### EXAMINING PRACTICE, UNDERSTANDING EXPERIENCE: AIDS PREVENTION WORKERS AND INJECTION DRUG USERS IN VANCOUVER CANADA

by

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#### Abstract

This study examines the experiences of HIV/AIDS prevention workers whose clients include injection drug users (IDUs). Via a mixed methods approach (survey questionnaire and interview) the specifics of workers' practices were documented, along with their perspectives on a variety of IDU, addiction and HIV/AIDS-related issues. Foucault's writings on knowledge and power were used as the theoretical framework for this analysis. Thirty-six workers completed a self-administered questionnaire, from which preliminary analyses were conducted to identify emergent themes for exploration during qualitative interviews. Sixteen participants subsequently discussed themes such as treatment options, social marginalization, and the workers' approaches to working with IDUs.

The findings reveal that the workers share some common beliefs. They are convinced their IDU clients would be able to practice better self care if they had access to safe and affordable housing. In terms of addictions services, the continued broadening of needle exchange programs (NEPs) is good, but that NEP itself should not be the only harm reduction strategy in place. With regards to abstinence-based services, none of the participants found satisfactory the existing meagre services accesible to their clients who want to stop using drugs. They were ambivalent towards methadone maintenance therapy (MMT), once used as an initial stage towards total abstinence, now more commonly used as a harm reduction instrument, by eliminating opiate use (and injection), or reducing the frequency of opiate injection.

Workers emphasized the substanial gaps between the services available and what is needed, in terms of harm reduction or (particularly) abstinence. These workers use their own, local knowledge about IDUs and addiction, and navigate their clients through the limited services available. As hundreds of IDUs continue to become infected with HIV each year in Vancouver, a dramatic increase in access to abstinence-based services, and a more explicit gradiation between "pure" abstinence-based programs and NEPs, could be put in place. Most workers support a more nuanced spectrum of treatment options for IDUs.

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#### Chapter One: Introduction

Acquired Immune Deficiency Syndrome—AIDS—begins as infection with the human immunodeficiency virus, commonly known as HIV. HIV is transmitted between persons via intimate sexual contact, during childbirth or nursing, or via direct blood-to-blood contact. HIV infection routinely progresses over years, during which by all appearances the person infected is healthy. It is only after several years that HIV progresses to AIDS. HIV essentially "tricks" the immune system to attack itself. Science's understanding of how HIV infects humans and becomes AIDS is solid: HIV attacks the immune system, rendering its victims unable to fight off any number of secondary (or *opportunistic*) infections, ones that would not normally cause illness or death. In other words, AIDS itself doesn't kill people with AIDS; instead, it leaves the body defenseless against other pathogens. These opportunistic infections lead to death.

Persons infected with HIV battle on two fronts: trying to keep the virus from further compromising their immune system, and simultaneously staving off opportunistic infections like pneumonia, meningitis, cryptosporidium and gastroenteritis. Treatments for HIV/AIDS in both regards—to slow the progress of HIV infection, and to treat and prevent opportunistic infection—have progressed greatly over the last decade, to the point where the number of AIDS-related deaths in British Columbia has dropped dramatically since 1995 (BC Vital Statistics Agency, 2000). But these treatments are costly, are difficult for persons with HIV or AIDS to manage, and frequently have severe and debilitating side effects. They also remain largely inaccessible to the majority of the

world's AIDS sufferers. Regardless of treatment advances, AIDS ultimately remains a fatal illness. AIDS is the number two killer of young women and men in the province of British Columbia, and approximately 50 percent of all new HIV infections are attributable to injection drug use (BCCDC, 2000). As medical researchers struggle to develop an effective and safe vaccine for HIV, prevention of HIV transmission is still the most tenable strategy for stemming the AIDS epidemic worldwide.

In various regions of the world the AIDS epidemic has manifested itself differently. In Canada, the United States, Australia and Western Europe HIV initially spread among gay men. In Africa, Asia, Latin America, Eastern Europe and the Caribbean, HIV began as (and largely remains) a heterosexually transmitted disease. And in certain areas—urban centers in North America and Europe, and in countries like China, Vietnam and Thailand—explosive AIDS epidemics have emerged among injection drug users (IDUs), those who use needles to shoot drugs into their blood streams (Stimson, DesJarlais & Ball, 1998). Across these contexts HIV<sup>2</sup> has spread through any number of ways, or modes. Gay men most often are infected with HIV during receptive anal intercourse ("getting fucked"), when an HIV-infected man ejaculates inside another's rectum; IDUs are most often infected by using the drug injection equipment of another, HIV-infected IDU. The circumstances under which these acts occur are distinct from one another. So too are the two communities represented:

<sup>1</sup> In British Columbia, all HIV-related medicines—for HIV infection itself, and opportunistic infection prophylaxes-are free.

<sup>&</sup>lt;sup>2</sup> There are actually several different strains of the HIV virus around the world: the common form of HIV in Canada is substatively different from the one in sub-Saharan Africa, as is the one in Thailand. Despite their differences, their shared pathology permits their discussion as 'the HIV virus' for this study.

gay men and IDUs. Technically and contextually, HIV epidemics are quite varied, including in Vancouver.

#### Different Lives, Different Risks

Unlike the rest of the world, about equal numbers of new HIV infections each year in Vancouver are from injection drug use and from sex between men (BC Centre for Disease Control, 2000).<sup>3</sup> A mere one kilometer separates two Vancouver neighbourhoods routinely associated with HIV/AIDS, the West End and downtown East side, respectively, yet in this localized area two people infected with HIV on the same day will likely be so under wholly different circumstances. In Vancouver, two very different AIDS epidemics are unfolding. The material experiences of the gay male and injection drug using communities, though not entirely discreet (there are gay men who inject drugs), differ dramatically. Gay men are more broadly represented across the full spectrum of economic and educational experiences (Low-Beer et al., 2002). Conversely, most IDUs are socially, economically, and educationally marginalized, and a disproportionate number are of Aboriginal descent (Strathdee et al., 1997). Both groups face social exclusion, discrimination and violence, but homosexuality is not criminalized and gays are recognized as an oppressed group under most provincial and federal human rights statutes—largely due to the ability of gay men and lesbians to lobby effectively for this status. Injection drug use, however, remains illegal and, while addiction is recognized as a genuine form of disability (ostensibly protecting IDUs from

<sup>&</sup>lt;sup>3</sup> MSM, or sex who have sex with other men, is a term commonly used in epidemiology. It is preferrred in that literature to try and capture *all*male same-sex sexual activity, even that involving men who view themselves as heterosexual. Many gay men in HIV prevention view this behaviouristic categorization as limiting and homophobic—limiting in its decontextualization of *how* sex most frequently occurs between

discrimination) under the same statutes that protect gay men and lesbians, little work has been done to ensure these protections are applied to IDUs. Perhaps the most significant barrier to the fomentation of any IDU-driven campaign against discrimination (as is true for impoverished persons generally) is the all-consuming lifestyle associated with injection drug use. A few IDU-initiated grassroots organizations do exist in Vancouver and other cities; to date their impact on the public sphere discourses related to injection drug use has been marginal. And few activists from other social movements have taken up the cause of IDU oppression.

Another critical difference between these two communities devastated by AIDS is how society views the issues of (homo)sexuality and substance use. While homosexuality is not universally accepted, in Western society, in many jurisdictions (including Canada, the European Union, Australia and New Zealand) there has been a consistent trend towards the acknowledgement of sexuality in general as a natural human instinct, particularly since the mid-twentieth century. Within this trend, the view that homosexuality is one particular manifestation of a core human experience has gained currency, at least to the extent that it permits the discussion of homosexuality as possibly being one manifestation of natural human desire. No similarly held view can be found for the use of intoxicants, particularly the use of injectable drugs. Thus, though gays and IDUs continue to face discrimination, even hatred, legally and socially in Vancouver IDUs are much more stigmatized and marginalized than gay men or lesbians. By example, HIV prevention initiatives that target gay men routinely posit gay male desires as normative and healthy, whereas IDU-focused strategies need to navigate significant

(gay) men, and homophobic in its use to avoid discussing candidly and affirmingly the varieties of sexual

tensions between competing discourses emphasizing ways to lessen the HIV transmission risks associated with injecting drugs (as being too permissive towards drug use), and cease drug use entirely.

Issues around HIV prevention for these two communities have *evolved*, as understanding of each community's lived experiences (and each's unique challenges) has grown. To highlight the differences is not to argue that HIV prevention for either group should be devoid of critical, perhaps contentious discussions about how gay men or IDUs live their lives. But even this cursory examination of the two primary contexts in which HIV transmissions occur in Vancouver make clear that a singular approach to HIV prevention, lacking nuanced and context-specific strategies for reducing new infections, is untenable.

#### Individual Behaviour Versus Collective Social Experience

AIDS prevention has largely focused on how individuals can modify their actions—their behaviours—to eliminate or reduce the risk of HIV transmission. This approach is the predominant strategy for disease prevention among public health professionals. To a large extent, examining risk behaviours and identifying ways to adapt them to prevent illness is a sound strategy: who today would challenge the value of exercising, eating healthfully and avoiding smoking to reduce the likelihood of heart disease? So the promotion of sexual fidelity and condom use with regards to HIV prevention among gay men was a reasoned choice, and one that doubtless saved many lives (including my own). Similarly the efforts to help IDUs stop using drug altogether (abstinence), or to lower the risks associated with injecting drugs by not injecting them or

by supplying users with new needles (harm reduction), have been used to some success. But what is absent from a solely behaviourist approach to HIV prevention is how our experience as social beings, specifically how our interactions with others, shape and influence the choices we make with regards to our behaviours. In short, how does the intersection of self and context, particularly (though not exclusively) with those around us, influence how we live our lives, and how could an understanding of this intersection be integrated into HIV prevention strategies? This principle of a contextualized approach to HIV prevention is reflected in how many prevention programs are designed to address understanding of target populations' lived experiences. Where this principle is not applied is in how individuals as practitioners of HIV prevention work are similarly influenced in their practice by their own beliefs, their training and their surroundings.

#### Two Research Paradigms

In a broad sense, we have two predominant sets of research about AIDS: biomedical and psychosocial. From the former we have learned a great deal about how HIV infects the body, undermines the immune system, and progresses into AIDS; we even know quite a lot about how this process can, in many instances, be impeded. The medical sciences have also helped us to precisely understand how HIV is transmitted during sexual acts, drug using practices, and blood product transfusions. This knowledge is a cornerstone of most HIV prevention programmes.

Our expanding psychosocial understanding of the communities most at risk for HIV transmission provides another key element to these programmes. With an accurate understanding of the perspectives and experiences of those at particular risk for HIV infection in a specific context, HIV prevention workers can create and implement

prevention strategies that are directly related to those targeted. Through this approach, many programmes for gay men have used quotidian terms for sexual discussion, reflecting a collegial acceptance of male-male desire as healthy and good. Harm reduction programmes for IDUs (such as needle exchanges) are now offered where IDUs are known to live, in order be readily accessible to drug users. This "on the ground" understanding of the need to adapt programmes to people's lives—rather than expect people to adapt their lives to access services—has not been well-articulated in the biomedical research paradigm. Behavioural and social science research more often speaks to the lived experiences of groups like IDUs and gay men.

#### Minding the Gap

We have learned a good deal about the pathology of HIV/AIDS, and about the lives of those at risk for HIV/AIDS in specific contexts. But what about those who do the prevention work, and what shapes their efforts? There has been little rigorous examination of how our biomedical understanding of AIDS is presented by prevention workers to those at risk for HIV infection. This study endeavours to bridge this gap. Studying HIV prevention in specific contexts (like Vancouver) gives us an opportunity to learn how strategies for prevention evolve as our understanding of the interaction between HIV, human behaviour, and the human social experience develops. Those who proffer the information, prevention workers, are an integral part of HIV prevention, who have heretofore been given little attention in HIV prevention research.

A variety of HIV prevention programmes for both gay men and IDUs are in place in Vancouver; with each group, both health service and non-governmental organizations (social service organizations) play significant roles. Health care professionals (i.e. nurses and physicians), social workers, and human rights activists are all involved in the practice of HIV prevention. Most of the community-based AIDS-specific social service organizations in Vancouver were founded by (and are still significantly staffed by) gay men, and form the core of HIV prevention services for gay men. Most of the community-based HIV prevention services available to IDUs are from social service organizations whose mandates are related to anti-poverty, substance ab/use, or anti-racism work (including Aboriginal, Asian and Latin)—not to HIV or AIDS specifically. Therefore, IDUs access HIV information from a much broader spectrum of sources than do gay men, with a corresponding spectrum of approaches, incorporated in different agencies' strategies.

### Research Questions

This study examines the experiences of HIV prevention workers whose clients include injection drug users. It considers how workers' organizational affiliation and role (particularly social service versus health service organizations), professional education and training, and lived experience may influence how they do their jobs. It endeavours to document the services proffered to IDUs by these workers, the workers' own experiences with licit and illicit drug use, and to find patterns among this complexity of interactions to help us understand what prevention workers do—and why they do it. Both the experiences of persons doing HIV prevention work with IDUs and the perspectives of these prevention workers regarding their work are scrutinized. In addition to a delineation of the techniques used to help IDUs avoid transmitting HIV, participants' opinions about drug use/abuse, and about addiction as a criminal, social or medical issue will be discussed. By engaging in this study I hope to explicate the challenges faced by

these workers, and uncover how these workers adapt their practices to their understanding of their contexts and their selves. A better understanding of these interrelations will help us better understand the challenges faced by adult educators whose clients are extremely marginalized; both the practical implications and the broader ramifications of doing this sort of social justice-oriented work will be considered.

The workers at the heart of this study are being viewed as adult education practitioners. While they may have other, more obvious disciplinary or professional affiliations (such as nurses, physicians, social workers, counselors, or peer outreach worker), their commonality is that part of their job is to educate IDUs about HIV prevention. Thus, while HIV prevention for IDUs is their shared activity, these workers often see their professional or social affiliations as more important. In this study, the question of whether these workers constitute a genuine population, to evaluate the reliability of sampling strategies in particular, needs to be problematized. In other words, the participants have a commonality of practice (in terms of goals, and often in terms of specific prevention techniques), but their values and beliefs vary. In adult education practices that link social justice issues and material experiences—often, but exclusively related to health and wellness—this paradoxical "sameness" and "differentness" are not uncommon. And none of the participants in this study would question the significance of questions of social justice to HIV prevention for IDUs; all participants either viewed IDUs themselves as a marginalized community (or population), or saw marginalization based on socio-economic status, gender, culture (most often Aboriginality), or sexual orientation—or a plurality of marginalizations—as a critical factor in why some people become IDUs.

Thus, the matter of power—between workers, workers and their IDU clients, and workers and their superiors (most critically, but not exclusively, policy makers)—is what frames my analysis. Adult educators working outside the classroom, in contexts where social injustice is a critical concern, are often navigating through different stakeholders' interests than adult educators working in formal, school-like settings. This study's examination of practitioners whose work occurs in various institutional and non-institutional contexts, and whose adult educator participants often wear a multiplicity of hats, shows the complexities faced by many whose work would easily be identified as adult education by those who research the field, but whom themselves wouldn't consider themselves as educators.

Adult education has always addressed concerns about justice and entitlements of citizenship, as well as the educative aspects of health care and social service workers' jobs. These themes are each integral parts of the way HIV prevention for IDUs is delivered, making adult education, as this study's disciplinary focus, an appropriate one.

The following questions were examined for this study:

- What prevention techniques are used by those involved in HIV prevention programmes?
- How do the techniques in government-delivered health programmes differ from NGO-delivered social service programmes, and what similarities and differences can be identified?
- In what ways are the approaches among those with commonalities of experience such as gender, culture, drug using (including but not necessarily experiencing addiction themselves) or educational background, different than their peers?
- How do the attitudes and outlook of these workers affect the strategies they incorporate into their prevention work, as well as how they present such strategies?
- To what extent do these workers view themselves as "successful" at this work—and whose measures of success matter?

These questions address the specific practices of HIV prevention workers, and these workers' perspectives about themselves, their work, and the contexts in which they work.

Their examination of these areas should lead to a better understanding of the practice of HIV prevention work for IDUs in Vancouver and have value for other IDU contexts.

From these findings, some recommendations will be made for public policy regarding injection drug use-related health issues.

The next chapter reviews the salient literature related to HIV among IDUs and HIV prevention targeting IDUs. In the third chapter, my (Foucauldian) theoretical framework is explicated. Chapter Four is an examination of my own position as a researcher with regards to this study, as one who comes to the research enterprise from a grassroots activist perspective. Chapter Five maps out the mixed methods approach used for data collection, and the specifics of how I conducted my analysis. Chapter Six looks at how these practitioners came to work in HIV prevention with IDUs, and the influence substance using histories and organizational affiliation play in shaping their practices. Chapter Seven offers an overview of these workers' practices and their opinions on matters of policy. Chapter Eight examines the beliefs held by these workers regarding IDUs, addiction, and treatment options. Chapter Nine summarizes the findings of this study, addresses its relevance to HIV prevention for IDUs and (in a broader sense) to other adult education practitioners, and concludes with implications for future research.

#### Chapter Two: Review of the Literature

My interest in community health began over ten years ago with my involvement in activism related to issues of health and safety for gay men and lesbians; I have also worked, as I describe further in Chapter Four, as a community educator with mental health consumer and substance abusers. These experiences cemented for me the importance of identifying social determinants in fighting disease and promoting wellness. Immediately prior to commencing graduate studies, I worked as a research assistant in AIDS epidemiology, on studies related to HIV transmission among IDUs and between men who have sex with other men (MSM). Our data revealed that a significant number of our studies' participants were aware of the technical means by which to reduce the likelihood of HIV transmission, yet some did not consistently engage in lower risk practices. These women and men were almost all socially and economically marginalized (Strathdee et al., 1996; Strathdee et al., 1997). These studies in which I assisted used survey and questionnaire data collection strategies, and drew their conclusions from quantification of participants' responses. In identifying a relationship between economic and social marginalization and inconsistent (or absent) harm reduction practices, the Vanguard Project and Vancouver Injection Drug User Study (VIDUS) have made substantive contributions to our understanding of how prevention efforts fail to reach some gay and bisexual men and injection drug users. But neither of these studies addressed the concepts embedded in the practices of prevention workers, nor did they uncover much information about the context in which safer sex and drug using decisions occur.

As indicated by the following review of adult education, sociological, anthropological, and epidemiological literature, there have been no studies about the experiences of HIV prevention workers whose clients include injection drug users (IDUs). In adult education literature, no studies about HIV prevention and injection drug use were located. There are some in other disciplines that examine the efficacy of specific programmes (or strategies within programmes, such as providing clean needles), but neither programmatic issues nor the experiences of those implementing the strategies being discussed are represented. However, social science and epidemiological studies have significantly contributed to our understanding of injection drug use, and its related risks for HIV transmission. Since the mid 1980s there have been hundreds of studies in conference proceedings, scholarly texts, and refereed journals, specific to IDUs and HIV transmission; rather than attempt to integrate this entire body of literature here, recent key studies are represented.

#### Injection Drug Use: No Accident

To most people, the act of sticking a needle filled with drugs into their body to "get high" (viz intoxicated) defies reason. This assumption is correct; few people become involved in injection drug use on a casual or "social" basis. During my more than ten years' grassroots work with addicts, not a single injection drug user (IDU) with whom I have worked began their drug use by injecting drugs. For them, injecting drugs was not an action borne of logic: most injected drugs in order to deaden the painful legacy of lives scarred by physical, emotional and sexual abuse. For most IDUs—some of whom were using during our acquaintance, others who were "clean" (abstinent)—injecting drugs was a desperate attempt to avoid the physical pain of drug

withdrawal and the emotional pain of terribly difficult, marginalized lives. By the time most realized that injecting drugs creates its own horrible type of pain, the snare had been tripped. Today, we understand that achieving abstinence is extremely difficult for IDUs; there has been a subsequent shift away from the abstinence paradigm towards harm reduction, particularly with regards to the spread of HIV (Stimson & Chopanya, 1998; Strathdee et al., 1997).

Injection drug use-related HIV transmission is a global problem. By1995, injection drug use had been reported in 121 countries, including Canada (Stimson & Chopanya, 1998, p. 1). Epidemiologists, public health officials, social scientists and community activists agree that the sharing of drug injecting equipment—most importantly, needles—is the route through which AIDS is transmitted from one injection drug user to another. McKeganey, Friedman, & Mesquita (1998) reflect a strong consensus among scientists studying the IDU-related AIDS epidemic when they said, "where injecting equipment is widely available and accessible to injectors, sharing tends to be low . . where availability and accessibility are poor, sharing tends to be high" (p. 23). The provision of needle cleaning kits (bleach, sterile water, and cotton balls in a sterile container) and sterile needles have become cornerstones of many IDU-targeted HIV prevention programmes around the world (Stimson, Des Jarlais & Ball, 1998).

The estimated IDU population in Canada is between 50,000 and 100,00; Montréal, Toronto and Vancouver, as Canada's three largest cities, are widely perceived to have the greatest number of IDUs (Stimson & Chopanya, 1998, p. 6). In the last five years, the rapid spread of AIDS among Vancouver's IDU population has received a great deal of attention in the media. According to the special report on injection drug use,

AIDS and hepatitis C (a liver virus which is transmitted only by blood-to-blood contact, and which is almost as lethal as HIV) by the Provincial Health Officer in 1998, most new infections of HIV reported in British Columbia in the previous year were related to injection drug use. Drug overdose and AIDS are the first and second leading causes of death among British Columbians aged 30-39 years (Millar, 1998). The report called for a dramatic increase in harm reduction programmes—needle exchanges, safe injecting sites, and government-dispensed heroin—along with a broader, more aggressive campaign against child abuse and child poverty, two life experiences shared by the vast majority of IDUs in BC (p. 21). Reference to life experiences occurring prior to the health issue being examined (viz injection drug use) represented a shift in how public health officials in British Columbia looked at health issues. Childhood neglect falls into the category of social determinants, within the recently implemented population health paradigm of health services management in Canada.

As defined by Edwards (1999), population health builds upon "the experience and knowledge gained from lifestyle and health promotion efforts, [and] focuses our attention on inequalities in health status and their determinants" (p. 10). Thus, broad health promotion (i.e. wellness and disease prevention) programmes are tailored to the contextual realities of identified vulnerable communities. Most of the literature on community health and population health uses medical paradigms for its analyses; important knowledge has been generated by such research, contributing to our understanding of the complex interaction of environment and behaviour which puts us at risk for disease. But health promotion activities are viewed more as an educational endeavour than a medical one. Whether health educators come from non-governmental

organizations (social service organizations) and are unpaid peer educators (whose membership within a specific community is often their primary qualification as educators), or are physicians, nurses, social workers or other professionals employed by government, their shared focus is on the adaptation of knowledge about the pathology of disease based on an understanding of the contexts in which diseases are spread. Embedded within such an understanding is a familiarity and cognizance of the material experiences of those vulnerable. This notion of population-specific service provision—via health workers or others—is important, when discussing injection drug use. Currently, services in Vancouver for IDUs are framed as targeting IDUs as a population. Generally, planning HIV prevention programs for IDUs starts with the medical, technicist knowledge contributed by epidemiology. This needs to be adapted to an understanding of the context in which the target population (IDUs) live; these sort of adaptations are the hallmark of a population-based approach to public health. How epidemiological knowledge has been adapted (and delivered) to IDUs remains unstudied. Based on this, my study of both the practices and perspectives of HIV prevention workers is a logical next-step in the pursuance of better HIV prevention for IDUs in Vancouver, under the population health paradigm.

### Adult Education and HIV Prevention

In adult education, Boshier's (1992; 1993) popular culture analyses about AIDS offered some insight into discourses regarding AIDS, but did not speak specifically to HIV prevention as a practice. Sessions & Cervero (1999) examined the American public discourses on HIV prevention over nearly two decades. Their findings were not rooted in preventative practices per sé, but do acknowledge the importance of planners' values and

ideals in setting program objectives. Archie-Booker, Cervero and Langone (1998) studied HIV prevention strategies implemented at an AIDS social service organization in a southern US city. From a consumer/client perspective, they determined that most information lacked critical nuances or adaptation, particularly for African-American women; the preponderance of programs targeting white, gay men served to isolate these women, limiting their access to HIV prevention information. Whether these women's risks were linked to sexual transmission or injection drug use was not clarified. This study's contribution to knowledge was more as an analysis of the experience of persons accessing programs and information; it did not address specifics of programme content, or embedded values and knowledges.

#### Sociological and Anthropological Contributions

Sociological and anthropological research about HIV are dominated by issues related to the sexual transmission of HIV, particularly between males. For example, in AIDS Activism and Alliances (Aggleton, Davies & Hart, 1997) only one of fourteen chapters focuses on IDU-related HIV issues (Philip, Bruce, & Shuksmith, 1997): its focus is not the efficacy or relevance of HIV prevention programmes for IDUs, but the reasons for the marginal female participation in government-sponsored IDU health programmes. As in the adult education literature, programmatic responses—and the knowledges embedded within them—are not addressed. Stimson and Donoghoe (1996) map the evolution of needle exchange programmes (NEPs) in Europe and North America, using both sociological and epidemiological data collection strategies. This study makes two critical contributions to the literature on IDU-related HIV transmission. First, IDUs are capable of changing their drug using practices, given the means and information to do so.

