and asthma and hypertension.” At various points while discussing his health, John showed concern for the effects of being homeless and having no insurance on the health conditions he knew he had. He explained:

I had hypertension for a very long time. That I knew. So you know when I was homeless I knew that I had hypertension. The thing was that all the time I was walking around I didn't have insurance. I used to say, “How am I going to get medication?” and I knew my blood pressure was high because I could feel it.

Eventually, John was able to see a doctor through a homeless outreach program run by a local hospital, and he expressed deep gratitude for this connection to health care. As John explained, he is now dealing with the health consequences of a couple years spent without insurance and therefore, without medication. John said:

You see, that was probably why I had the aneurysm because I was walking around for a couple of years without no medication. So the fact that I was walking around and my pressure was sky high probably caused the aneurysm to happen. And like I said all the time I knew that I had high blood pressure but I had no way to take care of it and the fact that now, you know, when I found Dr. Marquez and I'm getting meds now it's almost like, you know, I'm getting the meds but because of the waiting time of going a couple of years without meds caused the aneurysm to happen. You know, so then I used to worry about it a lot. “Oh my god, what am I going to do? I can't get meds. I can't do this.” I didn't know that I had the aneurysm. All I knew was I had high blood pressure. I didn't know I had COPD

and I knew I had a slight case of asthma because everybody used to tell me, “you breathe really heavy,” but now I don't, I don't feel like... I mean, I know I'm not real healthy. Like I said the things that I need to be taking care of right now are being taken in. I'm seeing the doctor that I need to see.

In an explanatory mode, John described how two years without health insurance contributed to why he isn't “real healthy” at present. John's injection drug use did not figure into his explanation of his health. It seems that he has other overwhelming concerns. John's current health conditions stem from his social marginality living on the streets and outside of our health care system. Job loss and temporary work is common in our current faltering economy, where some of the most vulnerable workers, the working poor, face insecure employment and a declining number of options for work. John was hit particularly hard by his loss of employment, which left him living on the streets. Unable to plug into any social safety nets, John's health conditions worsened and he was left permanently affected by ailments that could have been ameliorated if he had access to health care and stable housing.

Joshua, a 27-year-old white man, who was temporarily and precariously housed in a “three-quarter house”<sup>13</sup> at the time of our interview, explained his difficulty in procuring care for multiple psychiatric conditions. Joshua came from a middle-class family on the west coast and had a bachelor's degree. He found his way to New York City through an internship at a non-profit that offered a living stipend, but that internship ended a year prior. Joshua had been unemployed ever since. He explained:

I had a bunch of savings when I moved to New York. Then, the contract ended at the

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<sup>13</sup> Joshua explained that a “three-quarter house” is similar to a half-way house but with less structure. Three-quarter houses offer semi-structured living for people with substance use problems in exchange for full access to residents' monthly public assistance allowances.

internship that I was at so I figured I would take a couple months to relax and start applying for jobs, and get a job very quickly afterwards, but I was still shooting heroin. I hadn't got the methadone yet. By the time I got on methadone, and stabilized on that, the money had run out, and I was having a difficult time finding a job.

Still intermittently shooting heroin while on methadone, Joshua explained that he had been in the shelter system "on a couple of occasions for no longer than like a month or two" but found the three-quarter house "a lot more comfortable."

When I began to ask Joshua about his health, he immediately voiced his desire to address his multiple psychiatric conditions saying: "I definitely need to see a psychiatrist... I am diagnosed with ADD, depression, anxiety, and panic attacks." He continued:

I'm having a very difficult time finding a psychiatrist. One reason is because Medicaid is basically partially privatized. So we have these HMOs, and when you're signing up for it, they really don't tell you what the pros and cons of an HMO was. So I just took the first one, Affinity. It started with an A. They're at the top of the list. I didn't know at that time. If I had known what I know now, I would have picked one of several other ones that are better. But my particular HMO, I call them. I try to get a provider directory. I can't talk to a human being on the phone.

Not receiving information on the qualities of the various HMOs he was offered as a Medicaid recipient, Joshua quickly chose his insurer and later realized that he had chosen poorly. Now he is faced with the unfortunate consequence that he cannot gain access to a provider directory in order to locate a psychiatrist covered by his insurer. He explained the outcome of this struggle: "So I've been having a very hard time getting psychiatric help... So I need medication, and so I'm forced to get at least anti-anxiety medication illicitly as a result of this."

Joshua also cited the time commitment required to maintain and use publicly provided assistance, such as cash benefits or psychiatric care at a clinic, as prohibitive of seeking care. He explained:

Then a lot of the psychiatry services that are provided are clinics, and I have so much stuff to do regarding HRA<sup>14</sup>. Any time I have an appointment for HRA, it's a whole day. So these clinics--it's a whole day. It's very difficult to have a full-time job on welfare.

You need time to navigate your welfare. So I haven't been able to get the help that I need. Though Joshua does not have a full-time job on the books, he makes the point that maintaining an open case with HRA requires a time commitment that would undoubtedly interfere with full-time work. Even without a full-time job, Joshua is overwhelmed with all of the demands made upon him by HRA ("I have so much stuff to do regarding HRA"). Going to a clinic that provides psychiatric services would take an entire day and Joshua does not have that kind of time.

When I asked Joshua about his main health concern, he reiterated his desire for psychiatric care and added that his untreated mental illnesses needed to be stabilized for him to move forward. He stated:

My main health concerns are, like I said, getting adequate psychiatric care, getting stabilized on medications, like anti-depressants and anti-anxiety stuff. Then, also ADD, I think would be helpful. I thought I grew out of it. So for me to really re-enter the workforce, I think I really need the psychiatric stuff to be stabilized through medication, and also counseling.

Joshua's narrative of illness illustrates the effects of dysfunction within the bureaucratic organization of public assistance programming for the poor. Unable to speak to a human when he

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<sup>14</sup> HRA, which stands for Human Resources Administration, is the organization that administers public assistance in New York City.

phones his health insurance company, Joshua cannot access psychiatric care, and thus his illnesses go untreated, or at least minimally treated through the illicit procurement of anti-anxiety medication. As he takes personal responsibility for his illnesses, he puts himself at risk for arrest. In fact, Joshua seems exasperated by the amount of responsibility he is required to assume in order to access the most minimal of services. The amount of time to keep his public assistance case open is onerous to Joshua who is already busy with other unspecified<sup>15</sup> activities to stay financially afloat. Unable to access treatment for his mental illnesses, Joshua feels unfit for entering the workforce. He mentioned at one point that he went to the emergency room two times in the last year for panic attacks (“I have gone to the E.R. twice this year for panic attacks”). Living in conditions of economic marginality has meant for Joshua that his mental illness is minimally treated, leaving him unfit for employment, and thus keeping him in poverty and mental distress.

## CONCLUSION

Through discussions of health with economically marginalized people who inject drugs, it was clear that despite their status as risky subjects, these individuals did not often prioritize the concerns focused upon by harm reduction interventions—HIV/AIDS, hepatitis C, and overdose. Rather, people talked about common chronic ailments such as diabetes, asthma, and pain. The structural roots of the circumstances that led to their illnesses are related to inequality, and the inadequacies of our social welfare and health care systems. Often conditions of poverty and homelessness made access to health care services and specifically attaining health care insurance difficult if not impossible.

What was also clear from the interviews was that the interviewees constructed themselves

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<sup>15</sup> Joshua chose not to speak about the work he does to make the money he needs above and beyond his public assistance allotment, which is garnished by his three-quarter house.

as responsible individuals by discussing how they monitored and addressed their health risks and the conditions from which they currently suffered. Speaking about health in terms of risk reveals evidence of neoliberal governmentality wherein individuals are enjoined to self-monitor.

Responsibility is shifted to the individual even when his or her living circumstances and access to resources make it difficult to address health concerns. As the illness narratives demonstrate, personal responsibility is also exercised among those who speak about their health in terms of current illnesses. However, for those interviewees already suffering from an illness (i.e., not just at risk for an illness) exercising personal responsibility proved to be inadequate to the task of managing illness. Despite multiple visits to the emergency room, Dan was unable to gain regular access to his diabetes medication. John monitored his health while homeless but was unable to access health care for two years. And Joshua tried in vain to contact his health insurance company to obtain a provider directory. These illness narratives can begin a process of questioning the ethics of the ideology of personal responsibility.

Since the forty individuals I interviewed were all actively injecting drugs, they could fall under the care of the harm reduction movement and most of them did, though as I discussed, this movement mainly addresses health in terms of its relation to unsafe drug use practices. However, looking back upon the roots of the harm reduction movement to the *Junkiebond*, reveals that a broader sensibility with regard to the concerns of drug users is possible. Several researchers have noted the limitations on the parameters of care posed by harm reduction interventions and in doing so, issue an implicit and sometimes explicit call for more expansive care practices.

In her ethnography of addiction in New Mexico, Angela Garcia (2010) situates the limits of harm reduction in a critique of, “the twin processes of devolution and privatization [that] have shifted responsibility for health care from the public to the more intimate domains of family and

community...” (p. 193). Garcia sees overdose prevention training and needle exchange as exemplifying this shift. She asserts they limit, “... even as they extend—residents’ capacity to care for the addicted” (Garcia 2010: 192). Garcia (2010) concludes, “... these strategies, while important, are not inclusive forms of care; rather, they are the bare minimum” (p. 193). Perhaps not invested in the expansion of harm reduction, Garcia notices how it provides a stop-gap measure that allows the state to provide the bare minimum of services.

Syringe exchange outreach workers themselves have noted the limits of harm reduction services, though they do not necessarily articulate the connection to state devolution of services. Nonetheless, the workers experience these limits firsthand and provide a knowledgeable critique. In qualitative interviews with syringe exchange outreach workers in Ontario, Canada, Strike, O’Grady, Myers, and Millson (2004) found among their respondents a common sentiment that harm reduction services were inadequate to the needs of the drug users encountered on the streets. One outreach worker described the harm reduction services they provided as, “... a band-aid reaction to what’s really happening out on the streets...” and further, “... the risks for HIV go well beyond, and our little intervention is important but let’s be a little bit serious...” (Strike, O’Grady, Myers, and Millson 2004: 212). In describing the outreach workers’ criticism, Strike et al. (2004) write, “According to the workers, HIV prevention efforts cannot be confined to interventions directed only at injecting and sexual behaviors because a complex constellation of disadvantages (e.g., mental illness, poverty, homelessness, frequent incarceration, violent victimization, disease, lack of social support and limited job skills), if left unattended, undermines their efforts” (p. 213). Frontline harm reduction workers are well-positioned to identify this failing of harm reduction and to understand on an intimate level the range of disadvantages that make people who inject drugs vulnerable to the risks associated with the



transmission of infectious disease.

Highlighting the range of needs, drug use-related or not, among participants at a harm reduction center in the Bronx borough of New York City, McLean (2012) shows in her ethnography that these participants repurpose the harm reduction center to meet needs that emerge more from poverty than injection drug use. Her examination of the “off-label” or unofficial uses of a harm reduction center reveals that attendees use the center for nutrition, temporary daytime shelter, and transportation fare. Her findings can be used to argue “... for a (re)expanded mission for harm reduction in the United States” (2012: 301). She suggests that this (re)expanded mission could include measures that address housing, hunger, and employment among drug users living in a society that, “harshly punishes and stigmatizes certain types of drug users” (McLean 2012: 301). The fact that drug users repurpose harm reduction centers to meet needs unaddressed by the official mandate of harm reduction reveals the limits of a strictly public health intervention that focuses mainly on needle use and its consequences.