Second, efforts to stem the spread of HIV among IDUs (or efforts to help IDUs become abstinent) are of limited value if the material experience of most IDUs is characterized by demoralization, stigmatization, and suffering. Technical strategies cannot inspire marginalized persons to change their self-limiting practices, if the quality of their lives is unlikely to improve substantively as a result. This finding reflects one postulation I have as to why so few IDUs achieve long-term abstinence: the difficult and painful lived experiences which lead people to addiction in the first place do not magically disappear once abstinence is achieved. The awareness among IDUs of their marginal place in society—and the concomitant hopelessness such exclusion brings—has received scant attention in the literature.

Stephen Koester largely pioneered the ethnographic study of IDUs. Though widely cited in anthropological and sociological literature, his work—wholly qualitative—is virtually absent from the epidemiological canon. He explicates how the experiences of addicts as insiders (of a community of fellow addicts) and outsiders (to society, and specifically to law enforcement and health officials) substantively influence the risk taking decisions they make, with regard to their drug using and sexual practices (Booth & Koester, 1993; Koester, 1994; Koester & Booth, 1996). One article focuses specifically on prevention strategies delivered through outreach services (1996b). The programmes discussed (they are not identified as occurring in any specific milieus, though Koester's other studies involved Denver and Boulder Colorado IDUs) rely mostly on individual risk assessment (IRA), where an outreach worker evaluates an IDUs' drug using and sexual choices, and gives concrete suggestions on how to reduce HIV transmission risks. He recommends both quantitative and qualitative summative

evaluation of outreach activities. But here the focus is on programmatic and administrative issues related to offering outreach services to IDUs; the experience of prevention workers themselves are not priorized.

Since the mid 1990s, Philippe Bourgois (working with several collaborators) has been the pre-eminent ethnographer of injection drug users, having conducted lengthy fieldwork in New York (Bourgois, 1996; 1998a; 1998b; 1998c) and San Francisco (Pearson and Bourgois, 1995; Bourgois, Littiere and Quesada, 1997; Bourgois, Agar, French & Murdoch, 1998; Bourgois, 1999; Bourgois 2000; Bourgois, Agar, French & Murdoch, 2001). In his New York (East Harlem) study, he documents how a street culture centered around drug selling, envelops an entire neighbourhood—not merely drug users; in this context, the omnipresent drug trade was normalized by the community, to the point where parents, children and drug dealers intermingled on hot summer evenings. Through participant-observation he has documented how materially and socially "righteous dope fiends" (heroin users) and "crackheads" (users of cocaine) differ (1998a, p. 39), and delineated how misogyny and racism (1998a, 1998b, 1998c) are powerful forces in drug using cultures.

In San Francisco, Bourgois and his colleagues spent many hours living among encampments of indigent heroin addicts. In a direct challenge to public health's preoccupation with informed personal agency (vis á vis, 'just say no'), Pearson and Bourgois observe that, "following the tenets of methodological individualism and psychological behaviorism, most researchers treat unsafe practices as instances of individualized decision-making writ large, when in fact such behaviors are contradictory outcomes of politics, economics, ideology and culture" (1995, pp.155-156). More

specifically, he notes how "the urgent necessities of fragile income-generating strategies mandate these risky practices" (p. 159), and that "virtually all (heroin addicts) recognize that a dope fiend in withdrawal has the right to use any means necessary to obtain a dose of heroin. Running partners—even lovers—regularly rip one another off on the street. Such behavior is considered intelligent, 'street-wise' prowess" (p.161). Even when the price of a bag of heroin dropped from \$20 to \$7, sharing practices among IDUs in San Francisco did not, cementing for Bourgois his contention that "the importance of the moral economy of sharing" among homeless heroin addicts (1998c).

Unlike Koester, Bourgois' work is concerned with HIV prevention, and the extent to which IDU-targeted programmes are of relevance. While some aspects of the San Francisco context differ from Vancouver—most specifically that syringes are legally for sale in Canada without a prescription—his observations are applicable to what happens here in Vancouver. In 1998 he called for the removal of limitations at needle exchange services in San Francisco (and elsewhere), citing "the puritanical paranoia that curbs needle exchange programs converts syringes into a scarce commodity that artificially inflates their monetary value on the street and logistically encourages addicts to share and/or steal them" (Bourgois, Agar, French & Murdoch, 1998, p. 2336). He actually challenges the notion of syringe exchange, suggesting instead that public health officials should flood "shooting encampments with clean syringes...[as] the ideal way to curb HIV infection." (p. 2338). And Bourgois challenges the notion that methadone maintenance (where a synthetic opiate is used to mitigate withdrawal and cravings for heroin users) is morally or practically superior.

Bourgois has also examined issues of research practice, both in terms of methodological approaches (ethnographic versus quantitative) and epistemologies (subjective versus positivist). He strongly critiques the appropriation of the term "ethnography" by epidemiologists doing brief interviews as an addendum to surveys, noting "the confessional context of paid self-report interviews and well-meant outreach messages humiliate addicts" (Bourgois, Lettiere and Quesada, 1997, p. 166). He also takes on the dichotomous debate between quantitative *versus* qualitative approaches, showing benefits of both methodologies when used judiciously, and often in complement to one another through interdisciplinary collaboration (Bourgois, 1999).

#### Epidemiology Reports

Vancouver's IDU-related AIDS epidemic is one of the most studied outbreaks world-wide, if from a single methodological approach. Nearly 100 journal articles and conference papers have been presented on its epidemiology; all but four of them have employed wholly quantitative (survey/questionnaire or modeling) data collection and analytic strategies. Though many of these publications have made critical contributions to our understanding of HIV transmission through injection drug use—specific to Vancouver, but transferable to other milieus—their findings are limited. In particular, this preponderance of survey/questionnaire-gathered data means the findings reported are constrained by the questions the research team (researchers and community advisory panel) deemed important. The use of multiple-choice response formats in many questions further constricts the depth and nuances of the answers reported. One advantage of a qualitative approach is the ability of participants to articulate *in their own voices* their

experiences, perspectives, and issues. That having been said, different data collection strategies provide different advantages and disadvantages.

All studies of the Vancouver outbreak have their origins in studies co-ordinated by the Government of Canada-sponsored British Columbia Centre for Excellence in HIV/AIDS (CfE); of particular note is their longitudinal study of IDUs in Vancouver's downtown East side (DTES), the Vancouver Injection Drug User Study, or VIDUS. Studies of HIV prevalence (viz., percentage of a population estimated to be infected with HIV) among IDUs in the DTES first appeared in 1995. In various studies, rates of HIV prevalence among IDUs in the DTES ranged from 3.2 percent in 1992 (Strathdee, Hogg, & Schechter, 1995), increasing to an estimated 6 percent in 1994 (Strathdee et al. 1995), and jumping to 23 percent in 1996 (Strathdee et al., 1997a) and 33 percent in 1998 (Patrick et al., 1997). This represents a 400 percent increase in HIV infections in four years, an astronomical change in a milieu where over two million free needles were exchanged by IDUs annually, *prior* to 1994 (Strathdee, Hogg & Schechter, 1995).

With the initial reporting of high prevalence among IDUs in Vancouver, the question of NEP's efficacy came under scrutiny. After 1996 the CfE studies began to shift their focus towards examining why HIV prevalence soared among IDUs in the DTES despite the availability of clean needles. Currie et al.'s qualitative case control study of eight HIV negative IDUs (1996) revealed that IDUs who are cognizant of ways to reduce the risk of HIV transmission often disregard this knowledge due to addiction, and to a disregard for their own welfare. Strathdee et al. (1997a) contextualized the availability of needle exchanges as but "one component of a comprehensive programme

including counselling, support and education" (p. F59), not as a panacea regarding the injection drug use-related AIDS epidemic.

Archibald et al. (1998) used a case control design of 89 newly HIV-infected persons and 192 non-infected IDUs. They concluded that needle exchange programmes (NEPs) attract IDUs who are more likely to engage in needle sharing, due to unstable housing, poverty, and to injecting cocaine rather than heroin; IDUs whose lives are more stable cited pharmacies as their more frequent venue for acquiring needles. Archibald et al. viewed NEPs both as a prevention service and as a potential venue to offer additional services tailored to higher-risk users, such as counselling and health care. Similarly, Schechter et al. (1998) examined the role of mobile (i.e., van) NEPs and their clientele. They concluded that mobile users are often from higher risk sub-groups of IDUs, particularly street-involved sex trade workers; their study also called for creating complementary prevention services at the site of exchange. In a later study, Schechter et al. (1999) found that higher-risk IDUs are more frequent attenders of all (storefront or mobile/van-operated) NEPs, accounting for higher HIV prevalence than less frequent attenders. In 1998, Whynot examined the social context in which women IDUs in Vancouver live, and how matters of context—particularly domestic violence and sex trade work—make women IDUs particularly vulnerable to HIV. Most recently, Spittal et al. (2002) found female IDUs in Vancouver more vulnerable to HIV than their male counterparts, mostly attributed to vulnerabilities around sexual violence and sex work.

In a broader analysis, O'Shaughnessy et al. (1998) conducted a meta-analysis of the impact of public policy on the DTES HIV outbreak. Their rather condemnatory study cites several policy decisions as contributing factors: withdrawal of federal support for

social housing (and the subsequent reduction in social housing availability), the warehousing of persons on social assistance into single-room occupancy (SRO) hotel rooms, the eviction and exclusion of addicts from social housing, reductions in in-patient services for persons with mental illness, the reduction in detox services, and inconsistent support for NEPs, particularly mobile NEPs. According to O'Shaughnessy, these events conspired to create a ten-block area of downtown Vancouver characterized by poor housing, a preponderance of IDUs, and a lack of basic entitlements such as shelter and food. Robert Remis from Health Canada, voiced similar concerns in a commentary in the Canadian Medical Association Journal in 2002 (pp. 908-909).

Two qualitative studies of note have emerged from Vancouver. Schilder et al. (1998) conducted focus groups with ten transgender, HIV-positive women. Though prevention was not the focus of their study, all but one of the participants either self-identified as having an injection drug using history or as participating in methadone therapy, which is almost exclusively used as treatment for injection heroin addiction. Six participants believed their HIV infections had occurred as a result of sex with a man (one during a sexual assault), three via injection drug use, and one through exposure to infected blood products. In respect to accessing services for addiction, several of the participants found the local detox to be sensitive to gender issues for female-to-male (FTM) transgender women, but found a dearth of longer-term treatment options. One participant was successful in securing a bed in a halfway house, but stayed only one month due to transphobia and homophobia among staff and fellow residents (p. 107). This study highlighted the shortage of detox and treatment options for IDUs who wish to become abstinent.

Harvey et al. (1998) conducted 30 to 90 minute interviews with eight HIVnegative IDUs and eight HIV-positive IDUs, using a case control design. From their analysis three themes emerged: addiction, prevention and social determinants (a better categorization of the latter might be 'material challenges'). All participants highlighted how the craving for drugs supersedes both the motivation and foresight to avoid sharing needles, even with persons known to be HIV-positive. Under social determinants, the poverty, exploitation (physical and sexual abuse), racism (particularly toward Aboriginal persons), feeling of powerlessness, and the challenges of street life were each frequently cited by the participants. In discussing these things as social determinants, Harvey seemed to be linking her finding to the population health paradigm of health services management. But her adaptation of the term social determinants to this study obfuscates the findings. Whereas the other two categories, addiction and prevention, describe activities and recent common experiences of the participants, social determinants is commonly used in health research to discuss previous lived experiences which are believed to cause or influence current health problems. The content of this third category could have been categorized perhaps more effectively in her conclusion as social determinants.

Montréal's Hôpital Saint-Luc cohort is the only other in-depth study of IDUs in Canada. Brogly et al. (2000) found that many IDUs are familiar with harm reduction strategies, but continue to practice these techniques inconsistently. Those who shared needles more frequently were much more likely to become infected with HIV. Bruneau et al. (2001) also found differences in HIV vulnerability based on gender. Men were

more likely to be infected with HIV (12 vs. 8 percent). Women were more vulnerable to sexual transmission of HIV, whereas men shared needles more frequently.

A plethora of studies are available on IDU-related HIV transmission in the United States; some of these are germane to the foci of this study, in terms of a more nuanced understanding of what influences IDUs' risk taking decisions, or (to a lesser extent, due to its absence in the literature) aspects of prevention efforts targeting IDUs. It must be clarified that US law (federal, and in some instances state and municipal) either prohibits or greatly restricts needle exchange programmes; so too is the carrying of drug injecting paraphernalia. These laws encourage IDUs to hide—and reuse—injection equipment, or, when they buy their drugs, to share someone else's. Where the mere act of carrying a needle is criminalized, there is little incentive for IDUs to seek out known NEPs for clean ones. Given these constraints, NEPs role in comprehensive harm reduction strategies is smaller than in Vancouver and in Canada as a whole, where needles are both legal and can be sold by pharmacists without a prescription. Notable exceptions, from which most of the studies cited here originate, include Baltimore and Oakland. US sites of highly restricted NEP operation include San Francisco, Philadelphia and Milwaukee.

Bluthenthal et al. (2000) compared a cohort of IDUs in Oakland (n=340) to determine whether attendance at NEPs impacted on IDUs' sharing behaviour. Over four years they found (through multivariate logistical regression analysis) that initial *or* continued attendance at NEPs was independently associated with cessation of needle sharing. Examining a sub-sample of this same study group, they found gay and bisexual male IDUs at much higher risk for HIV infection, due to their more likely involvement with sex trade work—similar to the particular risks related to women in other contexts

(Bluthental et al., 2001). Other recent additional studies described IDUs and their risk-taking behaviours in specific sub-communities of IDUs, including Asian-American IDUs (Nemoto et al., 2000) and recent participants in drug treatment (Woods et al., 1999) in San Francisco; and women in East Harlem (Tortu, et al., 2000) in New York City. Strathdee et al. (2001) found men had different risk factors (cocaine injection) than women (sex trade work) related to HIV exposure. Doherty et al. (2000) and Colon et al. (2001) found younger IDUs to be particularly vulnerable to HIV, based on their preference for stimulants like cocaine or speed and their more frequent number of average daily injections.

Rigorous public policy debates have occurred in many parts of the world over the value and risks of initiating NEPs in residential neighbourhoods; this is commonly known as the "NIMBY" (Not In My BackYard) debate. It has been posited that NEPs serve as venues for IDUs to create new, higher risk-taking social networks; Junge et al. (2000) used a sub-sample from an ongoing, longitudinal study of IDUs in Baltimore to study new NEP attenders. Their study confounds such claims—these IDUs did not form new "higher risk" networks from attending NEPs. Galea, Ahern, Fuller, Freudenberg and Vlahov (2001) found no link between rates of violent crime and the opening of a NEP in New York City. Latkin and Forman found that Baltimore IDUs, who used NEPs as their primary needle source (which was difficult, since Baltimore NEPs operated on a much more limited base than Vancouver), were much less vulnerable to HIV exposure; users who relied on the black market sale of needles—many of which were actually previously used—were at an elevated risk for HIV exposure (2001). These studies clearly refute allegations that NEPs might have a role in hastening the spread of HIV. Only one report

was located where any evidence was found of the fruitlessness of NEPs. Mesquita et al. (2001) report that a recent decrease in HIV rates among IDUs in Brazil are attributable to a switch from injecting cocaine to smoking crack cocaine among local users; efforts to initiate an NEP have been unsuccessful. Few, however, would endorse this approach to reducing HIV rates among IDUs in other jurisdictions.

Other modes of treatment have also shown evidence of modification of risk-taking by IDUs, even if harm reduction was not an explicit outcome sought. Shah et al. (2000) found heroin IDUs who enrolled in methadone maintenance therapy (MMT), ostensibly to achieve abstinence, rarely shared drug injecting equipment, though they often did not remain abstinent. Sabbatini et al. (2001) found that participants in abstinence-based treatment programs in Northern Italy often returned to drug injecting after completing treatment. Many of these IDUs also greatly reduced their needle sharing habits after treatment. Gossip, Marsden, Stewart and Treacy (2002) found that English IDUs who enrolled in MMT or abstinence-based treatment programs generally took less sexual or injecting risks after treatment participation.

### Relevance to Study

These studies consistently identified the value in harm reduction approaches (including NEPs), the challenges for IDUs to consistently engage in safer injection practices, and impediments to consistent safer injecting practices related to the criminalization of drug use and the carrying of drug paraphernalia. All these research projects have made critical contributions to our understanding of the social and medical understanding of injection drug use and addiction. From epidemiology, the specific modes of HIV transmission between IDUs have largely been identified (sharing drug

injecting equipment and sexual intercourse). Knowing the specific routes of transmission allows prevention workers to target behaviours relevant to these specific activities. But the work of anthropologists and sociologists has shown us that IDUs make decisions regarding their drug using and sexual activities that are often informed by issues other than HIV risk. This allows those of us concerned with HIV prevention for IDUs to try and adapt techniques based on IDUs' realities. Studies which incorporated questions about prevention strategies have largely shifted away from a technical examination of drug injecting prevention (viz., harm reduction) techniques, towards the contextualization of harm reduction techniques into the lived experiences of local IDU communities. But HIV transmission between IDUs continues, particularly in Vancouver. Between the medical understanding of the pathology of HIV related to injection drug use and the social science understanding of the circumstances under which IDUs live, there are gaps which mitigate the efficacy of prevention programmes. In researching the experiences of HIV prevention workers working with IDUs, this study endeavours to uncover knowledges which will further stem the tide of new HIV infections, by identifying—and bridging—these gaps.

Chapter Three explains the theoretical framework used in this study. By using a social theory regarding knowledge and power—two critical issues in both the proffering of prevention knowledge to IDUs, and in their ability to put this knowledge into practice—this study examines more than the *what* and *how* of practice. It also considers *why*—and why not—many IDUs seem unable to avoid HIV infection.

# Chapter Three: Framing A Foucauldian Analysis

One must set aside the widely held thesis that power in (our) societies has denied the reality of the body in favor of the soul, consciousness, ideality. In fact, nothing is more material, physical, corporal than the exercise of power.

--Foucault, 1980a, pp.57-58

This study examines the values and knowledges of HIV prevention workers assisting injection drug users (IDUs) to prevent HIV transmission, as a field of adult education practice. Any theoretical or methodological approach to examining this field of practice must consider how individuals make meaning of their experiences, beliefs, and actions, bearing in mind the ongoing negotiation between self and society, and the role power plays in that negotiation.

Michel Foucault's scholarship traverses history, anthropology and philosophy; across these disciplines the subjects of his research have included criminality and punishment, mental illness and sexuality. While he has contributed substantially to each discipline's body of knowledge, his approaches to research have impacted on many other areas of humanities and social science research. Few scholars from the latter half of the past century have produced a body of work as oft-referenced as Foucault. Economics, sociology, education, literature - in these (and other) disciplines, the ideas of Foucault are commonly cited as important sources for both ideological and methodological considerations in the research process. A propos to my research on HIV prevention education, aspects of his methodologies form the frame by which my data was analyzed, and in his writings I found clear articulations for many of the values that guide my practice as a community educator/activist. Interestingly, no empirically-based, peer-

reviewed adult education research that used Foucault's work on knowledge and power (or any of his work) as its theoretical framework was located.

In using a "foucauldian" analysis, it is necessary to demarcate precisely what aspects of Foucault's rich and varied scholarship form the theoretical framework of this study—and which do not. Foucault's structural period, of which The Order of Things (1989) is his major work, deals with the organization and hierarchization of typologies. For the study of an applied field of practice such as HIV prevention, Foucault's archeological method seemed too static. Foucault's later (post-structural) works include a series of examinations of power in society —so varied that they cannot be construed to represent a singular discourse on power. To many, Foucault's treatise on crime and the penal system, Discipline and Punish (1995), with its focus on surveillance and control, would seem the appropriate period of Foucault's work from whence to consider the experiences of IDU-related HIV prevention work: injection drug us is illegal. But even here, Foucault seems to exert a great deal of effort to describe how society's institutions exert control over its citizens; resistance to these controls, and his examination of wholly institutional settings, do not lend themselves to examining practices bounded by target population rather than space and place. And the workers in this study often bring their practices to their IDU clients, rather than waiting for their IDU clients to come to them. Thus for this study, a particular collection of Foucault's works, which allow for the complexity of experiences of power, and which are not bound by institutional settings, serve as the theoretical framework.

Linear cause and effect, force and counter-force dichotomizations are dubious according to Foucault, as are superficial applications of the dialectic: "as always with

relations of power, one is faced with complex phenomena which don't obey the Hegelian form of the dialectic" (1980a, p. 56). By their very nature he sees simplified analyses of power with respect to subjects as complex as HIV prevention as either irrelevant or inaccurate. My analyses were conducted with this caveat in mind. Foucault's work also validates a commitment to the importance of priorizing a contextual understanding of practices, be they personal or professional. In doing so, Foucault endorses the validity of such bodies of knowledge based on their relevance and utility to those who possess it, within the settings from which they spring. He rejects any external "required level of cognition or scientificity" (1980b, p. 82), which could be used to denigrate the value of such knowledges; acceptance and validation of these knowledges have traditionally come from their own milieus. But Foucault moves one step further with his endorsement of transgressing the borders which ghettoize these knowledges to their local contexts, excluding them from the larger "mainstream" society. He refutes the notion of a singular, concrete hierarchy of knowledges that gives authority to the academic enterprise over other forms of knowledge.

What has historically been employed to dismiss these contextually-based knowledges--Foucault calls them local, regional, subjugated knowledges--has been whether they are "true" or not. The exclusion of these knowledges by hegemonic regimes of thought (1980b, p. 81) is ensured by the broad, institutionalization of mainstream knowledge, often as "science." The university and the State (and today the corporation) collude to ensure that a largely homogenous body of "knowledge" is reified in the public sphere, to the exclusion of any local knowledges that may contradict it. These mainstream knowledges, though priorized and strongly favoured, are not wholly

hegemonic; local knowledges still impact the contexts from which they spring. Their exclusion is in the difficulties encountered in disseminating local knowledges from local contexts into the mainstream public sphere.

As such, these local knowledges are not disregarded or rejected in the mainstream; rather they are silenced and concealed by those in power, from the general populace. By keeping them from mainstream society's purview, the question of their veracity or validity is never posed. Yet, the exclusion of local knowledges from the mainstream does not wholly inhibit their being heard beyond their context of origin; what has merely been determined is whether the ideas are overtly or covertly expressed. While one might be tempted to extrapolate from Foucault a rejection of institutional knowledges (vis à vis positivism as a refutation of academic hegemony), Foucault instead endorses a greater integration of different types of knowledge. He certainly posits that there are a plurality of epistemologies in the Western tradition. In describing this "local character of criticism" (1980a, p. 81), he writes:

...what this essentially local character of criticism indicates in reality is an autonomous, non-centralized kind of theoretical production, one that is to say whose validity is not dependent on the approval of the established regimes of thought (1980a, p. 81).

It is a localized criticism—examination—of the local knowledges of HIV prevention workers in which I have engaged here. Rather than use textual discourses for this study, I instead engaged with the agents of these programmes—the workers—since HIV prevention with IDUs is almost exclusively conducted as an outreach (i.e. face-to-face) activity.

### Power And Interests

As will be explicated in the following chapters of this study, it is the differing interests among prevention workers whose clients are IDUs in Vancouver—differing along racial, and gender lines, but also between health professionals and those whose backgrounds do not include medical training—that helped to shape how the local response to AIDS among IDUs took form and subsequently evolved. Taking from Foucault's writings on the intersections of power and knowledge, this study seeks to locate differences in interest as expressed in the experiences of HIV prevention workers from a variety of contextual, experiential and ideological stances. These activities give evidence of how both grassroots social service and government health workers do this work, the nature of their *individual* responses to AIDS work targeting IDUs. This notion of stance can also be applied to HIV prevention workers who do/do not consider themselves drug addicts.

Foucault challenges the Marxist assumption that power dynamics are most often between "the oppressor" and "the oppressed." To this end he defines power as "not an institution and not a structure; neither is it a certain strength we are endowed with; it is the name that one attributes to a complex strategic situation in a particular society" (1990a, p. 93). Consideration of power is, then, to consider its interactive nature. Rather than looking for instances of opposing forces, the location of different interests' interactions (which may be taken as opposition, in collusion, as complements, or a myriad of any number of other dynamics), is more informative. In The History of Sexuality Volume One: An Introduction, he asks:

What were the most immediate, the most local power relations at work? How did they make possible these kinds of discourses, and conversely, how were these discourses used to support power relations? How was the action of these power relations modified by their very exercise, entailing a strengthening of some terms and a weakening of others, with effects of resistance and counter investments, so that there has never existed one type of stable subjugation, given once and for all? How were these power relations linked to one another according to the logic of a great strategy, which in retrospect takes on the aspect of a unitary and voluntarist politics of sex? (1990a, p. 97).

In other words, what mechanisms of the knowledge-regime (the institutionally-centered mainstream knowledge of the university and state) seem to have been in use, and how might these mechanisms have interacted with other forces to possibly shape the prevention strategies for AIDS and IDUs?