If harm reduction is taken to be solely a public health intervention into the injection practices of people who inject drugs, then it has mostly succeeded in disseminating its messages to the drug users I interviewed here. Some have even internalized certain harm reduction messages and use them to understand themselves as ethical subjects. However, if harm reduction’s goal is to reduce harm, as its moniker implies, then its success is limited. The injection drug use practices targeted for intervention have largely changed since the early days of the AIDS crisis resulting in a decrease in HIV transmission (Des Jarlais et al. 1996; Gibson, Flynn, and Perales 2001). Thus, harm reduction public health interventions have reduced the harmful impact of HIV/AIDS among people who inject drugs. However, examining the narratives of risk and illness among the forty drug users I interviewed, reveals that this group has

many other health issues besides HIV/AIDS and hepatitis C that cause them harm. Presently, the narrow public health mandate of harm reduction externalizes these health-related-issues to other service providers, as well as the individual drug user leaving him or her to self-manage often in a position of extreme vulnerability. This is not to say that harm reduction in the mode of health promotion should expand its intervention into the lives of drug users, intervening in new places and on new levels of intensity. Rather, harm reduction as a social movement must focus on a more structural level to reduce the harm experienced by low-income people who inject drugs. This should involve efforts to mitigate the harm perpetuated through the ideology of personal responsibility. This ideology is evident in the obstacles to accessing health care put in place by the politics that guide bureaucratic programs of public assistance.

Social marginalization manifested through poverty, homelessness, and the stigmatization of drug use detaches people from necessary resources and support, furthering the damage of physical and mental health problems, as evidenced by the experiences of Dan, John, and Joshua. Harm reduction's public health mission has met a fraction of the needs of the people who inject drugs in this study, missing in large part issues of homelessness and poverty that increase one's vulnerability to risk. Its tendency to individualize risk and responsabilize structurally disadvantaged people renders it incapable of targeting the causes of poor health, which are always social and usually class-based.

Harm reduction's earlier iteration in the Netherlands reminds us that the movement does not have to remain focused on technical safety precautions. However, reverting back to the tenants of the *Junkiebond* may be impossible given the political and moral climate of the U.S. Presently, syringe exchange is not supported by the federal government, and thus no federal funds can be used to support it. This should not preclude the harm reduction movement from

expanding in other directions. The narratives of the interviewees in this chapter call for social change that will ameliorate the socially structured effects of poverty, rather than technical solutions to niche problems. An inclusive re-formulation of what is meant by harm that does not focus solely on the prevention of certain diseases and recognizes the harmful effects of unemployment and unstable housing, for example, could be the beginning step toward building networks of care that also work for social change. These networks would involve a bonding of movements that are concerned with socially and economically marginalized communities and could include organizations and movements that focus on employment, nutrition, and housing among other areas. The findings of this chapter point to the need for a movement that provides care, broadly construed and easily accessible, to those most negatively affected by inequality and the neoliberal emphasis on personal blame, rather than narrowly-focused movements that parcel out only certain types of care. These networks of care should be paired with an effort to interrogate the ethics of situating a cultural and institutional emphasis on personal responsibility in a social environment structured to produce inequality.

## Chapter 6

## Conclusion: Care and Power

Kelly: Let's talk about health because that's what this research is about.

Tara: I have hep C.

Kelly: You have hep C.

Tara, a 51-year-old Latina, was quick to respond to my prompt, even though I had not asked her a direct question yet. Assuming a public health identity, Tara immediately confessed her position with regard to a common infectious disease associated with injection drug use. However, as she began to explain her hepatitis C infection in more detail, it became clear that she actually did not have hepatitis C. She explained:

But I never took the medicine for it. I see my primary doctor all the time, and he told me that I do not show no symptoms, and I never took the medicine. And he said there's people that are just like that. They have an immune that kills the bacteria. We don't know what it is because we're not in there. We don't know what's going on, but it cleaned it. You still have it, but it's like you drank the medicine.

After a few more questions I ascertained that she tested positive for the antibodies to the hepatitis C virus, but her body had fought off the initial infection. She was, in fact, negative for hepatitis C. Why had she so quickly told me she was positive for an infection that she didn't actually have? Further into our interview she detailed struggles with a heart infection associated with injection drug use, and asthma. Why hadn't she mentioned the conditions she actually had first?

In part, this dissertation sought to answer this question by understanding the articulation of certain health concerns as the power-effects of public health governmentality. This governmentality has roots in the early days of the HIV/AIDS epidemic when people who inject

drugs were identified as a risk-group. Its trajectory was sustained by the harm reduction movement's educational and material interventions. When beginning this project I thought I might find that many drug users understood their health through discourses supplied by harm reduction. I also wondered if health care practitioners would mobilize harm reduction discourse when discussing drug-using patients' health. I did find this, but I also found so much more. I found that health care practitioners also thought in terms of disease when considering their patients' well-being, and people who inject drugs were often more concerned with chronic ailments unassociated with injection drug use. This meant that health was not solely or even primarily defined in terms of risk, as has been suggested by current social theorizations of the meaning of health (e.g., Dumit 2012; Petersen and Lupton 1996).