Finally, Foucault differentiates between the technologies of power--its mechanisms--and power itself; practices such as censorship, propaganda, and imprisonment are not examples of power, but are actions which can be taken to demonstrate power and to seek its reinforcement. Censorship requires that knowledge be viewed as dangerous, and propaganda ensures primacy of the knowledge regime over other sources of knowledge: from these one can infer that alternate knowledges have power (1990a, p. 12). This theory of power calls less for any empowerment of the oppressed than for the identification and implementation of strategies which serve to engender one's own community's interests, acknowledge its local pertinent knowledges, and permit one's own community to access its own power. This observation does not binarize the use of knowledges as dominant versus subjugated; communities which have synthesized their own local knowledges can and do use other knowledges, including the dominant knowledge-regime. The embracing of one's local knowledge is not predicated on the total rejection of the knowledge-regime. In HIV prevention with IDUs a biomedical understanding of the pathology of HIV has been a keystone of today's more effective, context-specific HIV prevention strategies. But the continued ghettoization of

the Vancouver IDU experience even within Vancouver means that IDUs locally, nationally and perhaps globally are not getting information that could save their lives. Likewise, Vancouver HIV prevention workers cannot access other local knowledges from other contexts: the local burdens borne by these workers usually preclude any sustained effort to transgress these barriers.

## Subjugated Knowledges

Though most of Foucault's writings are not epistemic in their foci, the idea that different ways of knowing exist is reflected in many of them. A cornerstone of his scholarship is that differences in perspective (or outlook) are to be found between those in "authority" and those subject to said authority. Often those in authority use the institutions (such as the academy and government agencies) to disseminate their own perspectives as singularly correct. These regimes of thought (1980b, p. 81) seek to transgress all institutional and organizational bounds in their denunciation (or silencing) of other views. "Subjugated knowledges," Foucault wrote, "(represent) a whole set of knowledges that have been disqualified as inadequate to their tasks or insufficiently elaborated: naïve knowledges, located low down on the hierarchy, beneath the required level of cognition or scientificity" (1980b, p. 82). It would seem that the existence of such knowledges should imply their validity within their own contexts, but in fact it may take some precipitous event to focus a community's attention on its own knowledge. Subsequently, dissonance between the dominant knowledge and the local knowledge becomes apparent. Innumerable community projects, organizations, and some social movements were initiated within this paradigm. What is perhaps most intriguing is that sometimes a local knowledge manages to transgress all mechanisms that seek to contain

it; as a result this local and "invalid" knowledge enters the knowledge regime. The very notion of validity is largely a matter of context. Chapter Four addresses how issues of external validity are manifest in academic and community-based settings; between these two realms, conceptualizations of validity and credibility are not only distinct, they are at times in opposition to one another. This makes the tensions between local and mainstream knowledges critical.

This phenomenon certainly is true with respect to HIV prevention education for gay men in Vancouver; today's public health strategies for HIV prevention have significantly integrated community education practices whose origins are in the gay male community. These "indigenous" practices have also arguably allowed for mainstream (i.e. not for a specific risk group) HIV prevention programmes to discuss sexuality more candidly. Foucault identifies that knowledge itself has power and is shaped by power; he sees that by their nature knowledge and power interact, with each impacting upon the other. In writing about local, regional knowledges he seems to be prophesizing how AIDS education would subsequently evolve.

In the early 1980s, many gay men viewed waiting for a government response to the rapidly unfolding health crisis as an unrealistic option. Assuming a response was forthcoming, administrative and bureaucratic constraints would have meant that precious time would have been wasted. Seeing a veritable dearth of government response in both the United States and Europe (Shilts, 1987), a group of Vancouver's gay male community took it upon themselves to disseminate information amongst each other, shortly after the first AIDS cases were identified in British Columbia in 1981. Very quickly an emergent community response was formed, which by 1983 evolved into AIDS

Vancouver (Majoribanks, 1995). In bypassing the hierarchy of government, these men avoided what was perceived to be inevitable resistance to the candour with which gay male sexual practices were discussed (Shilts,1987; Majoribanks, 1995). In rejecting the normative communicative practices of society regarding sexuality (including their unwillingness to be complicit in perpetuating its silence about homosexuality), the initiators of this organic, grassroots endeavour engaged in the type of local criticism Foucault deemed both valid and vital (Egan, 2000).

But the IDU community, though also gravely affected by AIDS, lacks the resources and organizational capabilities to inculcate a grassroots response similar to that among gay men during the 1980s and 1990s. HIV prevention for IDUs in Vancouver has emerged as a field of practice, where workers with a variety of skills, backgrounds and beliefs are all trying to help IDUs to avoid becoming infected with HIV. And the marginal role that IDUs play in HIV prevention for IDUs—former or active injectors—means that there is a greater potential for missing critical components of the local knowledge because the workers are almost all outsiders to the local IDU community.

### Criticism and Activism

While Foucault endorses the inclusion of scholarly criticisms which do not conform to existing paradigms of the academy, he equally endorses other activities as forms of criticism. Grassroots programmes (such as the pre-cursor to AIDS Vancouver ) are not only functionary, their very existence also communicates perceived inequities and inadequacies of those existing institutions which they seek to eschew. While their common focus may be helping IDUs avoid contracting or transmitting HIV, one can

certainly argue that pursuance by these groups of their own programmes also challenges the notion that citizens need to (or should) acquiesce to the prevailing paradigms of public health. As Foucault wrote, "we are witness [to] an insurrection of subjugated knowledge, those blocs of historical knowledge which were present but disguised within the body of functionalist and systematizing theory, and which criticism has been able to reveal" (1980b, p. 81). Grassroots activists' "insurrection" against the status quo of public health ensured better prevention strategies for AIDS and other diseases, but also changed how public health disease prevention programmes were designed. Specifically, the actions of community representation, political lobbying, self-advocacy and client empowerment were all eventually priorized in relation to other health issues.

It is my contention that community based, grassroots AIDS prevention programmes targeting IDUs contain transgressive, local knowledges, which explicate how the specific norms of society regarding discourses on substance use differ from local practice. These differences are clear when we compare the systemic expectations (and delineations) regarding drug policy (in terms of treatment, most specifically to this study), and the actual interpretation and application of what policy requires versus what workers actually do. In its contextualization of drug using practices, community-based social service workers, when compared to their medically-trained, health professional colleagues, challenged regimes of thought related to disease prevention strategies, which employed medico-scientific information to encourage technical changes of personal practices (i.e. "hygiene"). As more information about the transmission of AIDS became available, such knowledge continued to be incorporated into the community's prevention

strategies, but in ways which adapted the materials to the community's own discursive practices, rather than vice versa.

### Dissemination Of Knowledges

Thou shalt not go near, thou shalt not touch, thou shalt not consume, thou shalt not experience pleasure, thou shalt not speak, thou shalt not show thyself; ultimately thou shalt not exist, except in darkness and secrecy.

--Foucault, 1990a, p. 84

The above discussion leads to an important question regarding the dissemination of different knowledges: does the wider dispersion of dominant knowledges grant them a presumed validity over other, subjugated knowledges? Though Foucault certainly thought this was true, he did not accept this practice as being in the best interests of society. Indeed he challenged it, going so far as to state his belief that hegemonic paradigms like these almost always were detrimental to society (1990a, p. 159). In this thesis it is argued that an analysis of HIV prevention campaigns supports Foucault's work in the areas of knowledge and power. The manner in which health was compartmentalized by the knowledge-regime into medical/scientific diagnoses (which gave assent to some desires and practices while repudiating others) make any decontextualized interventions suspicious or dubious to those whose practices (in this case, injection drug use) are outside the norms of mainstream society. Thus if a cogent community response had not catalyzed, an even more catalysmic pandemic would likely have ensued. Perhaps we must also be grateful that HIV is a very fragile and slowprogressing infectious agent; a more aggressive organism would have afforded much less time for the piloting of different strategies. For those whose lives include practices, desires and values which fall outside the norms of society, the wisdom of relying solely

upon government to achieve and maintain wellness quickly becomes dubious (or a "risk behaviour" of its own kind).

Foucault's primary caution is to avoid a solely "juridico-discursive" representation of power (1990a, p. 82.). This reiterates his challenge to any notion of power which concentrates only on the modalities by which hierarchical institutions demonstrate their power. With his hermeneutic that considers multiplicities (rather than a simple polarity) of power, other means of the exertion of power must be considered. So I "moved toward a definition of the specific domain formed by relations of power, and toward a determination of the instruments that will make possible its analysis" (1990a, p. 82). Foucault also iterates how analyses based on the more traditional juridico-discursive representations of power are found throughout the Western tradition, and are of limited merit insofar that they reflect only the normative values of an epoch. They thereby exclude the values (and interests) of those who may not have acquiesced to these norms. The effect of power is less evident when one is informed only by the interests of the powerful, and without those of the transgressors.

Like other subjugated identities, injection drug users have experienced this unreliability. But whereas a juridical prohibition against the practice of using heroin, cocaine or other drugs can drive users underground, prohibitions on the discussion of these desires in the public sphere does not interdict the desire or its expression. But such prohibitions can interdict the development of contextually-relevant programmes in response to issues, like AIDS. Exclusion of such issues does not prevent people from pursuing their desires, but they do ensure that the institutions of governance do not serve the needs of all citizens.

### Foucault and Adult Education

Others adult education scholars have incorporated Foucault's writings on power and knowledge, including Tennant (1998), Usher (Usher & Edwards, 1995; Usher & Solomon, 1999), and Brookfield (2001). Tennant uses Foucault's writings on power and knowledge (1908a, 1980b) to examine how adult educators' assumptions about the teacher-student dynamic can serve to replicate the sorts of inequities adult educational endeavours seek to assuage. Usher and Edwards have taken Foucault's analysis of the confessional (1990a), a sacramental function of the Church, and consider how new forms of confession have become means by which authorities manipulate and control persons who are marginalized. In particular, the rise of "prior learning (assessment), portfoliobased assessment, learning contracts, records of achievement, continuous assessment, (and) self-evaluation" (Usher & Edwards, 1995, p. 19) in guidance programmes for adult learners, requires a sort of 'act of contrition' from program participants. The power of adult educators in such circumstances cannot be ignored. Usher and Solomon's examination of issues of power in experiential learning (1999), draws on Foucault's critique of simplistic, hierarchical views of power in society. Building upon Foucault's generalized interactive idea of power (i.e. that power is diffuse, multi-directional, and rarely absolute), they warn that "Discipline in the contemporary workplace therefore works through a 'teaching' that is itself a teaching but which appears not to be, because, based on experiential learning, it seems to be free of 'discipline' "(p. 62). Brookfield reviews much of Foucault's writings about power prior to his history of sexuality series. In using Foucauldian frameworks for their work each has brought the complexities of power relations into adult education scholarship. In doing so, a subtle shift away from adversarial notions of power ("us versus them"), with concomitant dominant and victim,

has occurred. However, none of these scholars' work focuses on Foucault's ideas about the relationship between local knowledge and the regime of thought, or applies these concepts to an analysis of practice. For example, Brookfield refers repeatedly to adult education classrooms or schools (pp. 4, 8, 10, 12 & 19), without incorporating non-school examples of the Foucauldian notions he so clearly articulates. His analysis, in fact, silences the sorts of liberatory and emanicipatory adult education endeavours that would perhaps find Foucault's complex, nuanced examination of power and knowledge most useful.

Unlike Usher's, Tennant's and Brookfield's theorization from the literature, an empirical study of practice is the focus of this study. HIV prevention workers—educators—often do their work in almost any sort of venue (on the street, in alleys, in health clinics, NGO offices, community centres) *except* classrooms. Hence, this study takes notions of power, knowledge and resistance to a field of practice that, in its targeting highly marginalized learners (IDUs), often places questions of power overtly in the centre of practice. For the client network targeted by these workers (IDUs), access to accurate and relevant knowledges about injection drug use and HIV—two highly contested issues in the public sphere—necessitate a theoretical analysis that addresses power.

Before explicating the methodology used for this study, how I prepared to engage it merits discussion. In preparation for this study, it was necessary to interrogate my own position with regards to the study population, and the research enterprise in general. My own position is the subject of Chapter Four

## Chapter Four: Insider or Outsider?

Adult education has long laid claim to a critical role in the pursuit of social justice (Hart, 1992; Thompson, 1995, 1996; Marsick, 1990; Hill, 1995). But this view is belied by the marginal degree to which grassroots, community-created educational programmes—the sorts of activities that are almost always an integral aspect of the pursuit of social justice--are substantively examined as a locus of practice of adult educators. Adult education priorizes examinations of practice in institutional contexts, where education is a highly formalized (and frequently commodified) activity: grassroots activities get short shrift. Their absence is probably not due to conscious exclusion by adult education researchers; rather, in its most common manifestations, grassroots adult education—activities where people learn from their peers about their communities, their shared concerns, and their entitlements as citizens—usually occur 'below the radar' of most researchers. Their localized character makes such endeavours uniquely effective, while (paradoxically) obscuring them from the purview of mainstream society, including university-based adult educators. More and more of us who are activists see a place for our work in the academy, often in post-graduate adult education programmes. But a particular challenge for many of us is straddling the conflicting paradigms of practice—grassroots activism versus research--and how coming to terms with each measures the credibility of our work.

In the absence or inadequacy of existing institutional programmes, our activism is a political response to perceived community need. By operating *extra-institutionally*, our status as members—insiders—of our communities is affirmed. To mitigate feelings of exclusion or isolation, activists eschew mainstream society's formalized structures, so as

not to replicate (or be constricted by) their normative practices. Yet in the university milieu, it is precisely the adherence to ritualized, formal protocols of inquiry—research methodologies—that garners the researcher credibility to examine practice, most often as an outsider to the communities studied. This puts those of us who are activists in a strange position: we are expected to shift our primary notion of community from our grassroots home to the institution. Thus in choosing academe as a venue for our work towards social justice, our status as insiders within our communities comes into question. It is in my ever-growing awareness of this paradox that my perceptions of myself as insider/outsider continue to unfold.

This chapter is a critical examination of the insider/outsider question, contextualized in my own experiences as an activist and researcher. It calls attention to some of the unique challenges faced by increasing numbers of activists who do research in a university environment. It further suggests the need for a shift in purposes and methods of research in adult education. This shift will be reflected not only in individual researchers' practices, but in what constitutes normative practice for social science research.

### Identity. .

Identity is a negotiated, contested space. Issues of differentiated identities often emerge in relationship to questions of inclusion/exclusion, discussed in the realm of social science as positionality, or insider/outsider. Embedded in the notion of insider/outsider is the question of *personal agency*: to what degree can one assert power over one's material experiences (where to live, ability to work, physical safety and emotional security as examples), and to what extent is this agency--the ability to effect

substantive change in our own lives--effective? In liberalism this agency is exaggerated, and is often reduced to consideration of 'the ones who made it' as a continued rationale for a meritocratic society. That innumerable others do not overcome racial, social, gender or other exclusions is regarded as a 'choice' rather than a probable outcome.

How, then, can activists navigate through the treacherous waters of university-based research without betraying the principles (particularly empowerment) shaped in their community-based practice? For some, the pursuit of collaborative or participatory research methodologies offers a possible solution, though the number of disciplines that embrace such approaches remains small. In community-based health education research, the normative practices of medicine and epidemiology—the dominant, largely quantitative disciplines from which most health education research comes—cannot be disregarded if I want my own research on HIV prevention to appear in the canon of health education. Yet in seeking to create a research practice which honours both academe and activism, my efforts could generate findings of little consequence to either stakeholder group. The duality of experience as an insider/outsider in both grassroots activism and academe has necessitated a rigorous reflection on how the insider/outsider question relates to my research programme.

## .. Inside and out

The insider/outsider question continues to be an important area of enquiry for social scientists. Critical contributions can be found in research studies (Kondo, 1990; Myerhoff, 1980) and in reflections on the experience of doing social science research, particularly by feminist ethnographers (Stacey, 1991; Matsumoto, 1996; Hsuing 1996; Fine and Weis, 1996; Chaudhry, 1997; Fine, 1994; LeCompte, 1993). In adult education,

the issue has been examined to a much lesser degree. Merriam organized a symposium on the insider/outsider issue for the 2000 Adult Education Research Conference in Vancouver. This session was framed around the central question, 'what does it mean to be an insider or an outsider to a particular group under study?' Six women researchers (five of whom are women of colour: Botswanean, Taiwanese Chinese, Korean, African-American and Muslim Malaysian) recounted their experiences in conducting research studies in communities in which they claimed some degree of membership. In each case their insider status was mitigated by an equal (or greater) outsider status. Class, gender, age, and cultural differences--discerned by both researcher and participants--disrupted and at times subsumed commonalties of experience, which they as researchers had presumed would override any differences.

### From Activist . .

Ask activists their motivation for pursing grassroots projects and most will say, 'something had to be done.' These sorts of activities frequently begin as conversation over neighbours' fences, on front stoops, at the corner store, or in houses of worship.

From these conversations, an issue or concern begins to gain prominence, and inspires a more specific and purposeful dialogue. This is the precise moment when informal talk about what is happening in people's lives becomes *activism*. Soon these discussors become a group, among whom a plan of action is devised. Over its lifespan such a group may retain its nascent form; it might also end, if the issues identified are resolved. Or the participants may decide that a more structured approach would work better, at which time the group might migrate to existing community institutions (like places of worship or community centres), or formalize itself as a non-governmental organization (NGO).

Regardless of how the group is constituted in terms of its structure, at its very heart are the people involved.

My own story is similar; in nearly two decades of activism, I have been involved in pre-existing and nascent projects. Most of my work has been with the lesbian, gay, bisexual and transgender (LGBT) communities, mental health consumers, and persons with substance abuse issues. My activities have included co-ordinating an anti-gay violence hotline, acting as a peer counselor in a halfway house for addicts, facilitating member meetings for a self-run mental health consumer's housing co-operative, and delivering skills building training to AIDS activists from the developing world. Very little of this has been paid work; community volunteerism was my career, whereas my paid work constituted a livelihood—nothing more.

Grassroots activism can be energizing and tiring, rewarding but frustrating. Over the last several years, I found myself less inclined to work within an 'us versus them' paradigm. Years on the front lines had taken their toll; so too had working in the service industry, in a position I had come to loathe. Eventually I was forced to examine the meaning of work in my own life; I needed to find paid work that reflected my commitment to improving people's lives. And so I found adult education, in the form of post-secondary vocational training. Since many of the learners were recent Canadian immigrants (often refugees), or persons trying to leave social assistance, I saw myself as an agent of empowerment for these learners. By helping them develop the means by which to support themselves and their families, I could fulfill my desire to help improve people's lives in genuine, material ways. I also discovered that I had a gift as a teacher.

But in another important sense, I started this project feeling as an insider: I am an addict. In our public sphere there is a plethora of self-disclosures about the many challenges individual face and (hopefully) overcome. With such disclosures come benefits and risks; benefits often in terms of support, but a certain "soiling" of your person as damaged, less than. And so, while I saw early in my research studies the need to examine my insider status to the clients served by my informants (as addicts), I also knew that to address this issue in my research report was to risk a less favourable viewing of my work, either as biased (too close to the questions at hand) or ill equipped (addicts have impaired cognitive ability). I believe the weight of social science literature on the insider/outsider question, and the process of peer review (particularly for doctoral work) make the full spectrum of such critiques invalid. Yet, my story is a critical part of this study.

My substance use never involved injecting drugs; my addiction was to alcohol. While I certainly imbibed other licit and illicit drugs during my addiction, alcohol was what I sought, what held me in its grip, and what controlled my life for the better part of ten years. In general terms, I started drinking heavily in my early teens, and eventually achieved abstinence from alcohol at age 26 (a dozen years ago). Over the course of my drinking, I failed numerous courses at three universities (despite being "gifted"), lost a number of jobs, and eventually was unemployable, and living in a halfway house for addicts. For me, abstinence was achieved on the second attempt, though few of my peers who were involved with drugs like cocaine and heroin seemed able to maintain longer-term abstinence. Early in my own sobriety, I saw how different addictions had physical and social conditions. I counted myself lucky to "only" be alcoholic. It is also important

to note that, while some of my peers in recovery consider themselves "addicts" to any and all mood or mind altering substances, I have not shared this belief. I have seen numerous persons with a particular problem with one substance, who abstain only from, say, marijuana or cocaine, but who drink alcohol with no apparent deleterious effect.

Among addicts who have sought abstinence, there is a certain sameness, or kinship, whether abstinence is maintained over the long term. But some who have pursued abstinence—most often privileged persons whose addictions never included injection drug use—see harm reduction as more harmful than beneficial. These "sobriety Nazis" as they are sometime called in 12-step programs, expect what worked for them to work for everyone. Having lost everything—despite my being an educated, professional white man—and living with folks in the halfway house whose challenges made the chaos of my life seem quite fixable, showed me how addictions vary based on the context of substance use, the mechanism of substance ingestion, and level of social marginalization faced by the user. But between the two paradigms—100 percent abstinence or harm reduction—support was needed for individual users to find their own paths.

In approaching this research, my own experiences as an addict cannot and should not be discounted. From my own experiences with substance use, withdrawal and seeking support services, I have some insights that brought particular questions to this study. In several instances, where it seemed relevant, I identified myself as an abstinent addict.

### .. To Researcher

My lack of formal training in education eventually hindered my development as a teacher, so I began post-graduate studies in adult education. From the onset, however, little in my studies related to the technical, 'how-to' practice of adult education. Instead I found myself once again discussing the familiar issues of empowerment, entitlement, resistance and power: the canon of adult education literature to which I was introduced made frequent mention of empowering learners, and of adult education's role in democracy and social justice. As I became further ensconced in my studies, I found a significant gap between the claims to adult education's role in the pursuit of social justice, and representations of such pursuits at the grassroots level in empirical research studies.

Even Paulo Freire's popular education, though a viable strategy for achieving basic literacy while building towards critical consciousness, is actually predicated on outsiders determining and developing instructional goals and strategies. Freire used outsiders to determine what objects in a local context were of critical value, relegating learners to the role of "assistant" investigator (p. 91); a confounding approach to any genuinely localized approach to education. Popular education, as mapped out in Pedagogy of the Oppressed (1986), is never an indigenous practice when the materials adopted for the learning activities are selected by the educators and their colleagues from outside the context of practice (pp. 86-93); given the extent to which learners are objectified by this approach, to what degree are the participants' critical consciousness uncovered or imparted? Encountering this sort of paradox in scholarly works was unsurprising, even when the author is reified as a voice of the grassroots, as Freire has been. From my own work in both university-based and grassroots settings, traveling from

activist to researcher seems more plausible than the reverse, in terms of maintaining some degree of credibility at the grassroots level. Thus I decided to pursue this journey.

For an activist, the potential pitfalls in conducting empirical research with human participants were daunting. Long before beginning my post-graduate studies I viewed the research enterprise as routinely decontextualizing, oversimplifying and misrepresenting peoples' lives—particularly marginalized peoples' lives. A brief stint working in HIV prevention research in the year prior to starting my magistral studies convinced me only that some researchers seemed to value the ideals of inclusion and empowerment, but under the guise of methodological 'rigour' nonetheless replicated science's exclusionary and silencing practices.

Towards the end of the twentieth century, social science began to embrace theoretical and methodological approaches that were much more participant and community-focused. Ultimately, I was convinced that exploitation was not inevitable in the research process, and began to plan my first research study. Leery of conducting semi-structured interviews, I opted for the ostensibly 'safer' route of document analysis. Yet in analyzing the printed materials used in HIV prevention programmes in Vancouver (Egan 2000), I did not avoid the issue of insider/outsider. Though my 'informants' were not human, the materials analyzed were created *by* people, *for* specific purposes, and *under* particular conditions. In examining different discourses targeting gay men versus 'mainstream' society, I found myself specifically fearful of critiquing the materials created by other gay male activists. My theoretic concerns about conflicted loyalties as an activist/researcher were real, even without 'real people' participating in my study. To proceed, I had to ascertain why this issue haunted me so.

I came to the conclusion that as an activist or researcher I could only commit to engaging in an examination of a local, contextualized practice. Much of social science theory only addresses examples of local experience in support of generalized, high theory. It was this tension, between local and generalizable knowledges, that disconcerted me. Having come to the academy, and thus having consented to taking a role in scholarly enterprises, I realized that if I wanted to 'work for social justice' as a researcher, it would have to be in a manner that honored my grassroots experiences, and that also met the standards of rigour and validity of my university peers. In effect, I had to resolve my own conflicts about my insider/outsider status as a researcher among activists, and as an activist among researchers.

## Asserting The Subjective

In 1993 Kirin Narayan asked, *How native is a 'native' anthropologist* (1993); one might also ask, 'how activist is an activist-researcher?' In examining discourses about sexuality in HIV prevention, I sought meaning both in the work of government health workers and community volunteers, of whom many of the latter were gay men. These men's work quite possibly saved my life—without the information proffered about sexual harm reduction I would quite likely have contracted AIDS. As a beneficiary of this work, if I were to engage in a critique of the materials it would have to be a *respectful* critique. A decontextualized, 'objective,' *a posteriori* examination of materials created fifteen years ago would be facile, insensitive and inaccurate. Identifying embedded local knowledges about AIDS and sexuality in the materials would need more than an 'objective' review; the approach of greatest value to both my community and adult education would be to consider the *subjective experiences* from whence these materials

came. I employed both my naturalistic urban gay male lens, and my learned 'straight-acting' lens—the lens foisted upon me by a homophobic, heterocentric culture--to examine how the materials originated from (and spoke to) different subjective experiences.

Making this sort of shift tenable required my belief not only in its feasibility, but also in its value. It necessitated that I be prepared to articulate my understanding of how both lenses are constructed, how they differ, and how they interact--for both secular and academic audiences. For scholarly peer review, this required drawing upon scholarly literature (mostly from outside adult education) to justify this plurality of subjectivities. There is a wealth of critical literature (post-structural, as in Foucault's case, but also post-colonial and from various feminist frameworks) that offers ample evidence of how excluded people often *need* to learn how their oppressors' lenses operate in order to survive. I was confident that, for my activist peers, only the language used in academic theory might need clarification; the concept of subjectivity is reflected in our shared experiences as grassroots activists, who pursue a local understanding of local issues to develop local solutions.

## Outside Community And Comfort

My current research examines how experience, knowledge and venue (i.e. place of practice) influence the practice of HIV prevention workers whose clients include injection drug users (IDUs). One contested facet of this work is a perceived dichotomy between (paid and unpaid) workers from social service organizations, and those who work for health care and social service systems. To what extent do the practices, perspectives and experiences of these two groups differ? How consistent are

practitioners' opinions within these two groups? And how does personal experience with injection drug use—one's own or that of a loved one—mitigate one's beliefs and practice? These are some of the themes emerging from this combined qualitative and quantitative study.

To some extent I claim affiliation to the community of IDUs in Vancouver, deeper than a *de facto* commitment to social justice. As a gay man I know too well the fear of facing a deadly disease, with no relevant support—and often hostility--from the state. The issue of addiction has affected my life in very personal ways; experience has formulated my opinions that to some degree do not concur with the literature on addiction. And a brief stint of impoverishment in my mid-twenties also gives me confidence about bringing a sensitive and informed perspective to this work. But I have never used injection drugs, nor have I lived for years in abject poverty. So I feel qualified to speak as a close ally to IDUs, and from a position much closer to their lived experiences than perhaps most social scientists. But I remain an outsider to the IDU community.

Identity is contested space; at different times our many affiliations, attributes and experiences jockey for prominence in how we describe who we are in the world, to the world. For me—gay man, activist, researcher, Canadian, Irish, Catholic, teacher, learner—these terms occupy a nebulous, ever-changing shape. Often, some of these identities are obscured partially or wholly by others. Sometimes I am a paradox of competing and seemingly incompatible identities—in particular when the gay man and nice Catholic lad assert themselves simultaneously! Looking at the contexts in which my

life unfolds, I find that usually one or two labels are of greater importance than the rest.

This seems to hold true in my research as well.

The gap between the *ideal* of social justice, and research that examines grassroots activism's role in the *pursuit* of social justice, is real. But adult education continues to be a place in academe to which activists seeking researching training are drawn. Our discipline's espoused commitment to justice, and the increasing representation of critical theories in our literature--all of which to some degree validate the need to understand context-specific local knowledges--will continue to attract activists. Activists, in turn, are making the research enterprise more accessible and accountable. Activist-researchers, in endeavouring to conduct research that explicitly examines the material experiences of marginalized and excluded persons have an unique potential to effect change both at the grassroots and policy levels, by giving voice to those long silenced.

The tensions within my aspirations as an activist and researcher make examination of my insider/outsider status ultimately a question of integrity. In doing research in my own community—geographic, social, cultural—the extent to which any such labels were shared by stakeholders offered me both unique privileges of access, and great responsibilities. But with this study, though I share affiliations with some participants, I am not working 'from the inside.' For this study, my being an outsider affords me less privilege on a colloquial level with the participants; but my position of privilege in society at-large as a university-affiliated researcher is intact. Yet, though the degree to which I am researching 'my own people' informs my approach to a research study, my responsibilities to the participants remain the same, whether I am an insider or outsider. Or both. As long as there is some 'we' between myself and the participants,

empowering research is possible. As an activist or a researcher, there doesn't seem to any other sort of research worth doing.

The next chapter details my methodological approach for this study, including data collection and analysis strategies.

## Chapter Five: Methodology

In the literature on HIV/AIDS prevention for injection drug users, there is marginal consideration of the technical strategies related to injection drug use, and no one has substantively examined how the values and beliefs held by individual HIV prevention workers impact their work. An important body of epidemiological and social science research has demonstrated that hopelessness is a trait shared by many IDUs. In some studies, addicts explicitly identify this lack of hope for a meaningful, happy life as a primary reason they do not pursue abstinence, or do not more consistently use safer injecting practices to avoid contracting AIDS. Bearing in mind these (largely medical) discourses on HIV prevention—and those of adult education as an applied area of social science inquiry—the data collection strategies for this study are both quantitative and qualitative. The 36 study participants each completed a detailed questionnaire to record demographic information, specifics of practice (venue, method, strategies), and their beliefs related to HIV transmission and IDUs. From these questionnaires, 16 informants participated in extended (one to two hour) interviews.

This comprehensive analysis of the experiences and practices of these adult educators will inform matters of practice (and, to a lesser extent, policy), here in Vancouver and other settings where HIV prevention programs target IDUs. Gaining a better understanding of the specifics of practice, and how educators' efforts are impacted by the context in which they practice and their own biographies could save millions of dollars (Laufer, 2001)—and many lives.

Examination of how HIV prevention workers' practices—and what may or may not shape their actions—is by its very nature an ambitious task. The complex interaction

between individual identity, context, and different paradigms of practice necessitates a methodological approach that allows for representation of the fluidity of these workers' experiences. Those whose work is on the streets and those who see clients in a clinical setting (medical or counselling) cannot be compared linearly, if the subtleties of their experiences are to be compared. Akin to this, the Foucauldian framework used to analyze the data need also acknowledge the co-existence of differing perspectives—within and between individuals—in order to unpack how such differences impact practice.

An additional methodological consideration is the audience for this thesis. Though this study has been conducted from a social science perspective, the dominant disciplinary voices in the scholarly discourse on HIV prevention are medical, most commonly epidemiological. Epidemiology's almost exclusive use of quantitative methods could serve to exclude this study (and others like it) from its deserved place in the literature on HIV and IDUs. To facilitate comparison of this study's findings with quantitative studies, as well as to mitigate possible "ghettoization" of a wholly qualitative data collection strategy, a mixed methods approach seemed wise. Rather than attempt to transfer current epidemiological methods to a portion of the data collection, the most common method of data collection on individual behaviour—use of a survey—was adapted to have a more sociological (and less behaviourist) orientation. This made the questionnaire both a means of collecting empirical data for analysis on its own terms, and as a way of locating emergent areas of inquiry for the qualitative component of the data collection. This process will be described in greater detail in the data analysis section of this chapter.

## Site And Participant Selection

With its localized IDU population, and the numerous HIV prevention programmes implemented there, Vancouver's downtown East side (DTES) was the obvious site to conduct this study. While most of the cases of HIV infection in Canada have been transmitted by sex between men, in the DTES the overwhelming majority of those infected with HIV have been IDUs. This neighbourhood also has the distinction of having the lowest per-capita income of any postal district in Canada: poverty, homelessness, and illiteracy are endemic (Strathdee et al., 1996). The downtown East side is also a vibrant neighbourhood, many of whose residents lead complex and fulfilling lives. The enormous challenges faced by some in the neighbourhood should not be generalized to represent "the community" of the neighbourhood. As in any other neighbourhood, downtown East side residents have a variety of different experiences, perspectives and values. But to focus only on DTES-based programmes would be to perpetuate the assumption that all IDUs in Vancouver are in the DTES and seek services there. I therefore recruited from agencies both in the DTES area and from other parts of the City of Vancouver. Nevertheless, most of the respondents did identify the DTES as a target area for their HIV prevention work.

Most HIV prevention programmes directed towards IDUs are not coordinated by AIDS service organizations; rather, they are offered by community groups whose existence predates this epidemic and whose primary foci are poverty, mental health, sex trade, women, specific cultural communities (Chinese, Latin, and Aboriginal, among others) or substance abuse. Injection drug use has been concentrated in the DTES for many years. With the recent appearance of cocaine in the area as the primary drug of choice (Patrick et al., 2001; Patrick et al., 1997) the practices of IDUs have changed

dramatically. The cocaine addict's need for more frequent injecting (or "fixing") exponentially increases the cumulative number of injections taken and, therefore, the number of opportunities for HIV transmission to occur. Several studies have shown that, in the absence of a clean needle (or "rig"), many IDUs have used unclean rigs borrowed or bought from others, or used ones found in the trash (Strathdee et al., 1996). While cleaning needles with undiluted bleach does lower risks associated with sharing needles, it does not kill all the HIV present. Abdala et al. (2001) showed how in laboratory settings bleach was as effective in removing HIV from needles as flushing a needle thrice with clear water. That these results were recorded in a laboratory—much more controlled than the circumstance under which most IDUs would clean their equipment—makes the strategy of cleaning used needles even less tenable.

Recently the Vancouver, British Columbia, and Canadian governments have all increased funds in response to the AIDS crisis in the DTES. These funds are largely distributed through programmes under the auspices of the Vancouver/Richmond Health Board, or programmes delivered by social service organizations. The various levels of government have given assent to a large but limited needle-exchange programme and to an emphasis on drug treatment. Social service organizations have more often called for unlimited needle exchanges supplemented by safe injecting sites. In some ways the perspectives and interests of these two stakeholder groups are quite different.

# Sampling Strategy

A purposeful sampling strategy was used for this study. It proved extremely difficult to ascertain how many HIV prevention workers in Vancouver work with IDUs; one can challenge whether these practitioners, with their diverse backgrounds, training

and life experiences, form any genuine population at all. Many social service organizations rely on volunteers for this work, some of whom work several hours per week; still others volunteer irregularly, particularly if they are themselves actively injecting drugs. Among paid workers, HIV prevention is usually one of several issues being addressed, with poverty, racism, and substance ab/use jostling for their time and efforts. Most of those who agreed to participate in the study are paid workers.

Based on comprehensive research and recruitment over a period of seven months, I would estimate that there are 42 social service programs (nested among 25 agencies) involved in this work; some large agencies run as many as seven distinct programs, each of which potentially provided unique services to the IDU community in Vancouver. Each program has at least one full-time worker (paid or unpaid) who devotes at least 10 hours per month to direct client outreach. Similarly, 28 (general) health or mental health clinics in the city of Vancouver were included in recruitment; rather than assume that HIV prevention for IDUs is only done by health services in or near the downtown East side, all municipal clinics were contacted for this study. Of the seven health organizations that supplied participants, all but one are located in downtown Vancouver. The contrasting and overlapping contexts in which this work is done make it impossible to give any reasonable estimation of a "population" size, in terms of who does this prevention work currently in Vancouver. Most empirical studies of adult education practice feature practitioners whose work occurs in institutional settings, most often classrooms. This study of adult education—HIV prevention for IDUs—is delineated by the client system/target audience (IDUs) and common goal (HIV prevention), rather than the venue of practice.

Participants were recruited, based on the following inclusion criteria: affiliation (paid or unpaid work) with a government or non-governmental entity operating in Vancouver whose clients include IDUs, and whose work involves direct communication with IDUs about HIV prevention.

### Data Collection

For this study, a mixed methods approach was chosen: document analyses, survey questionnaires, and interviews each played a critical role in this emergent design.

\*Document analyses\* included programme and project mission statements, programme descriptions and other similar documents from organizations known to be involved with injection drug users or HIV prevention in Vancouver. Organizational goals and objectives and philosophical/ideological inclinations were culled from these documents.

Information Services Vancouver's The Red Book (2001) was a primary resource for locating potential participant agencies. These were used to identify which specific organizations (health and social service) had staff who engage in HIV prevention education with IDUs. Few of these turned out not to be AIDS service social service organizations, indicating that HIV prevention workers were affiliated with a broad spectrum of organization types, often where HIV prevention was one of several issues being addressed.

Self-administered questionnaires were mailed to each of the 70 programs identified in the document analysis portion, as possibly engaged in HIV prevention work with IDUs. In these recruitment mailings, a questionnaire (Appendix A), letter of invitation (Appendix B), consent form (Appendix C), and participant information sheet (Appendix D) were included. Potential participants were all advised that this study had

received ethical approval from UBC's Office of Research Services, that their participation was wholly voluntary (and they could withdraw themselves or their responses from the study at any time), and that their identities would not appear in any reports of this study's findings (hence, all names included here are pseudonyms). Each program was asked to have at least one of its paid or unpaid staff who engaged in prevention interventions with IDUs complete the questionnaire. Ten programs reported back that none of their staff were available to participate; another 5 indicated that their projects were outside the scope of this study. Over half did not respond to written, telephone, fax, or e-mailed invitations to participate. Two follow-up mailings were sent out to all programs that did not return a completed questionnaire; follow-up e-mails and phone calls were placed to those who expressed interest in participating, but who did not return a completed questionnaire. One of the remaining programs provided as many as seven respondents to the questionnaire; in most cases, only one person per program participated in the interview portion. In two instances, greater gender balance or representation of a marginalized voice (Aboriginal, person of colour, or gay) was facilitated by adapting this "one interview per agency" guideline. Of the 70 programs initially contacted, 18 supplied at least one participant, for a total number of 36 participants. Participants returned completed questionnaires and signed consent forms; all data from their responses were placed in a separate database where only participant ID numbers were included; participant names and addresses were placed in a separate, password-protected database.

The questions included some that were specific to practice, in terms of what information was provided to IDUs verbally, by demonstration (e.g. how to clean injecting

equipment) or for their use (e.g. condoms, new injecting equipment). Participants' opinions on matters of policy related to AIDS, drug use, and social justice were also sought. Demographic information regarding gender, education, ethno-cultural self-identification was collected, as were specifics of the type of work, and type of organization in which participants worked. The workers' perspectives on a range of social and legal issues related to HIV/AIDS and addiction were also queried, as were what they thought should be prioritized in terms of public policy regarding injection drug use. Finally, the specifics of what they did and did not proffer as HIV prevention strategies for their IDU clients were documented. The questionnaire was piloted with seven IDU prevention workers in Seattle, Washington (contacted via AIDS prevention research colleagues at the City of Seattle), to solicit critical feedback on the instrument; a few changes in wording (to ensure construct validity) were made, but the questionnaire was unanimously endorsed by the pilot group, with respect to content and face validity.

Wherever possible, respondents were encouraged to give discrete, specific responses to questions (such as gender, postal code, job title), or to select a range of values into which their specific response would fit (age). Questions that measured the extent to which respondents agreed with a statement (agree, somewhat agree, unsure, somewhat disagree, disagree), the extent certain circumstances occur (never, occasionally, sometimes, frequently, always), or the perceived veracity of statements (definitely true, probably true, perhaps true or false, probably false, definitely false) used five point Likert scales. Due to the (small) sample size, these scales were collapsed into three point scales (agree/unsure/disagree, unlikely/unsure/likely, and false/unsure/true) for data analysis. In the policy section, where respondents ranked a list of choices in

order of priority, median scores were compared to ascertain sample and sub-sample rankings. The questionnaire is included here as Appendix A.

#### **Question Wording**

The statements used in the questionnaire were written in the vernacular, and at times were purposefully quite "black and white" in terms of the perspectives expressed. Discussions at the public and policy levels regarding services to IDUs are usually polarized. For many people in Vancouver, the question of substance ab/use is informed by a Western value system that views addiction as a weakness of character, not as an affliction. It seemed both prudent to avoid the assumption that *none* of these workers held this sort of perspective; it was also important to pose the questions in a form that reflected the often muddled discourse on substance use in our society. Wording that communicated specific ideas common to discourses regarding drug injection in the public sphere, in the vernacular, were finally chosen for the instrument.

Several respondents still found this form of question framing to be problematic. In an area of the questionnaire offered for feedback on the instrument, several participants commented to this effect. Caleb, a physician said, "The issues around IV drug use are complicated and to summarize in statements as you have in this questionnaire seems like it is over-simplifying the issues." David, also a physician, felt that "the questions (were sometimes) poorly written, i.e. addiction is a medical condition not a criminal problem. Perhaps I disagree with both. There were several questions that were too black and white and yet the middle of the road answer looked like partial agreement, i.e. 'I encourage harm reduction techniques over abstinence.'" David and Caleb (and a few other participants, many of whom worked in health care) would have

preferred more formal language; perhaps the sort of language with which they were most comfortable. But many of the workers in the target population are not health care workers; for them the use of overly-formal language would have communicated a bias in favour of health care workers. One such worker's comment: "thanks for this opportunity."

A descriptive statistical analysis (frequency distribution, mean, or median for each question, depending on question format) allowed for the establishment of areas where little disagreement was found, versus those where a variety of opinions and beliefs were held, or where the specifics of practice varied. In addition, most participants availed themselves of an open-ended question (with a full page for their responses) for additional comments. Thus, themes for the qualitative interviews were identified. These included treatment options, success, reasons for commencing HIV prevention work with IDUs, and the nature of addiction.

Interviews of participants who indicated a willingness to be interviewed in the questionnaire were conducted. This data supplemented and helped contextualize the data collected via the first two methods. The questions used came from exploratory analysis of the survey data. In particular, areas lacking consensus were targeted for further discussion. For example, virtually none of the participants saw any value in quarantining IDUs with HIV, nor did many see addiction as a criminal problem: it seemed a poor use of limited interview time to revisit such notions. However, many of the components of proposed harm reduction strategies (supervised injecting sites and government-distributed heroin or cocaine) were much more controversial. How different workers make sense of

such conundrums were foci of the interviews conducted. Interview questions are attached as Appendix E.

## Data Analysis

Data from the questionnaires was used to produce descriptive statistics. Chisquare values between sub-groups (sub-samples) of the sample were calculated to
identify possible correlations between particular demographics or lived experiences (such
as having been an addict themselves), and specific perspectives on HIV prevention work
with IDUs (Tabachnick & Fidell, 2001, p. 55). Chi-square does not yield broadly
generalizable findings, but is an inferential statistic that can be interpreted for potential
transfer to other milieus facing similar issues. Internal validity of the survey instrument
was controlled by adhering to standard survey instrument design (Sudman, 1976; Fowler,
1993; Sudman & Bradburn, 1982; Bradburn and Sudman, 1988).

Identification of emergent themes came from the documents analyzed, the interview and questionnaire data, and the researcher's own experience as a community educator. For quantitative analyses of the questionnaire responses, a database was set up using SPSS 10.0 for the Macintosh software. Questions that used five point Likert scales, or that required ranking different options (viz. the policy section) were encoded as ordinal, discrete variables. Demographic questions were coded as ordinal variables, including such numerical data as salary and age (which were offered as ranges in the instrument). Questions that allowed for more than one response (cultural identity, reasons for working with IDUs) were coded as several sub-questions each, as binomial (0=no, 1=yes), variables.

In two instances, responses to more than one question were, after analysis, used to create "macro-variables." For example, the respondents were asked in different parts of the questionnaire as to their ever being an IDU ever, a non-injecting addict, or persons in recovery. These responses were examined for each participant individually; an affirmative response to any of these questions resulted in a "yes" response to the code "Ever addicted." This allowed comparison between two important subgroups in the sample: those who have experienced addiction firsthand, and those who have not.

Similarly, responses to questions about job title and type of organization were used to categorize organization type in a much sharper sense; every participant's role could be positioned at a non-governmental social service organization or a government-run health organization. This distinction between subgroups proved especially important.

For qualitative analyses Atlas/ti 4.1 software was used. Interviews were tape recorded and full transcriptions generated (or notes, in one instance where I chose not to tape record to ensure participation) were entered into a hermeneutic unit, along with the transcribed, open-ended qualitative responses from the questionnaires. These documents were read and re-read, and were initially coded for 55 concepts; these were eventually collapsed into 37 final codes. In most instances, different words or phrases were linked to one distinct code; "hope" was coded based on synonyms (faith, dream) and antonyms (hopelessness, despair, fear, dread) to capture a broader sense of what the participants had to say about hope—or hopelessness. Both manual and auto-coding were used in Atlas.

Once the coding was completed, the codes and their linked quotations were reread, to discern relations between codes, and larger concepts perhaps embedded in some of the codes. From this, five larger themes were identified. Three of these related to the different sorts of IDU services available related to HIV: abstinence, harm reduction, and methadone maintenance therapy (MMT). Using the Family function of Atlas, codes were then linked to each of three families based on these categories. Two of the initial codes did not seem to fit these categories and were left as "stand-alone" families: "(why) start (working) with IDUs" and "success." Since this is a Foucauldian analysis, how these themes related to notions of power was considered throughout the analysis. The resulting coding family is represented in Figure 5.1.

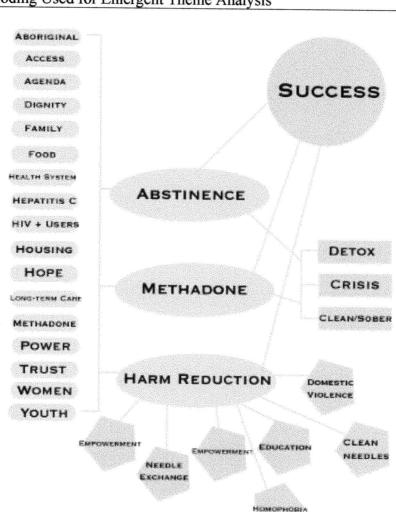


Figure 5.1: Coding Used for Emergent Theme Analysis

Finally, the findings from both the questionnaire and interview responses were compared to better understand how these workers make sense of their work and their world. Analyses of what commonalities exist among different sub-samples of the study sample—health versus non-government workers, Aboriginal versus non-Aboriginal persons, and those who have or have not been addicts themselves —at times were used to try and understand how certain knowledges about IDUs and AIDS are formed.

The next chapter looks at who the workers are, why they started (and in most cases) continue working with IDUs, and their lived experiences related to their working with this community.

This is a broad sample of workers engaged in HIV prevention targeting injection drug users (IDUs). A cross-section of lived experiences is represented, in terms of gender, age, and income. Also, the data captured via the qualitative and quantitative components of this study give great insights into the specific practices of these workers. It is this intersection of practitioners' own lived experiences, and their affiliations with different types of organizations, that help to shape their beliefs about their clients' lives. In each area of inquiry—work context, life experiences and opportunities, the respondents' motivations for working with IDUs to stem the spread of HIV—overall responses were analyzed. From the responses in the questionnaire, different sub-samples were also compared for analysis. For each question regarding practice, comparisons of the responses were made between persons who do and do not self-identify as having ever been addicted (and specifically having been IDUs), between men and women, between Aboriginal and non-Aboriginal persons, and between workers affiliated with communitybased social service organizations and publicly managed health programs. The purpose was to get more nuanced insights into ways in which practitioners' approaches are mitigated by their individual experiences, before and while working with IDUs.

Often, the organizational affiliation of workers resulted in striking differences in practice. It is clear that those who have been addicted have quite different experiences doing this work than their non-addicted colleagues. Similarly, gender, cultural, and educational markers of difference revealed distinct sets of values regarding IDUs and how to best help them avoid HIV. The conclusions drawn from these quantitative analyses are clearly supported, and in many ways better articulated, through excerpts

from interviews conducted with 16 of the 36 study participants, and the descriptions increase the findings' transferability. This and the next chapter interweave the quantitative and qualitative data.

In qualitative research, it is quite common to begin a discussion of results with biographical sketches of each informant. While this approach can result in a more personal and intimate representation of the informants—the biosketches ostensibly humanizing the excerpts from transcripts—this form of presentation is not without peril. For this study, to use such an approach would, in fact, put over half the study participants in jeopardy. HIV prevention work with IDUs is an *extremely* localized field of practice, so much so that a few key descriptors (gender, cultural identity, sexual orientations, job title, type of organization) could easily lead those familiar with the services available in Vancouver to identify (correctly or incorrectly) some participants. For some, whose opinions or practices transgress explicit or implicit expectations, job loss isn't implausible. For others, were their identities discerned by some of their colleagues, their subsequent inability to participate in the social networking of their prevention peers, and to access vital information and services for the clients, could be an equally dire outcome. Neither the participants nor their clients should be penalized for supporting this study.

Seven of the interview participants (Tino, Jerry, Dorothy, Felix, Cora, Janet and Pete) are health workers. They are nurses, physicians or general clinic staff. Nine interview participants, including Don, Karla, Kate, Loretta, Wim and Meg, are social service workers. Farah and Ted are social service workers of Aboriginal descent.

Suzanne is a social service worker and the only active IDU to participate in the study.

In this chapter, the participants' experiences with education, the conditions under which they work, and their gender and cultural identities are presented and examined. So too are their own experiences with substance, their reasons for initially beginning work in HIV prevention for IDUs, and the specifics of the practices. These questions were in the "Work and Community" (Section G; see Appendix A) of the questionnaire, except where otherwise indicated.

# Job and Responsibilities

Though not itself a marker of particular beliefs or practices, the range of occupations the respondents held are wide-ranging and diverse. Twelve participants (one third of the sample) were registered or licensed practical nurses. Six participants were physicians, three of whom specialized in addictions treatment. Six others were outreach workers. Four identified themselves as counselors or therapists. Three workers were educators; three others were program coordinators or supervisors (but whom also worked directly with clients). Two respondents were staff in treatment programs for addiction.

In terms of job responsibilities, 16 (almost one-half) of the respondents worked in a social service/outreach capacity. These included the counselors, group facilitators, street outreach workers and drop-in centre staff, whose places of work were non-profit, community-centered societies with mandates to serve particular communities (in terms of gender, culture, or geographic area). The other 20 were nurses, physicians, or detox staff working in a facility or program administered by the regional or provincial health authorities.

#### Education

Compared with the injection drug users (IDUs) whom they serve, the practitioners in this study have had greater access to education; all but one completed some post-secondary education, with a disproportionate number having attended graduate or professional school (42 percent). All respondents' answers to this question were taken verbatim. Table 6.1 described present educational backgrounds of the participants.

Table 6.1: Education Levels

Education Level	%
Some Graduate Study	42
University (4 Year) Degree	31
High School or Some University	27

\*All tables in this dissertation represent the overall sample (n=36), unless otherwise indicated.