The idea that drug use or addiction is a disease has persisted at the level of ideology for about two hundred years and at the level of science for almost one hundred years. The health care practitioners I interviewed evidenced this history in their conceptualizations of drug use. For example, Elaine, a medical doctor at an inpatient treatment program, said: "What I really learned over the years within this field is that I really see it much as a brain disease, you know, than as a strictly behavioral issue." New trajectories of research in neuroscience in the 1990s positioned the disease of addiction within the brain. Nearly all of the health care practitioners understood their patients' drug use as a disease, and several of them provided a way to treat this disease in the form of buprenorphine. Placing drug use under the category of disease positions it as a matter of health that must be treated (Zola [1972] 2013).

None of the people who inject drugs spoke about their drug use in terms of disease, though some referred to themselves as addicts. The diseases they did mention, such as diabetes, hypertension, and asthma, were usually articulated as their primary health concerns and were

unrelated to their drug use. For example, Kyle, a 23-year-old homeless white man, had been in and out of the hospital immediately prior to our interview for a condition he thought might be acid reflux. When I asked him what his main health concern was, he said:

Well um I'm dealing with, I have acid re... I think it's acid reflux or something related to acid reflux. I had blood work done so I guess there's no ulcer or something like that. I guess it's just acid reflux. I was hospitalized a few times in like one week. I had run out of my medication [for acid reflux], and I wasn't eating, and I was getting dehydrated as a result of all of it. So it kind of all just boiled down to me, you know, which is why I ended up getting hospitalized but, you know, I got medication. I got hydrated through IV. Now I have medication.

In discussing his primary health concern Kyle reveals two things important to the conceptualization of health among people who inject drugs. First, he articulated a health concern that was not tied to his drug use, and thus the harm reduction center where our interview took place was not equipped to address his concern. Second, he expressed personal responsibility for inducing a bout of reflux. Kyle is homeless and rotates sleeping at a friend's house, an internet café, on the subway, and on a bench or the sidewalk. In all of this he was managing to adhere to his medical treatment "morning and night," but then he ran out of his medication. Kyle takes personal responsibility for his health while living in conditions of extreme poverty.

That the drug-using interviewees discussed their health in terms of chronic illnesses from which they were currently suffering, bears witness to the stratified effects of biomedicalization. For the upper and middle classes the benefits of advances in technoscience, risk surveillance, and medical enhancement--key components of the biomedicalization process--are present and accessible, but for economically marginalized communities, these advances may be inaccessible.

Clarke et al. (2010) state that the unequal distribution of the benefits of biomedicalization “may exacerbate rather than ameliorate social inequalities along many different dimensions” (p. 29). Part of the biomedicalization process features an increased energy put into self-monitoring health risks, which can mean that health is defined through reference to risk (Dumit 2012). While some drug injecting interviewees did conceptualize their health in terms of risk, many were beyond risk. They were already suffering from a disease. Being economically marginalized and socially marginalized for their drug use, it is likely these individuals did not have access to new medical technologies for treating illness, as well as risk.

However, these drug users did have access to knowledge and materials that addressed their risk for HIV/AIDS, though many of them did not discuss their health in terms of this risk. In chapter three I detail the acts of governmentality which comprise the management of drug-using bodies during the early years of the AIDS epidemic. These acts built a subject position—the injection drug user—that had everything to do with risk. By discursively manufacturing a boundary around people who inject drugs, surveilling them through ethnographic research, differentiating their so-called culture, and working to free them from (some) legal restrictions, public health researchers created a particular subject position through governing it. In Foucault’s (1982) theorization of the subject there is a double meaning--subject to someone else by control and dependence, and subject to one’s own identity by a conscience or self-knowledge. The duality of this meaning becomes clearest when people who inject drugs, recognize themselves as injectors and begin to advocate for their health through efforts to legalize syringe exchange. Realizing a neoliberal subjectivity, people who inject drugs begin to self-govern. Understanding the “injection drug user” as a position created through governmentality offers the opportunity to see how power constructs subjects, which in turn, offers us the opportunity to question any

beliefs about the real-ness of this risk category. Realizing that the “injection drug user” is an effect of power, highlights Foucault’s (1982) encouragement to “refuse what we are” as a means to subvert power, whether disciplinary or pastoral.

In chapter four, the power infused in two frameworks for understanding and intervening upon drug use is explored through viewing enactments of the discourse of harm reduction and that of the disease model of addiction by health care practitioners. Health care practitioners enacted harm reduction through educating their patients about safer injection practices, such as using sterile water to mix their drugs, and by refusing to discharge patients who were actively using opiates. The disease model of addiction was mobilized by them to understand the lack of agency their patients had with regard to taking drugs, and to de-stigmatize drug use when speaking to their colleagues. Looking more deeply at a significant philosophical clash between these two models, the attribution (or rejection) of authority over oneself, reveals that it is through the lack of will imputed by the disease model of addiction that health care practitioners can express their commitment to harm reduction ideals of destigmatization. That is, by denying that drug users have control over their drug use, one can release them from negative social judgment. However, the discourse of harm reduction depends on drug users being able and willing to exercise control over the ways they use their drugs. By using both models to understand and respond to their patients’ drug use, the health care practitioners contingently impute and negate the will. The implication of this apparent contradiction is that drug users are managed by two types of power in biomedical settings—disciplinary and pastoral. The negation of will present in ascriptions of disease implies disciplinary power to produce a new type of subject out of a docile body. The application of harm reduction ideas implies a pastoral power, wherein subjects self-govern through personal risk management and other self-care practices. Furthermore,



understanding health care institutions as manifestations of disciplinary power has implications for the deployment of pastoral power in the form of harm reduction education. Pastoral power may take on a new, more urgent form when engaged in the context of a disciplinary institution.

Chapter five considers the power present in articulations of health concerns by people who use drugs and the implications for the harm reduction movement. As mentioned, most of these individuals expressed their health concerns by reference to chronic illnesses often associated with poverty. Others spoke about their health in terms of risk with some referencing illnesses which are the foci of the harm reduction movement. Using risk narratives to describe one's health concerns resonates with the neoliberal logic of personal responsibility whereby individuals self-monitor in hopes of preventing illness. Under neoliberalism, social and economic costs are defrayed by shifting responsibility for health maintenance to the individual level. For example, individuals are responsible for securing and maintaining health insurance that will meet their health care needs. The presence of risk narratives that reference HIV/AIDS, hepatitis C, or overdose, reveals the existence of harm reduction governmentality. This type of power enjoins people who inject drugs to keep themselves healthy through the use of certain drug use practices. Again, responsibility is placed on the individual. Personal responsibility was also apparent in narratives of illness when individuals discussed the efforts they made or felt they should be making to take care of themselves, despite living in extreme poverty. By asking people who inject drugs to outline their main health concerns, it became clear that the focus of the harm reduction movement was not broad enough to encompass many of the health issues I heard. Efforts to provide clean needles and education on how to inject safely were necessary but not enough.

## SIGNIFICANCE

This research is broadly situated in the literatures on health and governmentality, though in a unique way, by looking at both biomedicine and public health. This combination is most visible in chapter four when analyzing the medical response of health care practitioners to patients who occupy a public health risk category. Though there is some literature which discusses harm reduction in health care settings (Rachlis et al. 2009; Strike et al. 2014), it is mostly concerned with advocating for the infusion of harm reduction philosophy and practice into the space of health care. My study of harm reduction and health care offers an analysis of contradictions and power implications. The incorporation of public health education into biomedical practices of care is revelatory of the form health care is taking in the 21<sup>st</sup> century. This is connected to current re-conceptualizations of health that align it more closely to calculations of risk (Castel 1991; Dumit 2012). Previously conceived as disciplinary settings (Foucault 1979, 2007b), health care institutions are now inclusive of pastoral power evidenced by a concern for risk. The contingency of ascriptions of will that occurs when biomedicine and public health combine is significant for health care practitioners who provide care for patients actively using drugs. It may help them understand the contradictions implicit in their practices of care and frameworks of understanding. I believe this has implications for a more respectful relationship between doctor and patient.

Understanding the “injection drug user” as a figure created through public health governmentality has been suggested previously (Campbell and Shaw 2008), though an examination of how this occurs within research literature is new. While it is well-known that public health is a practice of governmentality (Petersen 1997; Petersen and Lupton 1996), examining a particular instance of this governmentality sheds light on specific acts of governing,

and may have implications for understanding the chronology of this practice of power. The existence of the “injection drug user” offers an example of how power is productive of identity. The struggle for legal syringe exchange provides an example of how this identity is inhabited and begins a process of self-advocacy and self-governance. Historicizing this risk category offers a much-needed critical intervention for a trajectory of research that began in the 1980s and aims to understand and describe the behaviors of people who inject drugs.

This research also sits within literature that criticizes harm reduction as a governing practice that focuses too narrowly on infectious disease (Fischer et al. 2004; McLean 2011; O’Malley 1999). Chapter five bolsters this argument by examining narratives of illness and risk among people who inject drugs. Asking people who inject drugs to define their health concerns opens a space for understanding the success and failure of public health governmentality. The finding that the services offered by harm reduction centers may not align with the self-described health concerns of their constituents means that this research is also quite significant for people who inject drugs. Adding my critical voice to those who have already expressed concern over harm reduction’s narrow mandate, may bolster a movement toward expansion that could result in a broader range of care available to active drug users. As my research shows, low-income people who inject drugs take personal responsibility for preventing and addressing illness. By expanding its focus to other forms of ill-health, the harm reduction movement could mitigate the distress caused by social systems, functioning under the logics of neoliberalism, that limit access to resources for low-income people who become sick.

This research can be broadly construed as sitting within the sub-field of medical sociology. By soliciting the lay knowledge of people who inject drugs, I was able to see how illness and risk narratives reveal processes that lead to health inequalities. I also saw that risk

narratives reveal the power effects of governmentality by showing that people present themselves as personally responsible for monitoring their health risks. By seeking lay perspectives on health among a socially and economically marginal group of people, I was able to show evidence of harm reduction governmentality. But, I also showed times where the effects of this governmentality were overshadowed by embodied concern for present suffering. My research linked two analytic frameworks—one, methodological and the other, theoretical. Listening for and documenting illness narratives offers a method for representing lived experience and the ways people make sense of it. Governmentality offers a theoretical framework for understanding the play of power in the way individuals articulated their narratives. This link adds another layer to the interpretation of illness narratives in medical sociology.

#### LIMITATIONS AND FUTURE RESEARCH

Of course, my analysis was not without its limits. As with any study based on interviews, I did not have access to direct observation of social processes. I relied on what my interviewees told me. However, this allowed me to narrow my focus to discourse and to think about how power is involved in the ways people describe themselves and their experiences. I took what my interviewees told me as representative of their thoughts and feelings. There was no way to account for the impact of the interview setting and my perceived social location on what I heard from the interviewees. That the majority of the interviews with people who inject drugs took place at harm reduction centers, could account for the framing of health concerns around HIV/AIDS, hepatitis C, and overdose that I heard.

My analysis of the effects of harm reduction governmentality among the interviewees could have been aided by participant-observation at the harm reduction centers where I

conducted the interviews. This would have allowed me to see when and how people are taught harm reduction ideas and practices. In turn, this could have revealed the interventions and other educational practices that shape and form perceptions of health. Conducting participant-observation by hanging out with my interviewees outside of the harm reduction center may have offered more access to the ways perceptions of health are governed. The challenge for future research on the health of people who inject drugs is to determine productive sites for participant-observation. Unfortunately, as I discovered in the formation of my research plan, the barriers to accessing health care settings are strong.