However, this access to advanced education cannot be generalized to the larger population of practitioners. If we look at mean levels of education completed *between* social service workers and health workers, it is clear that, while several of the social service workers have advanced degrees, virtually all the health workers do. With a sample nearly evenly divided between these two groups (16 social service versus 20 health workers), the over-representation becomes somewhat clearer: 80 percent of the health workers had achieved a baccalaureate degree or higher, versus 63 percent of the social services workers. Table 6.2 show these trends based upon a cross-tabulation of the means for each subset:

Table 6.2: Level of Education, Social Service & Health Workers

Education Level	Social Service %	Health %
Some Graduate Study	38	45
University (4 Year) Degree	26	35
High School or Some University	38	20

From these findings, it seems the practice of HIV prevention with IDU clients is one which relies on "credentialization"—the attainment of certificates, diplomas, or degrees—to ascertain qualification to do this work. But is it not paradoxical that, in order to serve a community that traditionally has had poor access to education and training (Patrick et al., 2001, p. 889), workers need post-secondary credentials? While there is value in having workers who have been adequately trained to work with this community, the over-representation of university-educated workers in the sample demarcates a distance—social and economic—between these workers and their clients. Alternatively, it may be that the persons who chose to respond were those with higher education.

# **Working Conditions**

Nearly half (42 percent) of the respondents spent 50 hours or more *per month* doing direct HIV prevention work with IDUs; another 33 percent spent between 21 and 49 hours per month doing this work. Presuming most of these are full-time (35 hours per week) workers, each with a monthly workload of 140 hours per month (4 weeks per month), these workers could be described as having prevention work with IDUs as one of their primary roles. The remaining 25 percent spent less than 20 hours a month doing this work, making their IDU prevention work a secondary (i.e. lesser) part of their job.

Table 6.3 shows the participants' self-estimates of hours per month each spends on IDU-targeted HIV prevention.

Table 6.3: Self-estimation of Hours Worked Per Month

Hours Worked per Month	%
50 + Hours	42
21 - 49 Hours	33
20 or Less Hours	25

The only appreciable difference between the two sub-groups of respondents, social service and health workers, is at the secondary level; 38 percent of the social service workers work less than 20 hours per month in IDU-related HIV prevention, versus 15 percent of the health care workers. These workers were each affiliated with organizations whose mandates were much broader than injection drug users; their programs targeted women, Aboriginal persons, the impoverished, persons with mental illness, and the generalized downtown East side community. Conversely, half the health workers worked in programs targeting IDUs, with the rest working in facilities whose catchment areas include injection drug users. This finding supports the idea that many grassroots HIV prevention workers are providing their IDU prevention services as part of a larger continuum of social justice initiatives. These comparisons are based on the cross-tabulation of organizational affiliation and hours worked per month in IDU-targeting HIV prevention, presented in Table 6.4 below:

Table 6.4: Hours Worked Per Month, Social Service & Health Workers

Hours Worked per Month	Social Service %	Health %
50 + Hours	25	55
21 - 49 Hours	. 19	30
20 or Less Hours	38	15

The questionnaire also asked whether the workers received wages for their work, since many organizations through which participants were recruited (particularly social service organizations) rely heavily on volunteer labour. Yet only two participants' work was wholly voluntary, constituting 6 percent of the overall sample. While somewhat worrisome, this under-representation of unpaid workers makes sense, given the material constraints faced by any organization that relies on unpaid volunteers to operate. In all likelihood, those who would be more likely to avail themselves of participation in this (or any) sort of research project would be workers most strongly affiliated with an organization, who are usually its paid workers. Moreover, agencies whose mandates include seeking to address inequities related to gender, class, sexual orientation, or culture usually are quite busy pursuing these broader aims. Health issues (like vulnerability to HIV infection) are but one manifestation of the larger challenge faced by the communities they serve: oppression. In reality, social service organizations often have more limited capacities (financial, as well as in terms of staffing) than publicly administered health services: ones that inhibit their ability to participate in activities like this study. But while only 6 percent were volunteer workers, another 25 percent characterized their HIV prevention work with IDUs as both paid and unpaid work; all

tolled, nearly one third of participants donated some of their leisure time to help IDUs avoid HIV.

Most of the participants, however (69 percent), did their prevention work solely as paid work. And since about half the participants worked for social service organizations; and social service organizations (from my experience as an activist) largely rely on unpaid workers to deliver their programs, one might argue that the low participation rate of voluntary workers somewhat limits the extent to which the findings can be described as reflecting the common experience of IDU-targeted HIV prevention workers, particularly from Social service organizations. But it must be kept in mind that for many IDUs, the burdens of poverty and addiction preclude any sustained involvement in focused work, paid or not, it is also difficult to ascertain how much direct prevention work is done by volunteers, as opposed to paid staff. Future research into the nature of work in social service organizations doing HIV prevention with IDUs would clarify this. Though some groups like the Vancouver Area Network of Drug Users (VANDU) are user-driven, most of the prevention work done with IDUs is by paid workers. Whether this is a genuine necessity or simply an outcome derived from a paternalistic delivery model of health care remains to be seen. In the next chapter, some participants describe the challenges in getting local residents, particularly IDUs, to become involved in this work.

Although most respondents were paid workers, their incomes varied considerably. Fourteen percent had total annual income of less than \$20,000 per year; another 25 percent earned between \$20,000 and \$40,000. Twenty-eight percent earned \$40,000-\$49,999 (this was also the median salary range), and 39 percent earned more than

\$50,000 a year. These somewhat high figures do make sense, considering how many of the participants have completed university degrees, may have professional degrees, and/or work in health care; any of these factors or a combination could account for the wage levels indicated. So too could the participants' ages; only 11 percent were under age 30, with the remainder of sample evenly split between those in their thirties and those 40-plus, as shown in Table 6.5. The range of ages and wages among the participants indicates a good cross-section of workers are included in the sample.

Table 6.5: Age Range

Age Range, Years	%
20 - 29	11
30 - 39	45
40 +	44

#### Gender

Overall, the participants were more often female than male (58 versus 39 percent; one person preferred not to answer), and health work proved to be a more gendered fields of practice than social service. Social service workers were evenly divided along gender lines, whereas 70 percent of the health workers were female. Males were more likely to be involved in HIV prevention for IDUs as a secondary area than their female counterparts, 36 versus 19 percent. At the other end of the spectrum, 53 percent of the women worked 50 hours per month or more in IDU-related HIV prevention, versus 29 percent of the men. Generally, women are doing a disproportionate share of this work. These findings are summarized in Table 6.6:

Table 6.6: Hours Worked Per Month, by Gender

Hours Worked per Month	Female %	Male %
50 + Hours	52	29
21 - 49 Hours	29	36
20 or Less Hours	19	35

Later in this thesis, several women discuss how their involvement with IDUs is an outgrowth of their broad commitment to social justice, particularly with regards to sexism.

## Ethno-cultural Identity

Unlike other questionnaires, the one used in this study did not ask participants to choose a single cultural, racial, or national identification/affiliation. As Canadian society continues to become more culturally diverse—especially in major urban centres like Vancouver—fewer people seem to describe themselves as "only" Canadian. Though 78 percent of the participants identified as Canadian, many of these described themselves as Canadian and European (28 percent of the overall sample), Canadian and Asian (7 percent overall), or Canadian and Aboriginal (6 percent overall). Three percent of the participants described themselves exclusively as European, Asian, Aboriginal, or American; another 14 percent described themselves as Mixed.

Four participants—accounting for 12 percent of the sample—identified themselves as Aboriginal, including two who described themselves as being both Aboriginal and European or Canadian. None of the Aboriginal respondents worked for health agencies; they all worked in social service agencies.

Several Aboriginal social service organizations were contacted to find participants for this study; their relatively low participation rate may be indicative of the reticence of some Aboriginal persons to engage in a university-operated research project, or how overwhelmed the downtown East side Aboriginal community is by the ongoing challenges of racism, AIDS, addiction and poverty. Of the four Aboriginal participants, three worked for Aboriginal-specific programs or organizations; perhaps the low representation of Aboriginal persons in non-Aboriginal-targeting programs is more disturbing. Still, it is unclear whether the few Aboriginal responses mean that not enough Aboriginals are being used by organizations doing HIV prevention work among IDUs, or if there are some other reasons why they are not better represented here. In all likelihood, some combination of these (and other) reasons apply.

Two of those interviewed for this study, Farah and Ted, are Aboriginal. Injection drug use occurs in each of the ethnocultural communities to which respondents claimed membership, but the rate of injection drug use is disproportionately high among Aboriginal persons; conservative estimates put the percentage of Aboriginal persons in BC infected with HIV via injection drug use at 10 percent, while the estimated Aboriginal population of BC is only 5 percent (Red Road, 1999). No other ethnocultural community has such a disproportionate vulnerability to injection drug use-related HIV infection. Thus, the perspectives and experiences of participants who self-identified as Aboriginal are particularly important. Though Farah spoke of her Aboriginal clients' experience, she did not frame any of her own responses in terms of her Aboriginal identity during our interview. For Ted, his work with IDUs has evolved from his own experiences with addiction as a youth:

That's basically how I got involved in all this. I really began to understand myself as an Aboriginal person, and it just led me from going back to school and getting my chemical dependency certification and just, the way that it all happened I started right away working on the downtown East side...

For Ted, being Aboriginal and garnering a sense of how he was oppressed as an Aboriginal person, led him to working with IDUs who are also Aboriginal. Farah never discussed her Aboriginal-ness.

# Becoming Involved—Why?

Participants were asked to identify what motivated them to begin working in HIV prevention with IDUs. The questionnaire offered a list of lived experiences (detailed below), and directed them to choose as many as applied. In discussing challenging tasks like HIV prevention for IDUs, there is a temptation to deify the work performed by these women and men; in popular culture, those who sacrifice personal wealth, family life, or any other personal ambitions to help the disadvantaged are often held up as icons, role models for us all. But a postulation that all workers doing this sort of work do so primarily out of altruism, a commitment to democratic ideals, or a religious or spiritual calling would be inaccurate. Among the participants, often complex intrinsic and extrinsic motivations led them to this work. Working with extremely marginalized (and therefore often depressed or angry) people requires the ability to mix fortitude and compassion; to be clear and absolute in some instances, and flexible in others. From their responses, it is clear that every worker who participated in this study is aware of these (sometimes) paradoxical agendas. While they all believe that harm reduction an important way to help IDUs stay well while still using, most also agree that some clear boundaries between themselves and their clients are important to remain effective in their

work. They are often authority figures to their clients, and wield a certain amount of power over their clients. None of the interviewees seemed to bear this responsibility lightly.

But what brought these workers to these clients—what motivations or circumstances? How did these individuals come to choose their jobs, and the contexts in which they perform them? And how much "choice" did each really have? Though such questions have a range of answers that vary from person to person, a broad sense emerges of why they initially came to HIV prevention work with IDUs, and why most (with the exception of one worker who has subsequently left this work) continue this work, despite its challenges.

Participants were asked, "Why have you become involved in HIV/AIDS prevention activities with IDUs? Check ALL that apply" (see Appendix A). Since the participants were allowed to select more than one response, the percentage values for each of the ten possible responses are discrete from one another, and do not tabulate to 100 percent. Respondents checked as few as one and as many as five of the ten items (including others, where they supplied their own reasons) available. Table 6.7 summarizes the frequency of responses:

Table 6.7: Reasons for Becoming Involved with IDUs

Reason	%
A commitment to social justice	69
Knowing someone who was an IDU	33
Other	28
Knowing someone 'street involved'	25
A required part of my job	25
A religious or spiritual commitment	19
Knowing someone who was a (non-injecting) addict	17
I was/am an IDU	14

#### Social Justice

Over two-thirds (69 percent) of the participants cite a personal commitment to social justice as one of their reasons for working with IDUs. It was by far the most common response. Many of the respondents who were interviewed cited some sort of community activism prior to working with IDUs. Don's introduction to HIV/AIDS was at home: his partner was diagnosed as having HIV, as were several members of his gay male circle. He began his "work with HIV, as we have talked about earlier, because my partner became ill. My whole social group had HIV. My work [now] with IDUs and HIV [rather than gay men] primarily comes through my work" as a mental health worker. His activism around AIDS and gay men broadened as his understanding of HIV changed. "As I said when I was the 'widow du jour' at the candle light memorial, the virus doesn't discriminate. It just doesn't." Neither does Don, in his commitment to stop the spread of HIV.

Don is not the only gay male participant for whom this is true. Pete spoke of how, as a gay man, AIDS affected his community; this inspired him to focus on HIV prevention and treatment, though not exclusively with gay men:

[Initially] I was interested in exploring the gay community in Vancouver from a [health] perspective, and spend time learning about HIV, and made a decision my first year that if I was going to provide HIV care, which I have decided I would, or primary HIV care, I would not limit it to one group affected by the disease. That I would specifically make an effort in my two years to learn about the Native community and to learn about the injection drug using community.

Pete was new to Vancouver, and over the next several years was able to choose where he wanted to work. Having spent some time doing community health work overseas, he wanted work in Vancouver that priorized helping the most marginalized. Thus he committed to working with any communities perceived to be at high risk for HIV infection, seeking work experiences with gay men, IDUs and Aboriginal persons. His was perhaps the most focused and strategized path into this work.

Caitlin's activism dates back to high school, and her work on social justice issues has been in several different realms:

Like a lot of people I kind of fell into it. I'd been a student at UBC doing my undergrad and had been involved in lots of social justice kind of movements along the way from the time I was a teenager. When I started at UBC I was volunteering at community agencies and ended up developing and coordinating an outreach program for the food bank and of course came into contact with lots of people living in poverty and people with substance abuse issues and from there I think because I was becoming more and more involved in women's organizing and the feminist movement, I just had a natural sort of affinity with the women's issues in the downtown East side.

I guess like most people it was kind of the personal experience and [I] certainly have addiction in my family and have lost friends to both overdoses and HIV, and so there was that personal experience although I do not myself have a substance abuse problem. There were lots of people close to me that have struggled with that so I've had that sort of

motivation but the big one for me was always the relationship between those issues and larger sort of justice concerns.

Caitlin's work on hunger, anti-poverty, substance abuse and women's issues, while each of value to her and those affected, more accurately reflect her broad commitment to social justice and creating change at the local level. Hers was the most generalized social-justice-based motivation for working with IDUs.

## Religious or Spiritual Commitment

Based on questionnaire responses, a significant number of participants cited the importance of religion or spirituality in their work; 19 percent saw their work as fulfilling a religious or spiritual calling. Given that faith groups have often provided programs to the margins of society, these numbers were unsurprising (at the same time, three faithbased organizations were contacted for this study; and each declined to participate). What was interesting was how an affirmative response to this motivation category was reflected in people's childhood and current religious affiliations. Of the 7 participants whose work was in part inspired by their religious or spiritual commitment, 4 of them (57) percent) claimed to have no current religious affiliation. One each considered themselves Roman Catholic or Buddhist (as in their childhoods), while the remaining participant described herself as being "at one with God and humanity. No words to describe it!" Only 9 percent grew up outside of any religious tradition, yet exactly half the respondents claimed no such affiliation as adults; only Buddhism (9 percent) and Judaism (3 percent) retained their adherents. Of 20 percent who were raised Roman Catholic, only 6 percent retained that faith. None of those who were raised in another tradition (including Islam, Anglican, Mennonite, United Church, Presbyterian, Lutheran, Dutch Reformed or

Unitarian) retained the faith of their childhoods. Persons whose religious/spiritual practices were Aboriginal were the only group that actually *increased*, from 3 to 6 percent (or one to two persons); of these, one was raised with both Aboriginal and Roman Catholic religious/spiritual values. During the interviews, none of the participants brought up their own religious or spiritual convictions, in general terms or in relation to their work with IDUs. Interestingly, non-university graduates were much more likely to cite their religious or spiritual commitments as a reason for working in IDU targeted prevention, than their university graduate peers [40 vs. 12 percent;  $x^2(1, n=36)=3.74$ , p=.05].

#### Street Involvement and Addiction

In addition to questions about substance use/misuse (Under "Substance Use," Section F of the questionnaire; see Appendix A), participants were also asked about their familiarity with addiction, injection drug use, and street life (personal or through loved ones), and whether it was a motivation for involvement in working in IDU HIV prevention ("Work and Community", Section G). It is increasingly common when designing programs for marginalized communities to include members of the target community, in both the planning and delivery of services. Thus, the questions about substance using behaviours, personal experiences with addiction, and having been "street involved." For the purpose of this study, street involvement is defined as having actively participated in street-based culture, characterized by economic and social marginalization, unstable or unsafe housing, and endemic violence, substance abuse, and crime. Just as a relatively low number of Aboriginal persons were represented, a mere 11

percent of the respondents cited their own experiences of street involvement; another 25 percent were inspired by knowing someone who was street involved.

Whether a familiarity with the lifestyle of the street-involved IDU is seen by decision makers to be a strong qualification for this work, or perhaps persons whose lives have been touched by the ravages of street involvement—their own or someone they know—seek this work out, is difficult to ascertain. However, it is clear is that two subgroups, Aboriginal persons and persons who have not achieved a university degree, were much more likely to have ever been street involved. Compared to their non-Aboriginal peers, half of the Aboriginal workers have been street involved, versus just 6 percent of their colleagues  $[x^2(1, n=36)=6.90, p=.01]$ . Similarly, 30 percent of non-university degree workers have been street involved, versus 4 percent of their counterparts  $[x^2(1, n=36)=5.00, p=.03]$ . But unlike Aboriginal persons, these less educated workers were also much more likely to know someone who had been street involved, prior to working in IDU targeted HIV prevention  $[x^2(1, n=36)=4.62, p=.03]$ .

Social service and health workers did view their motivations differently, as demonstrated in Table 6.8. None of the health workers were ever street-involved, while 25 percent of the social service workers were. Social service workers were twice as likely to cite having known someone street involved, to have been an IDU or known someone who had been an IDU, as reasons for getting involved with HIV prevention for IDUs. Social service workers were also nearly three times as likely to have been a non-injecting addict. Conversely, health workers were more likely to have become involved between the frequency with which members of either group cited their personal commitment to social justice as a motivation.

Table 6.8: Reasons for Becoming Involved, Social Service & Health Workers

	Social Services %	Health %	p‡
I was street-involved	25		.02*
I knew someone who was street involved	38	15	.12
I was an IDU	19	10	.45
I knew someone who was an IDU	44	25	.24
I was an (non-injecting) addict	13	5	.42
I knew someone who was a (non-injecting) addict	19	15	.77
My commitment to social justice	69	70	.94
A required part of my job	19	30	.44
Religious or spiritual commitment	25	15	.45

<sup>‡</sup>Based on Pearson chi-square test

In Table 6.9, the experiences of addicts (including, but not only IDUs) and non-addicts are compared. Some of the more striking relationships are deceptive, remember, when comparing a group of addicts and non-addicts, the questions about having 'ever been" an IDU or non-injecting addict essentially become moot for the addict sub-group. Perhaps most interesting is that both sub-groups are as likely to cite working with IDUs being "a required part of (their) job" as an initial motivator. There seems to be equal acknowledgement that working with IDUs might not have been a personal aspiration (so much as something their job expected of them), among addict and non-addict practitioners. Also, non-addicts were nearly 25 percent more likely to claim a personal commitment to social justice as a motivator. In all other areas—having been or knowing someone street involved, knowing someone who was an IDU, or a religious or spiritual commitment—addicts cited these reasons much more often, sometimes twice as much.

<sup>\*</sup> difference between groups significant at .05 level

Table 6.9: Reasons For Becoming Involved With IDUs, Addicts & Non-Addicts

	Non-Addict		
	Addict %	%	p‡
I was street-involved	17	8	.46
I knew someone who was street involved	33	21	.41
I was an IDU	42		.01*
I knew someone who was an IDU	50	25	.14
I was an (non-injecting) addict	25		.01*
I knew someone who was a (non-injecting) addict	25	13	.34
My commitment to social justice	58	75	.31
A required part of my job	25	25	1.00
Religious or spiritual commitment	25	17	.55

<sup>‡</sup>Based on Pearson chi-square test

One-third of the participants in the overall sample (n=12) are, or were, addicts.<sup>4</sup> A large representation of addicts (IDU or not) is quite common in programs targeting addicts. From my own work in community-based addictions programs, there is a delicate balance on this question, of which program managers need to be cognizant. Often those who have achieved abstinence from drugs have a strong desire to help those still using. While commendable, this inclination needs to be carefully measured against the risks to the (often newly) abstinent addict. For many addicts—particularly those who were IDUs—entering milieus where drugs are bought, sold and injected can trigger their own impulse to use. Most of us who have worked in this field have colleagues that have relapsed into using again, as a result of this exposure: some were unable to re-establish

<sup>\*</sup> difference between groups significant at .05 level

<sup>&</sup>lt;sup>4</sup> Two additional participants identified themselves as addicts to tobacco but no other substances; they were not included in analyses that compared addicts and non-addicts. While nicotine, caffeine and other substances can be addictive, the negative ramifications of their use in the long term are most often the concern. Thus for the purpose of this study addiction refers to licit and illicit substance use whose potential for severely deleterious effects in the short term, akin to DSM IV definitions for substance misuse

abstinence. These workers in particular put themselves at significant risk, when they commit to working with currently using IDUs.

Still, many of the respondents have had personal experience with addiction.

Fourteen percent identified themselves as former or current IDUs; another 8 percent identified themselves as having been non-injecting addicts. Three of the four self-identified IDUs who participated in interview--Suzanne, Ted, Jerry and Loretta--have achieved abstinence, and have worked with IDUs in HIV prevention for several years. Their *professional and personal knowledges* about addiction bring a particular kind of empathy to their work, as well as an ability to speak to their clients as peers—of a sort. Ted describes how his progression from alcoholism to injection drug use precipitated his seeking abstinence:

At that point in time I would consider myself very much an alcoholic at that point in time and I was starting to experiment with intravenous [IV] drugs, and I guess as soon as I started experimenting with IV drugs I hit my bottom...once I entered recovery I guess I went on my, well just like anybody I guess should when they enter recovery, goes into this major self awareness and do a lot of introspection. That's basically how I got involved in all this...it just lead me from going back to school and getting my chemical dependency certification and just, the way that it all happened I started right away working on the downtown East side, volunteering then the next thing you know I was working in a recovery house doing some work and stuff like and that's how I began getting involved specifically with IDUs.

Ted knows his own recovery led him to seeking post-secondary training to work with IDUs. But his story is atypical: very few IDUs seem to manage to achieve abstinence *and* to access the post-secondary education or training (in his case, a chemical dependency certification) required to work in substance abuse. Three factors, his finding

and substance dependence (American Psychiatric Association, 2000,) are included in all discussions about addicts and addiction.

solid and sustainable abstinence, his willingness to re-enter the IDU community as a worker, and his ability to access required post-secondary training, were each necessary for someone like Ted to work in IDU-targeting HIV prevention. Most probably, the fact that he was not street-entrenched (he was "starting to experiment with intravenous drugs" when he became abstinent) greatly improved his odds of becoming abstinent. Most of his street entrenched clients have injected drugs longer and face a much more difficult path to abstinence; of those who will "get clean," few will probably gain access to post-secondary schooling.

Jerry's experiences working with addicts have led him to foment strong beliefs about addiction:

By and large people don't, they don't like being addicted to drugs but they have lives you know. They have relationships and whether I have a judgment that geez you have a really dysfunction relationship with your boyfriend and you're girlfriend there is a real loser and everyone around you is ugly, that is not their experience of their lives. They have friends, they care about people and they're faced with the same thing that we're all faced, if they're faced with losing that, that's a terrible awful choice for them. It doesn't matter whether I think they're better off without [drugs], that's not how they see it.

So how do you get the people to move from, how do you get them to move from being entrenched? That's what entrenched means. It means that not only are they used to living on the street but that's their home. They feel about their life the way I feel about mine. It's my life. Okay well even so I do things that you don't like but it's my life, it's my life. You're asking me to change everything. I don't want to change everything. I just want to stop doing drugs but my understanding of the processes is that you have to be willing and you probably do have to change a hell of a lot about your life if you're going to change that habit. I don't know anyone, I don't know anyone who goes into it happy about that prospect.

Jerry continues, comparing his own experiences in achieving abstinence, with the realities of his IDU clients:

If you're sitting at a detox feeling wretched looking at losing everything that you care about and the only thing you have to do to make everything go away is to just walk out the door and say, 'maybe next time'. No wonder nobody, so few people get clean...what they need is support. It's like you have to grease the path for them to go through. They need a huge amount of support. When I got clean I was lucky, I had it, I could afford it, I paid for it, I bought the support I needed. These guys don't have that option. I don't even know if it's realistic to think that society can do that for them cause the cost to get me clean it cost thousands and thousands and thousands of dollars. I don't know. How do you solve that?

Here lies one of the great inequities of substance abuse treatment options: persons whose professional or personal resources are substantial can access much more support (long and short term) than street involved, impoverished IDUs. Like Ted, Jerry was an IDU, but never heavily street involved—a rarity. And he knows it, so Jerry doesn't see his own experiences as replicable for many of his clients. The cards are stacked against them.

Loretta was street involved, got off the streets, and back into mainstream society.

After many years working in an unrelated field, she eventually felt drawn back to the downtown East side and to working with street-entrenched IDUs:

How did I get involved? I was in [another field] for ten years, basically burnt out, went back to school and suddenly looked at the social service worker program, more as wanting a 9 to 5, but then it also was 'close to home' for me because I was previously involved/street entrenched as a youth. Then [I] really started accessing qualities within myself that I never even knew existed around everything from understanding situations to a certain degree of how women get involved, how they get stuck, how they become street entrenched, how they become addicted and how difficult it is to free themselves of those situations.