My analysis of the disease model of addiction and its implications for the erasure of will in chapter four could also be bolstered by further research. It is well-known that people who are dealing with addiction often voice a lack of will with regard to their consumption of drugs. While the disease model of addiction may ascribe a lack of will to addicts, individuals addicted to substances experience this loss of will on an embodied level. This means that, perhaps, addiction researchers and clinicians are not *ascribing* a lack of will, but rather responding to embodied knowledge. In this way, the science of addiction is not actively working to secure the negation of drug user will. Future research on this topic could benefit from in-depth interviews with individuals addicted to substances that include questions about their experience with addiction, and how clinicians have spoken to them about addiction. These interviews might reveal if and how they experience a lack of control, and if this idea of lack of control has ever been foisted upon them.

Another area that could benefit from further research concerns the type of “will,” or lack thereof, attributed to the disease model of addiction, and the type of “will” facilitated by harm reduction governmentality. Understanding these two attributions of will as distinct mean that the

contradiction alluded to in chapter four is not a “true” contradiction. The disease model of addiction refers to a lack of will over taking drugs. Harm reduction practices elicit the will of the drug user in taking care of his or her health. The will to take care of one’s health is different than the will to avoid using drugs. This is made clear in chapter five when I discuss the efforts my interviewees take to address their health. Though there may not be a “true” contradiction occurring within health care practitioners’ mobilizations of the disease model of addiction alongside harm reduction education and practice, both the attribution and denial of will are co-present, but nested within contingent circumstances. Health care practitioners contingently evoke and deny the will of their drug using patients. To delve further into this matter, research interviews that ask direct questions about this “contingency of the will” could be carried out with health care practitioners, as well as their patients. These interviews could offer a depiction of the experience (or non-experience) of contingent contradiction in health care interactions.

#### FINAL THOUGHTS

As I carried out the research and the writing of this dissertation project, evidence of a rising heroin epidemic began appearing in the media (e.g., McDonald 2013; Seelye 2014; Sontag 2014). People who had been addicted to prescription opioid painkillers were now switching to heroin because it was available and cheaper, and many were injecting. When interviewing the health care practitioners, I heard from a few of the physician-researchers that injection was on the decline, at least in New York City. This felt like a criticism when I heard it, though the physicians were able to back-up their statements by reference to research and their day-to-day experience with drug-using patients. When I heard media speculation that injection use of heroin may be increasing in prevalence, it helped me to re-affirm that my research is relevant. By following media depictions of this new heroin epidemic, I learned that much of the heroin use is

happening in rural areas. This is of concern since harm reduction centers are not often found in small towns. Narrow mandate aside, these centers can be a haven of resources and support for drug users who face harsh stigmatization elsewhere.

Though harm reduction may be a force of governmentality, I do not want to discount its pragmatic usefulness for those who need to address their immediate, injection-related risks. Harm reduction centers, through their drop-in areas, also offer a respite from the grim circumstances poor injectors often face due to stigmatization, but also due to a lack of resources, such as food and shelter. The criticism of harm reduction my research offers should not be read as advocating for an elimination of the services and material resources offered by harm reduction centers. It should be read as an effort to provoke reflection on how care for people who inject drugs can broaden and through this, allay some of the hardship experienced when low-income individuals are forced to expend a great deal of personal responsibility to get the bare minimum of care. It should also be read as an attempt to understand the diffuse channels of power that flow through the care offered by harm reduction services.

When thinking about the new rural injectors on which the media reported, I was concerned about the health care practitioners they might encounter when in need of care. Outside of New York City, in rural areas, health care practitioners may not be predisposed to providing non-judgmental, compassionate care for people who use drugs. This is, of course, speculation. However, knowing that smaller towns often do not have active collectivities of harm reductionists, it seems likely that health care practitioners in these areas might have less exposure to this philosophy. Though I also position health care practitioners as mediators of governmentality, as well as disciplinary power, through their uses of the disease model of addiction and harm reduction education and practices, the individuals I interviewed displayed

incredibly empathetic attitudes towards their drug-using patients. Power functions through care, even if the care is delivered with compassion. Still, I like to hope that some of the new rural injectors encounter health care practitioners who know about and use harm reduction philosophy. And, I'd rather see them use the disease model of addiction than moralistic understandings of drug use, though morals certainly have guided the formation of the disease model.

This dissertation shows that through care individuals are governed in certain ways. They are acknowledged as certain types of subjects. Power works through getting us interested in taking care of ourselves by recognizing our health in terms of risk. It also works within the very act of providing care, such as in drug treatment programs that treat the disease of addiction. It is compelling to wonder what this care will look like as neurobiological definitions of addiction gain nuance through further research in neuroscience. Also, what could harm reduction care look like if the movement were to expand its focus to include the non-drug-use-related illnesses I heard from my interviewees? What kind of drug-using subject will this care produce? As access to health care increases in the United States, what will the self-care practices of people previously without health care look like? The certainty is that power will continue to flow through these acts of care. The challenge is to recognize this power that makes itself invisible.



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Appendix. Professional Profiles of Researchers Interviewed for Chapter Three

*Samuel Friedman*

Sam Friedman started conducting research on people who inject drugs (then referred to as “intravenous drug abusers” or “intravenous drug users”) in 1983 when he was hired as a data analyst and project director by Don Des Jarlais for the first NIDA-funded project in the New York City area. Sam is now affiliated with the National Development and Research Institutes in New York City where he is the director of the Institute for Infectious Disease Research. When asked to give a brief history of his professional work as it relates to people who use drugs and HIV/AIDS he humorously said, “Sure, I came, I saw, I suffered.” Elaborating further he described early work on self-organizing among people who use drugs, racism as it relates to HIV among those who inject and other people, using the metropolitan area level of analysis to show the effects of policy on the dynamics of the epidemic and along with Des Jarlais the association between syringe exchange and HIV infection. Notably, Sam’s research has theorized the responses (or non-responses) to AIDS of some minority community leaders when according to Sam, “... they did everything they could to hide their heads for a number of years and oppose syringe exchange.” Through his research he also showed that metropolitan-level policies such as those prohibiting the sale of syringes over the counter were associated with more HIV infection. And with Des Jarlais he showed that syringe exchange prevents infection. Though he did not mention it, Sam has also conducted influential research on the social networks of people who use drugs and HIV and STI transmission risk. Sam has collaborated with numerous other researchers and mentioned them throughout our interview. One such person he collaborated with in the early days of the AIDS epidemic was an ethnographer named Ric Curtis.

*Ric Curtis*

Ric Curtis is now Professor of Anthropology at John Jay College of Criminal Justice where he continues to focus his research and activist efforts on people who use drugs. Initially interested in being a Caribbean scholar with a focus on drugs, Ric landed a research position prior to the HIV/AIDS epidemic involving the study of drug dealers and users in Greenpoint, Brooklyn. In 1989 Ric began working for Sam Friedman on an evaluation of an attempt by a local organization to organize people who use drugs into a union. This was when Ric was initially exposed to people who inject drugs whereas before he had only heard about drug injection but not witnessed it or visited shooting galleries. Ric went on to achieve his position at John Jay College and along the way conducted research on such topics as street-level drug markets, social and risk networks of people who use drugs and HIV infection, drug eras in Williamsburg, Brooklyn, and crime and drug use among women. Ric often uses ethnographic methods in conducting his research but recently has been involved in technically-advanced analyses of social networks. Ric is also on the board of directors of two HIV/AIDS prevention, community-based organizations and syringe exchanges.

*Sherry Deren*

Sherry Deren who is currently a Senior Research Scientist at New York University's College of Nursing and the director of the NIH-funded Center for Drug Use and HIV Research, began researching people who use drugs in the 1970s before the widespread appearance of AIDS. Sherry conducted this work as part of a state bureau that in the 1970s was referred to as the Drug Abuse Control Commission. It is now known as OASAS, Office of Alcoholism and Substance Abuse Services. Trained as a social psychologist and holding a Ph.D., Sherry took part in research that investigated the personality characteristics of people who use drugs. She also

was involved with evaluations of drug treatment programs including methadone programs which at the time served mainly people who injected heroin. In 1987 and 1988 when NIDA recognized that injection drug use was a major risk factor for HIV transmission, Sherry applied for a grant from NIDA and received it. One of her early studies focused on people who inject drugs and their sex partners and was based in Harlem. She then went on to research people who inject drugs and those who smoke crack in the 1980s when crack use was recognized as a risk for HIV in terms of sexual behavior. She was also involved in comparison research of Puerto Ricans who inject drugs in the United States and those in Puerto Rico, which revealed the effects of the availability of health care services and syringe exchange on the incidence of HIV infection. In 1997 Sherry applied for and received a NIDA grant to create a center to support drug use and HIV researchers in carrying out their research and implementing interventions based on findings. This grant has been continually refunded and Sherry serves as the director of this center known as CDUHR, Center for Drug Use and HIV Research.

*Brian Edlin*

Brian Edlin comes at this area of research from the angle of medicine as he was trained as an internist with a specialty in infectious disease. In 1989 Brian joined the Epidemic Intelligence Service at the CDC and began to conduct work related to drug use and AIDS. From 1997 to 2002 he directed the Urban Health Study at the University of California, San Francisco, which is the longest running longitudinal study of people who inject drugs in the world. In 2002, under Brian's recommendation, the NIH rescinded the restriction against treating people who use drugs for hepatitis C in its new guidelines and began to recommend hepatitis C prevention, testing and treatment programs for people who inject drugs and incarcerated persons. In 2005 Brian began conducting research on hepatitis C among people who inject drugs in New York City, which

included research on the provision of hepatitis C treatment to people who use drugs. Brian is a longstanding advocate for research on hepatitis C particularly among people who use drugs.

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**PUBLICATIONS**

Szott, Kelly. *Forthcoming*. "Contingencies of the Will: Uses of Harm Reduction and the Disease Model of Addiction among Health Care Practitioners." *Health*  
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**WORKS IN PROGRESS**

Szott, Kelly. "Beyond the Bounds of Harm Reduction: A Public Health Population and Its Health Concerns." Book chapter in preparation for *Critical Approaches to Harm Reduction: Conflict, Institutionalization, (De-)Politicization, and Direct Action*, edited by C. Smith and Z. Marshall. Hauppauge, NY: Nova Science Publishers, Inc.

Szott, Kelly, Alex S. Bennett, Andrew Golub and Ernest Drucker. "Meanings of PTSD in Contemporary Life: A Social Constructionist Examination of Recent Veterans' Experiences." In preparation for submission to *Sociology of Health & Illness*

**TEACHING AND RESEARCH INTERESTS**

Sociology of Health, Drugs and Society, Sociological Theory, Gender and Society, Qualitative Methods, Introduction to Sociology

## **FUNDING AND HONORS**

Behavioral Science Training in Drug Abuse Research pre-doctoral fellowship, National Development and Research Institutes, supported by the National Institute on Drug Abuse, \$21,180 per year (2011 to 2015)

All-University Doctoral Prize, Syracuse University (May 2015)

Sociologists' AIDS Network (SAN) Scholarly Activity Award, \$150 (Summer 2013)

Roscoe Martin Dissertation Research Grant, \$1,000 (Spring 2011)

Syracuse University Graduate Fellowship, \$20,000 per school year (2007-2008 and 2010-2011)