By integrating her professional training and her own experiences on the street,

Loretta was able to better understand how she became street involved, and subsequently
got out. She perhaps felt herself able to help those on the street today.

But Loretta has been off the streets and clean for a long time—two things that do create distance between her and her clients who are still IDUs. Another factor that creates distance is that, unlike most of her clients she was never wholly entrenched in the street life; her childhood was relatively stable, so when she became street-involved she traveled between her "normal" world and the downtown East side. And this happened a generation ago, and today's downtown East side is even more treacherous than when she was involved. Though quite empathetic, Loretta is not a peer to the women she assists—something she acknowledges:

[When I was down here I] was able to carry on that double life [between street and family] until it became so difficult that that's when it was one choice or the other. And for the sake of not wanting my family to know anything about this, I cleaned up.

So Loretta got out. But she knows that the resources available to her based on her relatively privileged upbringing (stable family unit, safe neighbourhood, and a positive sense of who she was because of this stability) are unusual for IDUs entrenched in the downtown East side—particularly the women:

Firstly and foremost I'd have to pinpoint family. I wouldn't say the most functional family, but certainly it was very strong, with very, very strong ties within society. Connections, not necessarily to people but enough that you sensed a lot of pride, even if not for yourself then for your family, I did anyway, and that's the way I was raised...

Loretta's sense of belonging to a strong, if flawed family unit, one whose members generally traveled comfortably within mainstream society, is where she found the strength to get clean. Since most of her clients don't have similar families, their abilities—"choices"—are more limited.

Of the three former IDUs who were interviewed, none were fully streetentrenched during their addiction. Two (Loretta and Jerry) had access to people and material resources to help them re-establish their lives or seek support. Ted sought his own supports and treatment options, early in his experimentation with injecting drugs. Each has been abstinent for approximately 10 years. So while each brings their perspectives as IDUs to their practice (and a particularized compassion and understanding), their stories should not be read a typical for most of the IDUs in Vancouver. The sorts of turnarounds experienced by Loretta, Ted and Jerry are exceptional, and their successes cannot be reasonably used as exemplars of how IDUs can change their lives. Their clients have generally injected over a longer period of time (thus having lived in poverty longer), and been isolated from mainstream society longer than these three were. Ted, Loretta and Jerry's efforts to save themselves and to help other IDUs are to be lauded; the path each took to find a way out are not available to many of their clients. This is why so few former street-entrenched IDUs work in HIV prevention—there aren't many former street-entrenched IDUs who get abstinent, access tertiary education, and are then willing to involve themselves with a lifestyle in which they were marginalized.

Suzanne's story is an exception: although she moved out of the downtown East side several years ago, she has maintained strong ties there. Rumours from old friends about changes in her old neighbourhood motivated her to check things out for herself:

Well, when I first came down here, years and years ago, I mean I was a working girl [in the sex trade] and needed more stuff [heroin] and then a mother in the suburbs basically and then...[I] heard that the streets had gotten all messed up, and I was thinking 'what's that about 'so I came back down. I went, 'my god, the place has changed, what behind this?' So that's how I started volunteering in general.

Suzanne works directly with IDUs, assisting them with health concerns and advocating on their behalf. Unlike any of the other participants who consider themselves

addicts, Suzanne continues to inject drugs. As the only currently using IDU to participate in this study, she made a vital contribution to this study; her ability to discuss these issues as a prevention worker and an active IDU—in today's context—proved invaluable, particularly in examining different treatment options for IDU.

Another third of the sample cited personally knowing at least one IDU as the inspiration for their work; an additional 17 percent of the sample credit similar involvement with non-injecting addicts. Perhaps it is presumed that these workers, for whom knowledge of active addiction is visceral and experienced-based, have particularly valuable insights for working with IDUs. Concomitantly, those who have seen friends or family battle with injection drug addiction, and who are willing to try and help other IDUs, have a certain strength of character for this work, rooted in their own prior experiences. Of all the sub-samples analyzed, university non-graduates were the only groups statistically more likely to cite having known an IDU as a reason for doing this work (60 vs. 23 percent;  $x^2(1, n=36)=4.43$ , p=.04].

## A Required Part of My Job

Twenty-five percent of respondents stated that helping IDUs avoid HIV infection was "a required part of my job." This response by some participants should not be construed as any sort of indicator that they approach their work half-heartedly or dispassionately; *none* of the participants cited this as their only reason for doing their job. But for many persons, the 'choice" between having or not having a job, or having a job that pays more, supercedes more intrinsic motivations like social justice. Assumptions about the character of those who acknowledged that part of their reason for working with IDUs is their job requires it—in other words, they might perhaps not do it otherwise—are

specious, not based on direct contact with the workers themselves. Conversely, nor should one's worldview, politically or spiritually fomented, be the standard by which we choose all workers serving marginalized communities. There's no evidence from this study that indicates those who are motivated by spiritual or social concerns do this work any better than those whose motivations are ostensibly material (and therefore) less altruistic. There was little difference between sub-samples as to the frequency of this response.

During the interviews, the participants' responses to the question "how did you get involved with IDUs and HIV prevention?" reflect a range of belief systems and motivations, but *all* seemed keen to provide what they see as being most helpful to their IDU clients. Meg, a counselor, explains how she became involved with working with street-involved youth, many of whom are IDUs:

I've been a counselor for about 20 maybe 25 years now...in the process of trying to find subjects and doing qualitative research, I connected with [her current employer], and was able to get some volunteers to talk to me about their lives. I was also doing a little bit of private practice at the time to keep me sustained through my research years so I started to see some of the youth who were coming to the office as clients as well.

While Meg's introduction to IDUs came about as part of a mandatory job placement during her graduate work, she discovered quite early on that she had an affinity for her IDU clients:

[I] realized that I really liked working with this age group and went through a number of other incarnations and a few years later came back. There again was an opening here which I kind of leapt at, it's been one of my favorite positions... I like the age group. I like their energy. I like their sort of activism as well, but they take...things have gone on in their lives that make it unbearable for them, wherever they are, and they done something about it. They take action and they get involved in all kinds of things that are really dangerous and destructive for them, so you can take that energy and move it up into a more positive direction.

Meg found working with street youth energizing. But she also saw their energy as having great potential to effect change in their own lives, if it could be channeled appropriately.

Kate has been a youth counselor in Vancouver for over a decade. Like Meg, her introduction to injection drug users came through her practicum placement during graduate school. After getting her degree and working in other contexts, she found herself wanting to work again with street-involved youth, including those who injected drugs. Here she related her first impressions of these youth, when she was as a student:

I was doing counselling with youth on the street, we work up to age 25. So I was doing counselling around a variety of issues. Everything that you can think of, emotional type issues, depression, suicide, nightmares, HIV, pregnancy, prostitution blah, blah, blah I can't even think, everything and anything. When I was a student I really liked it, I liked the challenge because it was very challenging, I liked the kind of adventure or the excitement of it because you never knew who was going to walk through the door and what they were going to present with and it wasn't sort of okay, you know everyone coming in with the same kind of issues. They were crisis, crisis, crisis, I like that kind of, I like working in crisis. I don't know what that says about me but it's kind of energizing.

Much of Kate's willingness to work with these clients came from inside herself.

She found the work stimulating, challenging and exciting. Like Meg, after working with other client groups, she migrated back to working with at-risk street youth.

Some workers became involved by happenstance, almost by accident. Tino, a nurse who has worked with IDUs for several years, described his introduction to the IDU community:

[It] was more accidental than by design. I happened to meet a nurse who worked for this program who said to me, hey, we talked about nursing and all the different things we'd been through and how I sort of felt burnt on nursing. I didn't really see that as being a future career for me anymore and she said you should try working for this program. You'd find it very interesting and they are actually looking for a male nurse. So I thought, ah, what the hell.

For Tino, being introduced to IDUs caused a shift in many of his assumptions about IDUs and providing them care. Today his understanding of IDUs—and of humanity in a much larger sense—has changed radically. Very early in his work, Tino saw a connection between these people's addictions and their being marginalized and disempowered. Asked what he learned, Tino responded:

The tenacity and the survival of the human spirit. People that have been abused, have been beaten, have been raped, have been on the streets on their own, have had turned to things that are probably distasteful to most of society, none of them would be standing on the streets as prostitutes, none of them would be jamming needles into their arms. These people are there and yet they come and they sit down across from you and they are every bit as human as you and I and they have as much humour in them and as much life in them.

In his role as a health educator, Tino has learned much about himself and the nature of injustice. Certainly his values have been refined (if not outright changed) through his work.

Of all the participants interviewed, Cora's involvement in working with IDUs is perhaps the most striking example of how this field of practice can catalyze a shift in perspectives. Not only was she unfamiliar with harm reduction approaches, she actually held strong convictions about certain harm reduction strategies. Part of the interview with Cora ran:

Interviewer: What were your opinions of needles exchange before you actually started working at one.

Cora: I didn't think they should have them. I thought it was a waste of money. I didn't think it was fair for other diseases not to have free syringes, why just IV drug users.

Interviewer: Like diabetics.

Cora: Yes, diabetics. And because I have a family member who is diabetic and they buy new needles and spend a huge amount of money

doing that whereas people that are using IV drug use can get free needles. I didn't agree with that, I thought it was wrong.

Interviewer: And you didn't want to send [your family member] down here to get needles.

Cora: No. No. But if they were the right kind I probably would give her some.

Interviewer: What's your opinion now.

Cora: Oh, we definitely need needle exchange.

Interviewer: Why.

Cora: It really is an addiction and I didn't see it that way before. I think because you see the people that come in here and how unwell they are, just that chance of them catching infections and supplies are just so worth giving...I still have friends and family that really disagree with the needle exchange and I have to say at one time I thought that myself but now that I've worked here I think it should be even more than what it is.

Cora had very strong—and negative—opinions of needle exchange programs, prior to working with IDUs. Today, she not only supports current programs, but thinks that she and her colleagues should "walk up and down the street and hand needles out to people and bring them in (to the clinic)." This comment represents a dramatic shift in perspective, which could only have occurred after working directly with injection drug users.

The questionnaire invited respondents to use the "What did we miss?" portion (Section D; see Appendix A) to describe in their own words why they do this work, which four participants did. Their responses were:

- "I have AIDS and hepatitis."
- "These are my friends."
- "As an extension of [my] gay male affiliation."
- "[It's] an important part of working with high risk population."

Perhaps these responses could have been "folded into" the existing categories. But each articulates the circumstances of these workers and their communities, and why some were compelled them to take action to fight the spread of HIV among IDUs. In all, these women and men bring a range of perspectives and motivations to their work with IDUs. Regardless of why they do this work, these workers find the work inspiring and rewarding, frustrating and disheartening.

# Particulars of Substance Use

In the "Substance Use" section (F) of the questionnaire, participants were asked about their substance using/misusing histories. They were asked whether they had ever used alcohol, marijuana/hashish, cocaine, heroin, speed, ecstasy, acid/LSD, mushrooms, or benzos (tranquilizers). Participants were given room to name up to five additional substances; though several mentioned tobacco, it was excluded from the results due to concerns related to substances able to cause rapid and debilitating intoxication.

Participants were also asked which of these substances they used over the last six months; only two respondents acknowledged use of any substances other than alcohol or marijuana, cocaine and ecstasy. Table 6.11 details the frequency of lifetime experience with various substances. It also differentiates between drugs like cocaine, heroin and speed that can be ingested via snorting, smoking, or injection.

Table 6.11: Experience Using Substances

Ever used Substance (mode):	%
Alcohol	94
Marijuana	83
coke (snort)	44
coke (smoke)	25
coke(shoot)	11
ecstasy	22
acid/LSD	47
mushrooms	44
heroin (snort)	8
heroin (smoke)	14
heroin (shoot)	14
speed (snort)	11
speed (smoke)	11
speed (shoot)	8
benzos	47

Nearly every participant had used alcohol or marijuana. But some of the other percentages are interesting, for a variety of reasons. First, both benzos and acid were used by about half the participants, with (snorting) cocaine and mushrooms following closely behind; One quarter had smoked cocaine, while just over one fifth had taken ecstasy (a hallucinogen currently popular with today's dance club set). From the overall sample, one might conclude that these workers generally have done a great deal of experimentation with substances beyond the ostensibly "soft" drugs of alcohol and marijuana; bear in mind that the frequency of heroin and speed use is much lower, between 9 and 14 percent. Curiously, more had injected or smoked heroin (14 percent each) than had snorted it (8 percent).

Comparisons between some sub-groups yielded significant relationships (ever been addicted, organization type); others (level of education, being Aboriginal), did not. At first there seemed to be significant differences based on gender, but when one respondent who preferred not to categorize themselves with respect to gender was factored out, no significant difference was found between men or women participants having used substances differently. Interestingly, the participant who did not categorize themselves as male or female (or as transgender) was perhaps the respondent with the broadest experience with substance use, having replied yes to all choices except ecstasy, mushrooms, and having snorted heroin or speed.

#### Addicts Versus Non-Addicts and Substance Use

It was clear that asking what substances one had *ever* consumed gave very limited—and easily misinterpreted—information. So the questionnaire also asked about each person's experience with substance misuse. Each was asked to choose a statement that best described their experiences with addiction. One quarter identified themselves as being a "recovered/recovering" addict, meaning having pursued and achieved abstinence. This term is in common parlayance among those whose abstinence has been in part achieved through participation in groups like Alcoholics Anonymous or Narcotics Anonymous, from whence the term originates (Alcoholics Anonymous, 1976, p. iii). One person saw himself as having been previously addicted to drugs, but currently able to use substances without deleterious effect, and is no longer addicted. In other words, a person did not need to abstain from substance use entirely, merely to curtail it. Another person—Suzanne—identified herself as being currently addicted to "drugs in general," meaning she identifies herself as an addict and still uses drugs, including via injection.

The remainder of the sample (66 percent) agreed with the statement, "I have never experienced addiction." One person declined to answer the question.

The responses means nearly one-third of respondents identified themselves as being or having been addicted to at least one of the substances listed. Participants were not asked to quantify their using: this is not a study of addicts, per sé, but a study of those who work among addicts. And, since most of the self-identifying addicts (75 percent) were abstinent at the time they participated in the study, the question is largely moot. It made sense to examine the experiences between those who identify themselves as addicts and those who do not. These figures are contained in Table 6.12:

Table 6.12: Experience Using Substances, Addicts & Non-Addicts

Ever Used Substance (Mode)	Addict %	non-Addict %	.37	
Alcohol	100	92		
Marijuana	90	81	.51	
coke (snort)	80	30	.01*	
coke (smoke)	50	. 15	.03*	
coke(shoot)	40	0	.01*	
ecstasy	50	12	.01*	
acid/LSD	80	35	.02*	
mushrooms	70	35	.06	
heroin (snort)	30	0	.01*	
heroin (smoke)	40	4	.01	
heroin (shoot)	30	8	.08	
speed (snort)	20	8	.29	
speed (smoke)	30	4	.03*	
speed (shoot)	30	0	.01*	
benzos	80	35	.02*	

‡Based on Pearson chi-square test

With the exception of alcohol (where a slightly higher frequency occurs among non-addicts), the non-addict sub-sample has, as would be expected, significantly less experience—typically half of the addict sub-sample—particularly with injecting drugs.

As per table 5.9, the greatest differences (and the only statistically significant ones) were

<sup>\*</sup> difference between groups significant at .05 level

with regards to having shot (injected) heroin or speed, or having taken acid/LSD. Frequency of snorted or smoked cocaine and ecstasy experience were each one-third lower among non-addicts. There was only slight difference in rates of mushroom use between the two groups (x²(1, n=36) =,23, p=.64). But *only one non-addict* (the same respondent) acknowledges having ever shot heroin, cocaine or speed. Clearly many of the respondents have experiences with a variety of substances; however the frequency of experimentation with substances other than alcohol and marijuana are consistently higher among addicts than non-addicts; virtually all those who have injected drugs were addicts.

Social Service Versus Health Workers and Substance Use

Given that there were differences in using experience based on personal experience of addiction, could one's organization type (social service or health care) account for any patterns of experience with substances? As shown in Table 6.13, workers with social service organizations were significantly more likely to have snorted, smoked or injected cocaine, taken acid/LSD, snorted heroin, smoked or shot speed, or used benzos. And in no instances were health workers more likely than their social service colleagues to have used any substance.

Table 6.13: Experience Using Substances, Social Service & Health Care Workers

Ever Used Substance (Mode)	Social Service %	Health %	p‡	
Alcohol	100.0	90.0	.19	
Marijuana	93.8	75.0	.13	
coke (snort)	62.5	30.0	.05*	
coke (smoke)	43.8	10.0	.02*	
coke(shoot)	25.0	0.0	.02*	
ecstasy	31.3	15.0	.24	
acid/LSD	68.8	30.0	.02*	
mushrooms	50.0	40.0	.55	
heroin (snort)	18.8	0.0	.04*	
heroin (smoke)	25.0	5.0	.09	
heroin (shoot)	25.0	5.0	.09	
speed (snort)	18.8	5.0	.19	
speed (smoke)	25.0	0.0	.02*	
speed (shoot)	18.8	0.0	.04*	
benzos	68.8	30.0	.02*	

<sup>‡</sup>Based on Pearson chi-square test

In comparing the frequency of addicts in each type of organization, it is clear that a greater percentage of addicts work in social service agencies than in health care ( $x^2(1, n=36)=3.66$ , p=.06). Whether this near-correlation (the  $x^2$  test falls just shy of the .05 value generally accepted for statistical significance) is related to some contextual commonality of either type of agency cannot be answered by the data collected here. In both groups, this work was both office-based and street-based, and did or did not involve providing needles. It seems that one-time addicts, if they want to work in this field, seek out social services more than health care. Whether this comes from their own negative experiences with health care as addicts or is a reflection of the societal barriers faced by many addicts (including, access to education) is unclear. Certainly, most of the health

<sup>\*</sup> difference between groups significant at .05 level

professions represented here require baccalaureate degrees (or higher) for credentialization.

# University Education

In some instances, patterns of experience differed between those who had completed university degrees and those who had not. Eighty percent of non-degree participants had snorted cocaine, versus 31 percent of their counterparts,  $x^2(1, n=36)$  =7.09, p=.01. Fifty percent had smoked cocaine, while only 15 percent of degreed persons had,  $x^2(1, n=36) = 4.62$ , p=.03). Forty percent—nearly half—of those without degrees have ever injected cocaine, versus *none* of their degreed colleagues,  $x^2(1, n=36)$  =11.70, p=.01. Similar correlations were shown with regards to ecstasy, acid/LSD, snorting or smoking heroin, and injecting or smoking speed (each of these findings are summarized in Table 6.14), while having ever used mushrooms [70 vs. 35 percent;  $x^2(1, n=36) = 3.66$ , p=.06] and having ever injected heroin [30 vs. 8 percent;  $x^2(1, n=36) = 3.01$ , p=.08], were just outside the .05 threshold for statistical significance. Clearly the respondents who have more intensive experience with harder drugs have been less successful in post-secondary education.

Table 6.14: Experience Using Substances, University Degreed & Non-Degreed

ver Used Substance (Mode) Non-Degreed %		Degreed %	p‡	
Alcohol	100	92	.37	
Marijuana	90	81	.51	
coke (snort)	80	30	.01*	
coke (smoke)	50	15	.03*	
coke(shoot)	40	0	.01*	
ecstasy	50	12	.01*	
acid/LSD	80	35	.02*	
mushrooms	70	35	.06	
heroin (snort)	30	0	.01*	
heroin (smoke)	40	4	.01*	
heroin (shoot)	30	8	.08	
speed (snort)	20	8	.29	
speed (smoke)	30	4	.03*	
speed (shoot)	30	0	.01*	
benzos	80	35	.02*	

†Based on Pearson chi-square test

## Aboriginality

Among Aboriginal participants, experience with harder drugs was also more common. Aboriginal workers were much more likely to have injected or smoked cocaine, smoked or snorted speed, or to have snorted heroin, as shown in Table 6.15. While the size of the Aboriginal sub-sample (n=4) does not allow generalizing these findings, this over-representation of injection drug users among Aboriginal participants may be reflective of the disproportionate number of Aboriginal IDUs in Vancouver. Strathdee et al.'s research found that 28 percent of the IDUs in their study were Aboriginal (Strathdee et al., 1997a, p. F61). Of the different patterns of drug use found between sub-groups, the relationship between completion of a university degree and

<sup>\*</sup> difference between groups significant at .05 level

experience with hard drugs is least readily interpreted, based on this notion of insider/outsider. But even here, many would argue that marginalized persons—including women, Aboriginal persons, and IDUs—have less access to (and different perspectives about the value of) higher education. The educational correlates could represent the dispersed effects of various forms of oppression (race, gender, sexual orientation, class), but this small sample does not lend itself to such nuanced statistical analyses.

Table 6.15: Experience Using Substances, Aboriginal & Non-Aboriginal

Ever Used Substance (Mode)	Aboriginal %	non-Aboriginal %	<b>p</b> ‡	
Alcohol	100	95		
Marijuana	100	81	.34	
coke (snort)	75	41	.19	
coke (smoke)	75	19	.01*	
coke(shoot)	50	6.3	.01*	
ecstasy	50	19	.16	
acid/LSD	75	44	.24	
mushrooms	75	41	.19	
heroin (snort)	50	3	.01*	
heroin (smoke)	25	13	.50	
heroin (shoot)	25	13	.50	
speed (snort)	75	3	.01*	
speed (smoke)	75	3	.01*	
speed (shoot)	25	6	.20	
benzos	75	44	.24	

‡Based on Pearson chi-square test

This question of personal substance using is critical to understanding the extent to which HIV prevention workers with IDUs can claim insider status to their clients. For the 14 percent who have *ever* injected a drug—heroin, cocaine or speed—being an insider to the IDU community is easier to claim. But, it must also be considered that not all IDUs, past or present, have used their drugs in similar contexts, geographically,

<sup>\*</sup> difference between groups significant at .05 level

socioeconomically, or culturally. In other words, not everyone who has ever injected drugs can—or would—claim affinity with today's street-entrenched users, who are the focus of most IDU programs in Vancouver. Similarly, it has been posited that women prevention workers can work with women IDUs) more easily than can their male colleagues (Whynot, 1998); this would imply that Aboriginal workers—a significant number of whom in this study have also had experience with drug injection—are most likely received differently by Aboriginal IDUs than non-Aboriginal workers. But it should not be argued that only those who have injected drugs—or who are Aboriginal, or women—can do this work credibly or effectively; many of the participants in this study are not IDUs, women or Aboriginal, yet all have a sense (for themselves or from their clients) that the work they do is successful; their notions of "success will be addressed in Chapter Seven. Still, a relationship between affiliations such as gender, culture, education, type of organization, or IDU history is apparent.

# Local Knowledges

These findings show how the practice of HIV prevention with IDUs varies between different sub-groups of practitioners. Gender, Aboriginality, and access to higher education each demarcate distinct sets of lived experiences in areas that seem critical to how workers approach this work. Similarly, substance use patterns vary between these groups, with women, Aboriginal persons and those who have not attained university degrees being much more likely to have engaged in drug use. From these patterns of experience with substances, and their apparent relationship with gender, cultural and other affiliations, what emerged were two areas for further analysis: to what extent do the *practices* between these groups differ, and do workers with similar lived

experiences share beliefs or values regarding IDUs, addiction, and related areas? Chapter Seven considers how such differentiations inform matter of specific practice. The workers' opinions about public policy regarding injection drug use and their notions of success are also examined.

# Chapter Seven: Matters of Practice and Policy

Twelve of the 28 questions in Section B of the questionnaire were related to the techniques proffered to avoid or minimize risk for HIV transmission for IDUs. Nine questions were about the specifics of what harm reduction techniques are available to their IDU clients, in terms of drug injection (five questions) and sexual activity (four questions). Two questions were about options for clients seeking to abstain from drug use altogether; one final question addressed broader issues regarding any tensions between the abstinence and harm reduction approaches.

Comparisons between addicts and non-addicts, and social service versus health workers, were examined. Although none of the differences were statistically significant, differences in practice between these sub-groups were evident in a number of instances.

## Sexual Transmission Of HIV and IDUs

In initial HIV prevention programs targeting IDUs, the presumed conduit of transmission was through sharing injection equipment, particularly needles. But as the IDU-related epidemic began to move through kinship circles—particularly partners, spouses, though the births of HIV-infect children also brought this to the fore—the role of sexual transmission of HIV from, to and between IDUs became clear. In the public debate regarding HIV prevention among IDUs in Vancouver, little has been said about this. But the participants in this study clearly view sex as a potential transmission route, and try to prepare their clients accordingly.

Eighty-eight percent of respondents often or always advise their clients to use condoms for vaginal intercourse; 94 percent often or always advise their clients to use

condoms for anal intercourse. A somewhat less but still large number—71percent—often or always suggest condoms for oral sex. And these workers are, for the most part, providing more than information; 74 percent often or always give their clients condoms. But providing the information and the condoms is only part of the strategy, as Ted explains:

I think the more and more people realize that it's not, but if a person picks up a needle or not, or whether if a guy doesn't use a condom or not, there are reasons why people are making these choices and we're never going to understand human behaviour until we start looking at why these people are making the choices that they are making.