## **TEACHING EXPERIENCE**

### **State University of New York, Ulster**

*Instructor*, Principles of Sociology (Fall 2013)

### **City University of New York, Brooklyn College**

*Instructor*, Introduction to Sociology (Fall 2011)

### **Syracuse University**

*Instructor*, Introduction to Sociology (Summer 2010)

*Teaching Assistant*, Introduction to Sociology (Fall 2009 and Spring 2010)

*Teaching Assistant*, Sociological Theory (Fall 2008 and Spring 2009)

## **TEACHING AWARDS AND TRAINING**

Certificate of University Teaching (2014)

Future Professoriat Program (2007-2014)

## **RESEARCH POSITIONS**

**Department of Medicine, Division of Infectious Diseases, SUNY Downstate Medical Center,** Brooklyn, NY (Summer 2009)

Research Assistant to Dr. Brian Edlin on two NIDA-funded projects "Community Health and Healthcare" and "Acute Hepatitis C Virus Infection in Injecting Drug Users"

**Department of Sociology, Syracuse University** (Summer 2008)

Assistant to Dr. Andrew London on evaluation of HIV/AIDS programming within organizations that serve the elderly

**Department of Sociology, Syracuse University** (Summer 2008)

Assistant to Dr. Steven Brechin. Data compilation and literature review on topics in environmental sociology

**Chemical Dependency Institute, Beth Israel Medical Center,** New York, NY (2005-2007)

Senior Research Assistant to Dr. Brian Edlin and Dr. Don Des Jarlais on two NIDA-funded studies "Community Health and Healthcare" and "Acute Hepatitis C Virus Infection in Injecting Drug Users"

## PRESENTATIONS

“Contingencies of the Will: Uses of Harm Reduction and the Disease Model of Addiction among Health Care Practitioners.”

Presented at the Annual Meeting of the *Eastern Sociological Society*, session on “Issues in Medical Sociology: Substance Abuse and Addiction” New York, NY (March 2015)

“Risk and Illness: The Health Concerns of People Who Inject Drugs”

Presented at *The 10<sup>th</sup> National Harm Reduction Conference*, panel on “What Do People Who Inject Drugs Care About?” Baltimore, MD (October 2014)

“The Absence of HIV/AIDS in the Narratives of Injection Drug Users and Health Care Practitioners”

Presented at the Annual Meeting of the *American Sociological Association*, Alcohol, Drugs, and Tobacco Roundtable session, New York, NY (August 2013)

“Can There Be a Healthy Drug User? Discourses of Disease and Harm”

Presented at the Annual Meeting of the *Society for the Study of Social Problems*, session on “Contested Medicine,” New York, NY (August 2013)

“Imagining Health: Constructing the Relationship between Health and Injection Drug Use”

Presented at the Annual Meeting of the *Society for the Study of Social Problems*, Drug Use Roundtable session, Denver, CO (August 2012)

“Capitalism Cares: The Biomedical Landscape for Drug Users”

Presented at the Syracuse University Sociology Graduate Student Assemblage graduate research symposium, Syracuse, NY (March 2012)

“Optimization Under Fire: The Health Care of Injection Drug Users in an Era of Biomedicalization”

Presented at the Annual Meeting of the *Society for the Study of Social Problems*, session on “Servicing Drug Users: From Harm Reduction to Drug Treatment,” Las Vegas, NV (August 2011)

“Why Are Injection Drug Users Not Getting Health Care?”

Presented at *The 8<sup>th</sup> National Harm Reduction Conference*, session on “Health Care and IDUs,” Austin, TX (November 2010)

“The Intersection of Injection Drug Users and Health Care: Overview of the Literature and Theoretical Underpinnings”

Presented at the Annual Meeting of the *Society for the Study of Social Problems*, session on “Crime, Drugs and Social Policy,” Atlanta, GA (August 2010)

“(De)Constructing Boundaries: Affective Economies, Biopolitics and Drug Users”

Presented at the Annual Meeting of the *New York State Sociological Society*, session on “Fashioning Deviants – Contested Spaces,” St. John Fisher College, Rochester, NY (October 2009)



**SERVICE TO THE PROFESSION**

Scholarly Activity Award committee member, *Sociologists' AIDS Network* (summer 2014)

Manuscript Reviewer, *The International Journal of Drug Policy* (on-going)

Sociology Editor, *Maxwell Review* (2007-2008)

**CONSULTING EXPERIENCE**

Composed grant report on peer-delivered syringe exchange, Chemical Dependency Institute, Beth Israel Medical Center (Spring 2013)

Subject Matter Expert for Pearson sociology textbooks, Ohlinger Publishing Services (Fall 2012 to present)

Research Study Liaison to Onondaga County Department of Correction for "Acute Hepatitis C Virus Infection in Injecting Drug Users" study, Principal Investigator: Dr. Brian Edlin, SUNY Downstate Medical Center (2008-2009)

**SERVICE TO THE DEPARTMENT AND CAMPUS**

Graduate Student Representative, University Senate (2010-2011)

President and Co-Creator, Sociology Graduate Student Assemblage (Fall 2010)

Member of Symposium Planning Group, Sociology Department (Fall 2010)

Departmental Workshop and Panel Co-Organizer, Sociology Department (2009-2010)

Sociology Department Representative, Graduate Student Organization (2008-2011)

**PROFESSIONAL ASSOCIATION**

*American Sociological Association* (on-going)

*Society for the Study of Social Problems* (on-going)

*Eastern Sociological Society* (on-going)

*Sociologists' AIDS Network* (on-going)

**LANGUAGE AND TECHNICAL SKILLS**

Written and verbal proficiency in Spanish

Data Analysis: HyperResearch, Dedoose