Loretta concurs: "First and foremost, harm reduction is about empowerment. You can't get the message or the education or the condom across until someone's there willing to receive it." Tino also agrees, but knows that the willingness of individual IDUs is largely shaped by the circumstances in which they live:

What I've learned is that any injection drug user taking that risk profile for HIV transmission could probably walk into my clinic and sit across from me and give me the information about how to not spread HIV, or Hepatitis C or any of those other blood born pathogens better than I could, in a language that is appropriate to them. They know it. They've heard the message, it's like condoms, put them on if you don't want HIV. Well, okay everybody knows that . But what's missing, and that's the other capital C challenge, is finding a way to impart the message in a way that fits into that social context, so that it makes a difference, so that it sinks in a way that will have some real harm reducing impact on their lives. But also within the context of that chaotic and scattered life.

Therefore, proffering condoms is a necessity, but condom use seems more likely to occur among IDUs who have stable housing and some social support. Increase the stability of IDUs lives, and their inclination to practice self-care—including minimizing exposure to HIV—will increase. The lack of stable housing was cited by *every study* participant as a necessary component of any broad-based strategy to prevent HIV transmission between IDUs.

But sex can take a variety of forms for IDUs, including sex work. Many IDUs (mostly women, but certainly many gay men) work the "strolls" in downtown and East side Vancouver. While there are a range of opinions about the moral implications of prostitution, this study examines the *realities* of sex trade work among IDUs, and the role sex work plays in their vulnerability to HIV exposure.

In Canada, prostitution is not always criminal; "street walking," or the public selling of sex, is against the law. "Escorting," where one sells sex privately (usually via advertisements) and as an individual, is legal. Canada's criminal code doesn't differentiate between selling oral or vaginal or anal sex; rather it judges the sale of sex based on the venues used for the financial or sexual transactions. Also, any sort of facility known to permit the selling of sex by more than one individual is considered a brothel; it too is illegal. These laws, ostensibly written to keep Canada "free of vice" (read: out of sight), serve as a mechanism to keep the street prostitutes out of society's purview. And being out of sight disempowers streetwalkers, in terms of accessing their entitlements with regards to safety and health care. Sex trade workers who work the strolls around Vancouver are also quite often IDUs.

The power relations between these two examples of sex trade work are enormously different. A woman escort working out of a private address has much more control over her clients than a street walker. The escort most commonly sets the terms of the transaction (price, services to be provided) in advance, and chooses the venue for the sex. Streetwalkers are more vulnerable to pimps, assault, robbery, and rape because they are outdoors, usually in industrial neighbourhoods (unoccupied at night), or in poorer neighbourhoods where street violence is a common occurrence. When a streetwalker

finds a client (the 'john'), she has to get into his car, at which point the power largely becomes his. The sex trade for IDU women is dangerous; often negotiating condom use is mitigated by the very nature of this work. Loretta explains:

Harm reduction around sex trade is huge and of course there's the physical, the condoms, female condoms, abstinence but who is initially there left in the car with that the 'john' but that woman. She's there alone so what harm reduction can you offer, but to let her know in no uncertain terms, totally unconditionally, that there is a support system there for her when the only support she thinks she's getting is whatever that John might give her.

Add to this circumstance, being coerced by a pimp, or becoming drug sick and in desperate need of a heroin fix, and it's clear how difficult consistent condom use for IDU sex trade workers can be. "And," Loretta adds, "the pimps would be (their) regular partners, and generally they don't use condoms with their pimps or regular partners because (the women are) expected to be trusted that they are using them with their johns." If their pimp or regular partner is also an IDU, this is yet another way in which these women are vulnerable to HIV infection. At the street level, power relations are often gendered.

#### Needle Exchange Programs (NEPs)

The logistics of providing new needles was one of the more contested areas of practice, in terms of how needles are distributed as even exchanges or not. Table 7.1 shows the responses to two statements: "all needle exchange transactions are 1:1," and "I distribute rigs without exchanging them for used ones."

Table 7.1: Consistency of Adhering to "Even-Exchange" Principle

26 11	11
	14
3	32 11

Almost half the respondents to both questions (40 percent) see this question as not applying to their work; some of the participants proffer *information* about NEPs to their clients, but do not provide needles themselves. Of the remaining 60 percent, there was no clear consensus of practice. Twelve percent of respondents never or rarely do even-exchange transactions, but 25 percent often or always distribute needles without an exchange of any type. Conversely, 22 percent often or always exchange evenly, while 3 percent rarely distribute needles without some sort of exchange. It should be noticed that no one who provides needles to IDUs claimed to *never* give needles without an exchange transaction. One participant articulated one possible reason for this range of responses:

[My colleagues and I] often said we'd like to just walk up and down the street and hand needles out to people and bring them in. The problem too right now is...it's a one on one exchange, well somebody comes in and has none, what's your dilemma? Your dilemma is we got all our stock from them and we're supposed to do their policy but we don't. Originally when it started you would get two for nothing and then it went up to five for nothing and now we're up to ten for nothing and then you have that dilemma of the same person that you just gave needles to yesterday coming in again with none and wanting another ten and you're thinking well where are those ten.

These workers need to navigate between the confounding concerns of disease prevention (health care) and sale of needles (criminal justice). Clearly the policy guideline for one-to-one exchanges without exception is untenable, though the workers themselves often share the concerns from which such policies emerge. Janet describes how they manage this dilemma:

If they don't [bring] any, it used to be that I would give them five but now I'll give them ten. And if they are giving me a song and dance about 'I'm going to a party on the weekend and there's no exchange in Kamloops', or you know, I'll give them what they need...our mandate here is more to get clean stuff out there and there are those that say, 'yeah but what if they're selling them?' Well, so what? They're selling clean ones. I don't want them to sell them, I want them to bring them back and they know that I whine and pout when they don't bring them back but I will also give them what they need.

This dissonance between policy and practice is clearly stated by Tino, whose responsibilities include needle exchange:

The point of restricting numbers of needles being distributed or exchanged is really under the microscope right now because my personal belief is that it's contributed to more disease transmission than prevention. If you are limiting the number of needles that somebody can have, the inevitability of them reusing one of those needle, or that needle going to somebody else, is much higher than if every time they use, they open a new package.

We don't advocate the use of bleach for disease prevention purposes anymore. We push for one fix, one needle. And making sure that there is enough needles out there so if people are going to fix 50 times in a day, they've got 50 needles.

A definite shift has occurred from when NEPs first opened in Vancouver in the 1990s. At that time, the transactions were much more regimented and restricted: one needle for one needle. But over time, the public will has shifted towards the ideal stated by Tino, though as a matter of policy, different NEPs have different guidelines governing needle exchanges.

Needle exchanges are not always done at NEPs; two participants spoke of incidents when needles have been given to IDUs, though the program was not a needle exchange. Cora told of working at a clinic where "we had a policy of not giving needles at all. But there were some staff that gave needles under the table kind of thing." Her colleagues apparently felt the need to get clean needles to their IDU clients could not wait for a change in policy that allowed it. Don offers his clients clean needles to "facilitate" participation in his (non NEP) program. Part of the interview ran:

Don: The needle exchange van comes up [near our offices] and I encourage people to do that. I encourage people, if they want to come in here and do it. It's not an official needle exchange....

Interviewer: But you have them available.

Don: If you need new needles, I'll give you new needles but you bring your old ones and you put them in there [in the hot box for used medical equipment]. I won't just give you new needles.

Interviewer: Right. Yeah that varies. Some places give them and some places don't.

Don: Yeah. It's an exchange for me. It's a currency.

Interviewer: That's your boundary...

Don: ...Yeah, and it's a currency thing and I use the needles as currency. It gets them here and sometimes you have to use that currency.

Don knows that his having clean needles gives him a degree of power over his IDU clients. But since his office is not an NEP per sé, he feels he's not abusing authority or coercing anyone. He's choosing to provide an extra service as an incentive for IDUs to seek care. Just as Don has chosen to offer needle exchange to his IDU clients as an enticement to participate in his program, sometimes staff whose jobs include needle exchange give more than needles. Janet explained during the interview:

Janet: I also give out soap and tooth brushes and razors and combs and stuff like that.

Interviewer: Where do you get those from?

Janet: I buy them from [one of our suppliers]. I also give out apples from me. It's very appreciated. Yep it's very appreciated.

Interviewer: Do people generally take the soap and toothbrushes and the combs and the razors.

Janet: Some people are pretty ticked off when I run out. 'Where's the toothbrush?'

Just as Don treats needles as a currency, so does Janet: a currency of humanity and of caring. "Sometimes," she says, "they might not even speak to me when they first encounter. They just come in, throw their rigs on the counter, I give them rigs back, the grunt and leave. Each time they come in, I might get a little bit closer each time and then, you know, they just find out we're a cool place to come to and sometimes they come in just to talk. So slowly we reel them in." For Don, Janet, and several other workers in this study, needle exchange isn't just important on the transactional level.

While all the participants believe getting needles out to the IDUs makes an incredible difference in their clients' risk for HIV infection, they also see the exchanges as points of contact, where perhaps services beyond "bare bones" harm reduction can be offered. Suzanne's program, run largely by IDUs for IDUs, offers limited needle exchange as part of a broader range of services.

Interviewer: How many people come through in a given week?

Suzanne: A lot!

Interviewer: Or, what's a busy day? How many people are you seeing?

Suzanne: I've never thought about it. I shift a five hour shift, busy day

would be 50-plus.

Interviewer: Wow!

Suzanne: Mind you these may be some of the same people returning.

Interviewer: Of course, of course...

Suzanne: But that's a busy...I've had some days, actually I've seen maybe 4 people coming to exchange, people sat down to say Hi and stuff....

Interviewer: Well that's a service too though.

Suzanne: Oh sure it is. It is what I was saying, what we do isn't really quantifiable. We're just trying to make the place more home for people. If you want a water, you can grab a water, grab a coffee.

For Suzanne and her colleagues, they provide needle exchange as a practical consideration. But their larger goal is to inculcate a sense of community among users, something that was of vital importance to her when she lived in the neighbourhood.

## Success?

Threaded throughout many of the issues examined here is the question of success—in HIV prevention for IDUs, what constitutes success? Each interview participant was asked if they considered their work 'successful,' which, to some degree, all did. Interpretation varied as to what constituted success, and whose criteria should be used to evaluate success. It is clear from this study that the interests of the workers, their IDU clients, and the criminal justice, welfare and health care systems each have notions of success—and these notions are rarely in synch. Responses revealed as much about the terrain of HIV prevention for IDUs, as they did about the individual respondent's experiences.

#### Measurable Outcomes

Many of the participants spoke of the outcomes for their clients: where were their clients in their lives after intervention? And in all cases, the avoidance of HIV infection

(and hepatitis C, if their client isn't already infected) is a key goal. Jerry spoke separately about a *personal* notion of success (as a practitioner), and in terms of outcomes for the client:

Well, yes...if you take, you know, in a very narrow sense that someone will come in ask me to do something and if it's at all within my power I generally do it. Sometimes it's not successful if you take the idea of my job is harm reduction. I am sometimes not able to reduce the harm to my clients.

Sometimes Jerry can concretely measure clients' success, in terms of their staying HIV-negative. But few of the goals of Jerry's work are as discretely measurable as HIV status.

Dorothy cited helping her clients access other services, in order to increase the level of stability in their lives, as an area where she's found success.

I think it's successful in that I've had success in how I've worked with certain clients. Getting them connected up with a doctor, getting them connected to methadone, getting them connected to AIDS Vancouver. I define that as success. Some of it, I think a lot of it is band-aid stuff. Band-aids stuff, you know we're fixing something but we're not really looking at the bigger picture.

Band aid stuff, the bigger picture... in other words, superficial. Dorothy feels that her work can only accomplish a limited amount, as long as her clients have poor housing, marginal access to healthcare, and face violence on a daily basis. Until these larger issues are addressed in her clients' lives, her client's ability to avoid HIV is limited.

Dorothy wasn't alone in her concern about the apparent superficiality of her work.

Loretta doesn't "put a lot of emphasis on success stories. I put more emphasis on little steps, and little steps has helped me ... once a week I'm going to chose one thing good that happened this week for one client I've been working with, that they're happy about to focus on."

Kate considers how each of her clients as an individual has changed, to evaluate how successful their work together has been:

I also am realistic because I think that if I said success was getting the kids off the street I wouldn't be at this job anymore because this is so few numbers out of the total that I've seen over the years who are actually off the street it would be like I am wasting my time if that's the only way I determined success. It's in a very, very small increments and then it just goes from there.

Kate, like several of her colleagues, seeks and celebrates the lower key success found by her clients. Their goals are based on each client's aspirations, which are greatly mitigated by the daily challenges of being an IDU.

A Sense of Dignity

Many of the participants saw their treatment of their clients as *persons*, rather than IDUs, as a primary goal. As they established rapport with clients, the interactions became less tense, often friendly. Janet values how "that young woman smiles every time she sees me. I love to see her on the street, greet her by name, that makes her happy." The warmth of their acquaintanceship gives Janet a sense that her work has had positive impact on her clients' lives.

Loretta values "being able to be one more person they can call on to support for support. Being someone that can be there even if it's just to talk." Felix recognizes success in how his clients' countenance change after entering his program. Part of the interview went:

Felix: It's amazing. These before and after things that people do, it's...I wish we could do that, take a picture of them and stick it on the wall if we could do that I would because...

Interviewer: ...smile of the month...

Felix: Exactly! Exactly! Because that is the most amazing thing. I don't know what other people would say but that to me is the biggest thing.

When Felix sees his clients' demeanors change, he knows his work is successful.

For many of the participants, working with IDUs requires keeping some sense of distance from their clients. But most of them also acknowledged that to *depersonalize* the work is to replicate the marginalization that made so many of their clients vulnerable to addiction to start out with. For Janet, making a commitment to treating one particular client ("Harry") with dignity, was very difficult. Discussing their history together was very emotional for her:

There was a boy I knew from (a previous job), and he was on methadone for a couple of months, non compliant, not ready but I really felt for him. I really wanted to get him and so I just, I can't...you know ,you can't be pushy or else they're gone. I didn't see him for more than a year, and then a few months ago, I saw him (here). I thought I recognized him, but I wasn't sure and he looked bad. I said, Harry, and I saw him start, but he didn't look at me. I said, are you Harry? I remember you from my other place. I'm really glad to see you. He looked up at me and looked really angry, like 'how dare you'...he didn't speak to me, and he went to the washroom and used.

Then I didn't see him for around a week, (but when he came back) I said, hi Harry. He didn't speak to me, he went in the washroom and used, he used too much so, he didn't overdose but he was nervous and scared so we sat (here) for a long time talking, and I finally got him to look me in the eye. I said I want you to look at me. You remember me from (the other place). You remember that we used to talk. Finally he looked at me and recognized me, and put his arms around me and started to cry. Oh my God, it was so beautiful. Then he went, he left. He didn't want anyone seeing inside him. He was annoyed with me. So then it was a really chaotic time for him and he overdosed twice in one week in our washroom, (we had to call) 911 twice.

Janet was able to connect with Harry—through his suffering. She continued:

He's on methadone now. He's not stable yet but he's showing up for appointments. He knows my name. That's really emotional stuff for me as you see. So yeah my work is really successful. My work is really successful when people are glad to see me. When they realize that they

are treated well here and that we are accepting them whatever they decide to do. I like working here.

Her sense of being successful with Harry is clear. What is especially intriguing was how hopeful Janet sounded for Harry, even after overdoses, disappearing for months at a time, and his struggle adhering to his methadone treatment.

Oh, I had hope for him from the first day I met him. I just saw a spark in him that he's a really intelligent man and that he has so much that he doesn't know about.

This last comment was another recurring theme from the interviews; many IDUs are vibrant, intelligent persons. From these workers, there is a strong sense that, had they lived in different families, or hadn't faced hardships like poverty, violence or racism, a good number of their clients would not have become IDUs. As Dorothy observed, "they've got total personalities and they're funny and warm and real."

# Tacitly Successful

But for all the workers, there was a intrinsic, tacit belief that their work was successful. Some expressed this as a sort of intuitive knowledge, difficult to articulate, but very real. Caitlin sees evidence sometimes when she sees former clients:

Like on some level I have some basic (understanding of my success), like I went to the Bridge opening and tons of women flew across the room and smothered me in kisses and screamed and yelled and were like, oh my god I'm here, look at where I'm at! I just thought, okay I did something right. I don't know what it was, but I did something, so there's that kind of...it has to be reduced to that on some level, 'cause I don't know how else to measure it.

She acknowledges the value of the material changes (like better housing) some of her clients have experienced. But, when such changes occur slowly, she—like many of her colleagues—has to use a less extrinsic measure of what constitutes "successful" work.

Farah has found that, in her current position, she can help make dramatic changes to her clients' material experiences, something she couldn't do as a crisis worker:

A lot of these people have very, very complex issues, health problems, also depression, and you sometimes need to do a bit of hand holding. If you can sit down and carry somebody for six months and work a plan around them that's just all about them...I've seen, the work that I've been able to do here, with the same group that I worked with for years. I am ashamed to say (compared to doing crisis work) the work that I can get done in a couple of appointments here is dramatic. It's life changing, because we have the time, and we've got resources, and we've got contacts and they are actually moving from those God-awful hotels into beautiful housing and these things are, food is being delivered to them, medications are being delivered, its all these little things that you'd never think would make a difference in somebody's life, but its <u>ease</u> and that's a weird experience in their world.

So in a very tangible sense, Farah's clients' lives improve with her help. "It's a great approach," she adds, "(it) calms my guilt." Her guilt? "Working years and years with that group and really feeling like I did very little. So it, yeah, I may have been a nice friendly face and gave lots of free cough drops and condoms and bleach kits but... very little beyond that really." While Farah celebrates the material improvements, she has her own sense of success for herself as a worker. And she feels more successful now than she did in her previous position.

Loretta felt her success limited by the bounds of her work, particularly time. "It's really difficult to try and be as successful as possible," she said, "with only 40 hours a week." She tries to do as much as she can, but her clients are numerous, and there aren't enough hours in the week for her to do as much as she feels would make her more successful. Part of the interview with her ran:

Loretta: You're dealing with people so there is no set rule of 'this is good, this is bad.' If that client feels it's good for today then I'm happy they feel it's good for today. It's irrelevant what I really truly feel...like you said, so they're happy, I'm happy!

Interviewer: What about when a client isn't meeting their sense of success yet you see them as having achieved success? Do you see what I'm saying?

Loretta: That's huge. That's more often than not and I'm not about to tell them or try and convince them that, I mean I'm there as a support first and foremost. You're not even looking at it like you should ...it's like, maybe if I could just change the picture a little. Maybe they're looking at it sideways when it should be the other way. Just change the picture, put it in options and ways that might be easier for them to see that yeah, small steps (are being achieved).

This excerpt articulates how interwoven a tacit sense of success for these workers is to how their clients view themselves. Any sense that improvements are being made by the client is of limited value, if the client can't themselves see improvement.

Suzanne spoke about her own experiences as a woman IDU, and addressed this dissonance—between workers' and IDUs' notions of success. She described her life in the downtown East side, and she views herself (and many of her IDU peers) in relation to mainstream society:

(We) don't fit. I honestly never was able...I tried, and I seriously tried to be that way. I worked at many jobs. The only ones I've been successful are on the street, working as a prostitute. I enjoyed the job. It's a good job. I enjoyed the customers, I enjoyed life, it was good. I honestly feel I did some good. It wasn't all horrible.

How do workers develop ways of evaluating the success of their work, when some of their clients have very marginal views of themselves in relation to society? Suzanne *knows* that prostitution was a good job for her. She endeavoured to do other things, but found little other paid work that suited her. Is she deluding herself about having made a "choice" to do sex work? Are her notions of success based on narrow, circumstance-limited options, and what would be realistic? Or is her self-awareness as valid as any other worker in any other context who has chosen paid work based on their

ability to do it, and it not being too loathsome. How do these workers—few of whom have ever lived in circumstance similar to Suzanne's—respond to her?

Suzanne's idea of success is her own, and it works for her. But in acquiescing to her beliefs, and similar beliefs held by many IDUs, are these workers empowering their clients, or perpetuating their disempowerment? How much do we, as outsiders, support a notion of choice amongst marginalized and stigmatized persons?

# Choice and agency

Do IDUs choose to inject drugs? Few of the respondents to this study think so. In discussing about drug use, the choice to not start using drugs is often misgeneralized to those already addicted. Getting clean is more than saying "no" to drugs. On a daily basis, IDUs "choose" to secure and inject drugs. But their actions are taken within an extremely narrow band of options available. For many the starkness of using or of experiencing withdrawal leaves only one tenable choice: more drugs. In reality, IDUs use drugs, with only a limited need to make choices around how and when to use them. Were more IDUs motivated to seek treatment for their addiction, the lack of services available removes getting clean from the options to consider.

But when we discuss choices for IDUs, we cannot presume that all *decisions* reflect purposeful and reasoned *choices*. This holds true not only for drug-using and sexual activities—the conduits through which HIV infection can occur—but for health in general, as well as place in society. But few of the workers spoke about encouraging their clients to more vigorously interrogate their clients' circumstance, including how they perhaps could be changed. There was a clear reticence to assert options to clients, or to challenge clients' inaccurate self-views. Doing HIV prevention work with IDUs

requires a sense of what choices are available to clients, making them aware of their choices, and (at least potentially) helping them make considered and critical choices about how to conduct their lives. Much of the experiences the respondents described can be categorized as either advocacy or mentoring.

# Advocacy

Many of the respondents saw a critical need to have a client-centered approach for their work to succeed at all. This meant they operated as *advocates*, who helped the clients to meet their own needs. The client's agenda almost always held sway among workers who largely viewed themselves as advocates, who work *for their clients*. Loretta was the most forthright about this:

My job description for my funders, I will definitely uphold and stay true to it as much as possible, not to appease them, certainly to at least keep that job going. But first and foremost as I said right from the get go, (it is) the women I work for, not the funders, not my co-workers, it's the women out there. The clients tell me where to be, when to be and how to be—as long it doesn't infringe upon my boundaries.

Loretta does what her funders funded her to do, without exception; she is not naïve. But she takes on many other tasks, in order to help her clients. When the interests of her organization, her funders, herself, and the women are not aligned, she does what the women want—within reason. "It's good to be able to say up front, listen I'm available for this but not for this," she said, "so let's try and work with what I can give you and what you can get from me."

Tino spoke at length about how, when he first started working with IDUs, he quickly learned to follow the client's agenda:

(When I first started working with IDUs) I had to let go of any sort of half baked notion that I had that I was going to make a difference and let

the client set the agenda. Hear who they were, have an interest in who they were, listen to their story, listen to their, and become engaged in that process in a way that then I could see a place for myself and they'd have to invite me in. I couldn't walk in at all. I learned patience in a big way.

Since Tino has never been an IDU, his outsider status made IDUs wary of him.

Tino believed, if he did not subjugate his own ideas to what was in the clients' best interests, he could achieve little. Eventually, he realized there were competing agendas—including his own—and that he needed to try and integrate them in some way:

The clients had to set the agenda and it wasn't my goals, it wasn't my agenda, and of course in later years what I had to learn was that I'm put out and paid to be out there by this organization for a specific purpose and I've got to integrate that into this relationship that I've built with these people...It wasn't good enough to just go out there and get to be known and get to know them but I have an agenda as well—but it's how I address that agenda with the population that was really the huge thing for me to learn.

Regardless, it is only when Tino's clients express a desire to become abstinent that those sorts of options are proffered.

Caitlin felt especially torn by her ideas about empowerment, and her awareness of some clients' limited ability to make critical choices. But she tried to follow her clients' agendas as much as possible:

There were women that were really clear from the get-go where they were at, and my agenda was always, there were women that, for example they would want me to get in touch with you because they were pregnant. There was always a sense of urgency like the woman's pregnancy, 'oh my God we've got to get her on meds blah, blah, blah', and that was something that I never did. I would just refuse if women had made it clear to me that they didn't want support so it really, I guess just say that it kind of depended where the woman was at, what I did with them.

What is interesting about the anecdote Caitlin provides is that it involves her advocating for a client seeking care from a large organization. In this sort of instance, Caitlin saw the potential of silencing her client to be the salient problem. Later, she describes how, in

other ways, she felt that she could have been more assertive with some of her IDU clients. As Pete observed, "It's deplorable to see people in and they look horrible and they're sick. Working the streets, I mean they can't be choosing that, cause you know..."

Dorothy sees clients who improve over time, then stumble:

Sometimes we work with some for a long time and they want to get on methadone, and they get on methadone, then they relapse or then the start injecting cocaine instead of methadone, and you realize that you can't...you've still got to be there for that person, regardless of the choices that they're making. So that sometimes happens, you just go 'oh well, its just the way it is.

And though it is her job, Dorothy, like all of the interview participants, was sad when she spoke about their clients' roller-coaster lives. It is clear the respondents build relationships with their clients, and do not merely provide care—they care. This seems to be a common approach amongst these workers, but must be a difficult boundary to maintain.

### Mentoring

A few did, however, speak about when and how they had to introduce ideas outside the client's agenda. In some instances, workers like Don felt it necessary to assert some influence over their clients, in a way that helped them move beyond their own (low) expectations of themselves. He described how he took a very assertive role in one client's life:

We got him decent housing, we moved him away from a relationship that was abusive. He was living with a man that was older than him who was abusing him financially. He was taking advantage of this young, handsome, buckish looking man, great sex and tolerated his schizophrenia and his delusional stuff, nice little hood ornament to have but we got him out of there because he yelled and screamed at my client all the time and the voices got worse. We moved him out of there into his own place, the voices are now collared.

For his IDU client with schizophrenia, Don didn't think it appropriate to operate (as a practitioner) on any generalized notion of choice; he did not automatically let his clients wholly decide for themselves how to conduct their lives—instead, he actively intervened. With this man, Don persuaded, even cajoled him into getting out of an exploitative relationship.

With another client, Don described how they worked collaboratively over a period of years, and how their relationships was changing still:

[He has] Hepatitis C now and he probably won't be able to take any of the anti retrovirals [for his HIV], because of his liver [shutting down; HIV meds are highly toxic, even for healthy livers], and doesn't want to go through that again because he gets really sick. He doesn't like being sick anymore and that's wonderful. I watch him come in and he's happy, he's reunited with his kids. He's just gotten into a relationship for the first time in 15 years. When he came to me he was a bone rack, not getting out of bed, with night sweats and not able to do his laundry. Now he's practically obsessive about being clean. We got him into housing, we got him into the Dr. Peter Centre and he got fed, he did some hard work.

Even when speaking about his influence on this man's life ("we"), ultimately Don separates what he can encourage his clients to do. With this man doing "some hard work" to rebuild his life, Don's mentoring can only instigate a process for change. Don cannot change his clients' lives.

Janet thinks some clients do have better chances than others, as in the case of Harry. "If you define success as abstinence, that's not what (we do)," she says, "you can self select from people that are going to become abstinent." With most clients she focuses on strict harm reduction techniques (needle exchange, avoiding self-injury and overdose, safer sex), with others she intervenes on a deeper level. Caitlin was always aware of this tension between her roles as providing support and helping people change

their lives. While she was willing to assert her clients' agenda when advocating with bureaucracies, client agency was clearly a complex issue in Caitlin's practice:

(There this) kind of enabling liberal like 'oh can I do anything more to help you be a drug addict?' perspective. That was what (women IDUs who became abstinent) often said to me, people (like that) didn't help (them). It was people, usually other women who were in recovery who were total hard asses about, not necessarily 12 stepping, not hard ass in the 12 step sense, but holding other women accountable and really encouraging them, in a kind of tough love sort of way. That's across the board (of all the women IDUs I know that are abstinent). So many women told me that was the way it worked.

Should HIV prevention workers whose clients are IDUs serve as advocates or mentors? In other words, to what extent should the services they provide fulfill client requests or proscribe choices? Currently, most of the workers in this study have focused on the former, operating as client-centered programs. To what extent is substantial change possible for IDUs, if most services that are provided do not help them consider ways to mitigate their marginalization—most obviously related to their active addiction?

Kate, to some extent, shares this perspective. She is at times frustrated with how harm reduction at a basic level is what seems to be the approach from which her work is seems always expect to come:

I guess I'm talking like a bit of a hard ass right, but I think that certainly a friend of mine living in Europe when she was wired to heroin and her experience talking about it, and she would just always say like this is total bullshit. She would show me all these things from resources that she had brought home with her cause she had gotten clean by the time she moved back here and it was just sort of an interesting sociological look at the programs.

They had all kinds of supports like in terms of housing and counseling but they were also expected to have clean piss tests, they were expected to not be using, they were expected to come to programs, to go to job training like all kinds of things. Her sense of it, this friend of mine and certainly other people that I've talked to, it's just that it didn't have that like, 'oh yeah you're going to just keep using', and, 'oh yeah this, of course you're going to still be using coke and benzos and methadone, you

know try it and see if it will make a dent but likely it won't', that was the attitude in the programs.

Is it appropriate for these workers to be trying to inspire, or *conscientizate* (Freire, 1986) IDUs, towards a better life? Or is holding any notion of what would constitute a "better" life for IDUs, itself inappropriate? A minority of the interview participants attempt to mentor their clients towards stability, at least some of time—a reasonable tack. If clients are disempowered, even ignorant, and you dare not challenge them—based on following a "client-centered" agenda—their oppression is being perpetuated by your unwillingness to intervene.

# **Policy Priorities**

While participants' administrative or managerial colleagues are to some degree involved in the policy decisions made regarding HIV prevention strategies for IDUs, front line workers themselves frequently are not. Their absence from the policy table calls into question the extent to which their experiences with IDUs—as gatekeepers of the knowledges and practices proffered to help IDUs protect themselves against HIV and other similar pathogens—are accurately voiced in policy decision-making processes. This strongly suggests that policy decisions are being made based on an incomplete understanding of the contexts in which IDU-related HIV transmission occurs, and the *pragmatic considerations* their policy decisions have on the ability of these workers to best help IDUs.

To this end, in the "Policy Issues" (Section E) of the questionnaire participants were invited to rank ten proposals for changes in injection drug use-related policies, from most important to implement (1) to least important (10). Participants were also instructed to mark an 'X" next to any proposal they rejected outright. The proposals themselves

were culled from the literature reviewed for this study, conversations with activists and health care workers familiar with the IDU community, and from my own (unpaid) work in substance use programs.

Since these were ordinal variables, median (rather than mean) values were compared. Where more than one statement shared a median value, the ranking of their sum values were used to rank them within its ordinal range. In a manner, this is analogous to how skills-based games like golf are scored: a lower score is considered preferable, as it reflects more frequent rankings near the top (1, 2 and 3) across the sample. Responses with median values between 3 and 4.5 were considered to have strong support. Median values between 5 and 6.5 were interpreted as having significant support. Proposals with medians seven or higher were deemed to have inconsistent support. Table 7.2 summarizes these rankings for the overall sample:

Table 7.2: Overall Sample Ranking of Policy Priorities

Proposal	Mdn	Σ	Rank
Detox on demand/more detox beds	3	152	1
Treatment on demand/more treatment	3	174	2
Free housing for IDUs	4.5	188	3
Unlimited needle exchange	5	227	4
Provide safe injection venues	5.5	237	5
Improved (non-addiction) mental health services	6	251	6
Decriminalization of drug use	6.5	237	7
Methadone on demand	6.5	248	8
Decriminalization of petty drug dealing	7	240	9
Government-distributed drugs	8	288	10

An examination of some of the sub-samples yields less unanimity on these issues.

Social service and health workers differed very little in terms of how they ranked these policies; health workers saw a greater need for improved mental health services (median

4.0, rank 4) than social service workers (median 7.5, rank 10). Addicts (n=12) and non-addicts (n-24) differed on two points. Addicts saw free housing (median 1, rank 1) and decriminalization of drug use (median 3.5, rank 3) as greater priorities than their non-addict colleagues (median 4, rank 3 and median 7, rank 9, respectively). Among participants who have ever injected drugs (n=5), only one proposal—greater access to detox—garnered strong support (median 4, rank 1). IDU participants voiced particularly inconsistent support for methadone (median 9, rank 7), government distributed drugs (median 10, rank 8), and the decriminalization of drug use (median 11, sum 49, rank 9) or petty drug dealing (median 11, sum 57, rank 10). These lower rankings probably reflect mistrust of government to fairly or effectively manage programs in the best interests of IDUs: mistrust of government entities like the criminal justice, welfare and health care systems was cited by many interview participants.

#### Gender

Men strongly priorized free housing (median 1, rank 1) over their female counterparts (median 4, rank 3). Women, ranked detox (median 2, rank 1) and treatment on demand (median 2, rank 2) higher than men did (median 3.5, rank 3 and median 4, rank 5), perhaps due to the striking inequity in women's access to detox and treatment. Men also put a greater value on methadone on demand (median 3, rank 2) than women did (median 7, rank 9). Women placed access to detox, treatment and housing as the greater needs of their clients; men strongly supported housing, methadone, detox and needle exchange access. Tables 7.3 and 7.4 detail how different women and men viewed these policy proposals.

Table 7.3: Women's Ranking of Policy Priorities

Proposal	Mdn	$\sum$	Rank
Detox on demand/more detox beds	2	63	1
Treatment on demand/more treatment	2	75	2
Free housing for IDUs	4	107	3
Decriminalization of petty drug dealing	5	109	4
Improved (non-addiction) mental health services	5	132	5
Provide safe injection venues	6	133	6
Unlimited needle exchange	6	144	7
Decriminalization of drug use	7	142	8
Methadone on demand	7	152	9
Government-distributed drugs	7	152	10

Table 7.4: Men's Ranking of Policy Priorities

Proposal	Mdn	Σ	Rank
Free housing for IDUs	1	63	1
Methadone on demand	3	78	2
Detox on demand/more detox beds	3.5	63	3
Unlimited needle exchange	3.5	65	4
Treatment on demand/more treatment	4	81	5
Provide safe injection venues	5	86	6
Decriminalization of drug use	5.5	77	7
Improved (non-addiction) mental health services	6	101	8
Decriminalization of petty drug dealing	8.5	113	9
Government-distributed drugs	8.5	118	10

# University Education and Aboriginality

Respondents who have completed university degrees, and those who are Aboriginal, also had some different opinions regarding the policy proposals. Those with completed (4 year or higher) university degrees (n=26) place housing (median 2, rank 1)

as a much higher priority than their peers who had not attained a university degree (n=10; median 5, rank 4). Their rankings on the balance of the proposals are almost identical. Aboriginal respondents (n=4) gave strong support to only three propositions: free housing (median 2.5, sum 23, rank 1), detox on demand (median 2.5, sum 24, rank 2), and treatment on demand (median 3.5, rank 3). The rest of the list garnered inconsistent support. Non-Aboriginal participants gave significant or strong support to *every* proposal. Like the IDU sub-sample, the much lower rankings given by Aboriginal participants probably reflect a high level of mistrust for government policy to represent the best interests of Aboriginal persons. The rankings of Aboriginal (Table 7.5) and non-Aboriginal (Table 7.6) participants are below.

Table 7.5: Aboriginal Participants' Ranking of Policy Priorities

Proposal	Mdn	Σ	Rank
Free housing for IDUs	2.5	23	1
Detox on demand/more detox beds	2.5	24	2
Treatment on demand/more treatment	3.5	27	3
Unlimited needle exchange	7.5	27	4
Provide safe injection venues	8.5	38	5
Improved (non-addiction) mental health services	8.5	39	6
Methadone on demand	9	36	7
Decriminalization of petty drug dealing	9.5	44	8
Government-distributed drugs	13	53	9
Decriminalization of drug use	13.5	53	10

Table 7.6: Non-Aboriginal Participants' Ranking of Policy Priorities

Proposal	Mdn	Σ	Rank
Detox on demand/more detox beds	3	132	1
Treatment on demand/more treatment	3	147	2
Free housing for IDUs	3.5	165	3
Provide safe injection venues	5	199	4
Unlimited needle exchange	5	200	5
Decriminalization of drug use	5.5	184	6
Improved (non-addiction) mental health services	6	196	7
Decriminalization of petty drug dealing	6	212	8
Methadone on demand	6.5	212	9
Government-distributed drugs	6.5	235	10

# Respondents' Suggestions

While some of the proposals included in this section of the questionnaire were seen as relevant by many of the participants, a number felt it necessary to add other suggestions or comments. Forty-nine percent supplied between one and ten additional suggestions. While these additional responses were not easily coded into the ten initial proposals, several themes clearly emerged from their responses. Of the 17 respondents who supplied additional policy shifts, nearly half their suggestions were modifications of the above statements for being "too black and white." Eight of those who gave explicit suggestions or comments (47 percent) called for an additional level of treatment/supportive housing, which straddles the ideas of residential drug treatment and subsidized housing. Four participants challenged the notion of "on-demand" treatment and detox, but with no suggested qualification or adaptation.

Of the seven respondents who made suggestions regarding housing, individuals urged "safe" housing, that such housing be "away from the downtown East side... as (staying in the area while seeking abstinence) triggers (desires to use)," and "only subsidize housing for those who remain drug free." Several respondents also suggested a need for specific services targeting women (29 percent), or youth (18 percent). Another 24 percent wanted more job training and education to IDUs. No suggestions were made regarding programs specific to Aboriginal persons (or any other cultural communities).

In a much larger sense, it is clear that none of the workers who participated in this study view current policies regarding injection drug, addiction treatment, and relevant legal questions as being adequate. Though there may not be unanimity, in terms of what changes need to be made at the policy level, they clearly see a need for dramatic changes, if HIV prevention programs for IDUs are to succeed.

## Local Knowledges

In terms of prevention techniques proffered, there was little variation between workers, regardless of lived experiences with substance use, gender, or Aboriginality. The specific strategies they offered IDUs, and the frequency with which they were offered, did not vary significantly between sub-groups. In technical terms, the knowledge regime (medicine) was viewed by most workers as a credible source for technical information regarding HIV prevention.

How workers measured the degree to which their work did vary, though the patterns of beliefs were not as easily mapped as were the participants' perspectives (as delineated in Chapter Six). While all workers viewed IDUs testing negative for HIV as a clear measure of success, many saw value in giving their IDU clients a sense of

dignity—particularly as they struggle with their addictions. And others relied on an intrinsic sense of their work being tacitly successful—at times regardless of how well their clients' behaviours changed—to evaluate their efforts. These last two approaches, where their IDU clients' and their own criteria for success were priorized, represent a form of local knowledge; while the rate of HIV infection among IDUs is considered by many in the knowledge regime as the best indicator of programsuccess, these workers refuse to accept HIV incidence as the *sole* measure of success.

Finally, within the practice of HIV prevention for IDUs, there are two competing discourses regarding IDU empowerment and personal agency. Currently, the dominant discourse is that a client-centered approach is necessary to treat IDUs as individuals rather than objects; the dominant view is that advocacy is the most effective approach for IDU HIV prevention. But others take a more proactive approach, and act as mentors for (at least some of) their IDU clients. While cognizant of the risks of moving beyond the role of an "order taker", they feel that some IDUs cannot break out of their extremely marginal existence without outside intervention. The tensions between advocacy and mentoring are real. But what may be as important is *why* so few HIV prevention workers whose clients include IDUs follow this second tack. Within the local knowledge regarding IDU empowerment, there is a more localized, counter-knowledge that leaving the prevention agenda wholly to IDUs will result in few IDUs being able to improve their lives in the longer term.

It is also clear that, among study participants, women and men, Aboriginal and non-Aboriginal, and those with and without university degrees have different perspectives regarding many potential policy priorities. While the sample and sub-

samples placed detox, treatment, and housing as priorities, different groups valued different strategies. Arguably, while most IDUs share certain basic needs, some particular IDU communities (most clearly women and Aboriginal) have unique needs, which will be subsumed by policy priorities that consider IDUs as a homogenous community. While integrating these perspectives make policy questions more complex, it also increases the range of IDUs who will benefit from new policies implemented.

### <u>Summary</u>

From these data, it is clear that certain lived experiences—particularly with regards to substance abuse of all forms, but especially injection drug use—substantially informs how many of these workers approach their jobs. It is also apparent that, among the respondents, former addicts are more likely to pursue working in HIV prevention for IDUs via social service than health organizations. Social service workers have more prior personal knowledge of street involvement and addiction than do their health worker peers. Conversely, health workers have greater levels of education and are generally higher paid than the social services workers. Especially among health workers, this work is done more often by women than men.

Most of the respondents do this work out of a commitment to social justice, directly to their peers (Aboriginal persons, IDUs, women), or in a larger sense. Yet, equal numbers of social service and health workers are likely to describe doing this work because it's "a required part of my job." Of those who have been IDUs or street involved, limitations on their identification with the street, or newness to injecting drugs, allowed them to make a break from their addictions—something rarely achieved by most street-entrenched IDUs.

It is evident that these workers make their individual practices their own. Their reliance on technical knowledge is largely supplanted by their awareness of the contexts in which they work, and the contexts in which their IDU clients live. Doing HIV prevention targeting IDUs requires perpetual re-negotiation between the worker, their clients, and the context. To a significant degree, these workers deal with issues of power, in relation to their workplaces and their clients. Often they are asserting their authority and power over addicts, based on whose agenda holds sway in the moment—the institution's, their own value system, or what they think is in the best interests of the IDUs. These workers also voice consistent support for increases in detox, addictions treatment, and housing for IDUs, though how these (and other) policy proposals are ranked varies. IDU or Aboriginal participants were much more pessimistic regarding changes at the policy level; except for these three areas, they offered no significant support to any of the other suggestions.

But what about this reticence to take on the issue of empowerment? The next chapter moves into the participants' values and beliefs. It delineates these workers ideas about addiction, addicts and treatment, and reveals a startling link between the advocacy approach and the range of treatment options available for IDUs in Vancouver.

Chapter Eight: Approaches to Addiction, Addicts and Treatment

Having garnered an understanding of what constitutes practice for HIV prevention workers whose clients are IDUs, as well as a sense of how lived experiences inform their practices, this chapter examines these workers' beliefs regarding HIV prevention, addiction, addicts, and treatments for addiction (abstinence and harm-reduction based). Respondents' opinions about priorities for future policy decisions regarding injection drug users, addiction services, and broader determinants of health are also examined.

The data presented here is from responses to questions from the "Drugs and Addiction" (Section A) and "Social Context" (Section C) of the questionnaire (see Appendix A). Participants were asked about their attitudes, values and beliefs regarding addiction and addicts. Their perspectives of how addiction begins, why some addicts inject drugs and others do not, and what in the addicts' life experiences—pre-using and currently—makes them vulnerable to addiction. For each question, respondents circled a number corresponding to a value on a five point Likert scale; these responses were collapsed to three point scales, to avoid Type II errors (Spatz, 1997, p. 302).

### The Nature of Addiction

Virtually all (97 percent) of respondents agree or strongly agree, in principle, with harm reduction approaches to injection drug used-related health issues. Most study participants (88 percent) agree or strongly agree that addiction is a medical, not a criminal problem. Eighty percent agreed or strongly agreed that "IDUs don't get enough emotional support from family or friends." Jerry finds that younger IDUs have better

odds of accessing a support system, depending on how long they have been streetinvolved:

The earlier you get [someone street involved], the earlier people can try and stop, and they do have those supports in place and they do have, they're motivated and they still have a job so they can go back to their jobs, they still have family. The more they lose the more they become isolated, the less they're motivated to return.

Almost half of those interviewed spoke of better outcomes with younger clients than with those firmly entrenched in the street.

Eighty-one percent disagree or strongly disagree with the statement, "Most IDUs don't want to get clean"; in other words, 81 percent believe that most IDUs would like to be abstinent, were it possible. Sixty-nine percent disagree or disagreed strongly with the statement, "IDUs could quit using if they wanted to." Though one could argue a clear majority of these workers don't expect their clients to achieve abstinence (if, for no other reason, due to the difficulties in securing services in detox or residential treatment programs), 31 percent did wonder whether more IDUs could stop using, if they mustered the willingness. Is this uncertainty rooted in participants' beliefs about the personal agency of the IDUs? Or, do these workers view as implausible IDUs who want to getting clean, because of the power of addiction? Or because of the IDUs' level of disempowerment they face (and many will continue to face, even if abstinent)? Or, if the option of abstinence were proffered more frequently, under what conditions, and with what sorts of support, would it be possible?

Eighty-six percent agree or strongly agree that "IDUs use drugs to avoid painful memories of physical, sexual or emotional abuse." Several participants shared generalized and specific information about the commonality of pre-addiction abuse among IDUs, particularly women. Dorothy's experiences as a practitioner reflect this:

Some women have told me. They've come from really violent histories. Most of them have been abused a kids, been abused by family members. You hear a lot, especially from the women, a lot of stories of abuse by partners, by family, by mostly men in their lives. So I think that's a huge reason why they're down there, especially the young women, they don't feel safe at home. They've had quite a tragic past.

One women said when she was nine her Mom used to abuse her sexually, physically and basically put her out on the street when she was nine. She's 30 now and she's still alive but has been on the downtown East side for twenty years, fifteen, twenty years...Prior sexual abuse, yeah people have definitely disclosed that they had a history of previous sexual abuse. I think that's where the drugs come in handy cause it just kind of blocks all that out for them.

Dorothy expects her clients to have been abused in some way, quite often sexually; abuse no longer surprises her, though the specific stories are often heart-rendering. Caitlin makes an even stronger claim:

Every single woman that I have ever worked with on the downtown East side was sexually abused as a child. Without exception.

For Caitlin as well, these stark generalized observations become tangibly painful, when she recounts one specific woman's story:

She grew up in [the downtown East side], this woman, in a family with six kids, and the father—both the parents—had addiction issues. The father murdered the mother, the brother murdered the father, the other brother was pimping the younger sisters...eventually the younger sisters were the women that I met and when I met them, two of them, they were both pregnant at the same time, they were both highly addicted and both HIV positive. This was like, if you want the kind of snapshot from experience, this is the snapshot of many, many women's experiences.

These women's—their whole family's—experiences are harrowing. And working with a client base where violence and abuse are norms, establishing trust, while maintaining boundaries, can be incredibly difficult.

But these workers are not laying the blame for injection drug use on physical, emotional or sexual abuse. Loretta also believes that "women are out there because of sexual, physical and mental abuse in their pasts, being survivors of post-traumatic stress disorder (PTSD)." But she also qualified her position:

I do care, honest. [But] there's enough survivors of childhood sexual abuse that are not down here that I like to believe more firstly in the empowerment of the survivor and allowing them to chose whichever route of therapy they wish to. I don't think heroin is the best choice. Yeah you are right and you hit the nail on the head by saying maybe they are entrenched in this life because they don't want to go back to what had been offered before. Well let's make new offers.

Loretta doesn't see injection drug use as the de facto response to sexual abuse. But, in the absence of a nurturing, stable environment, adequate shelter and nutrition, and growing up with a sense of being valued, substance abuse of some sort is not a surprising outcome. Loretta's notion of 'a new offer' is a critical one: address the inequities and injustices faced early in life by today's at-risk youth (including, but not exclusively, survivors of sexual abuse), and there will be fewer who turn to drugs to deaden their despair later in life. In other issues, regarding addiction, the range of opinions was more varied.

#### Mental Illness and IDUs

The intellectual and emotional dimensions of IDUs' lives were considered in two questions. While 64 percent thought the idea that "better mental health services would mean fewer IDUs" was probably or definitely true, 22 percent were unsure and 14 percent though it probably false. This range of responses could be related to differing beliefs about mental health consumers who shoot drugs, specifically whether either problem (drug addiction or mental illness) catalyzed the other. This study could not resolve this sort of causality questions (social and behavioural sciences rarely can), but these workers' beliefs about the relationship between mental illness and injection drug

use may well determine what sorts of services IDU mental health consumers can access.

According to Don, safe housing is critical for those IDU consumers who seek abstinence:

Housing is an issue and you can as I say you can provide them all the treatment and all the reasons in the world to stop but if they don't, if they see that they are going to go back into hell and then you add a mental illness on top of that. The chances of success are nil.

Unfortunately, most residential programs for addiction (treatment or halfway houses) do not accept persons on methadone, or who take medications for mental illness. And supported living environments for mental health consumers are not set up to assist consumers pursuing abstinence from their addiction.

In her work with at-risk youth, Meg finds it difficult to discern whether the effects presented by her clients are from a mental illness, or substance abuse-related:

The specific kind of drugs that they are using now especially with the crack and the crystal meth are also bring out kinds of psychotic symptoms...we have a psychiatrist that we consult with and have started to us him so much more in the last year and a half, and we would only consult with him when we see a fairly serious mental illness that may require medication. Otherwise, you know we just sort of see the kids. That, that, the rate of that has definitely increased in the last year and a half.

I connect a lot of that to the crack and the crystal meth specifically now. It's very hard to discriminate what is a psychosis that is just sort of generic psychosis that's been induced by the drugs. We don't know even enough about crystal meth [a form of speed] now to know how long they have to be off it before we say well these are symptoms of the drug or there just basic symptoms that this person has.

These assessments are beyond Meg's clinical skills, and were not needed as frequently ten years ago as they are today. As different drugs enter the equation (like crystal meth), assessment and treatment becomes more complex.

Substance abusers who also have a mental illness are referred to as *dual*diagnosis. Some seek drugs as a form of self-medication; some may have induced or

catalyzed their mental problems with drug use. Regardless, they often fall between the cracks of both the mental health and substance use services. Don has seen clients with problems similar to Meg's, and has a difficult time finding services that will accept dual diagnosis clients:

[Our office] is way ahead of its time in having a dual diagnosis program. The guys that work or the people who work at dual diagnosis are hopping [busy], but to get psychiatric time for them is difficult because people or the docs, there's very few doctors that are willing to do that [work with dual diagnosis clients].

Being either an IDU or a mental health consumer means being extremely marginalized in our society; being both—dual diagnosis—even more so. And, just as many abstinence-based programs for addiction will not accept persons on medication for mental illness, many mental services will refuse to treat mental health consumers who are not abstinent, or who are suspected of abusing their prescription medications. One system thinks addressing the addiction comes before looking at the mental illness; the other works in the opposite direction. The result? A veritable whirlpool for dual diagnosis addicts, particularly IDUs.

#### Despair and Hopelessness

Fifty-three percent thought the statement, "despair or hopelessness is why most IDUs don't protect themselves from HIV infection," was true, though an additional one-third were unsure; 13 percent disagreed, and 3 percent did not answer the question.

While a majority of respondents acknowledged that a lack of hope is endemic among IDUs, what is less clear is how powerful an impediment they consider this hopelessness is to their clients' efforts to avoid HIV, via harm reduction or abstinence. The question of

hope, and the related ability to practice self-care, was a significant theme in the interviews.

Caitlin found it difficult to not only help her clients to be hopeful; she found herself sharing her clients' despair:

When you combine that sense of futility around the political stuff with women disappearing, women being found in dumpsters, that sense of the kind of hopelessness of women's daily existence it was kind of stick their head in the oven kind of feeling sometimes.

If workers like Caitlin find their clients' circumstances daunting, they can only be more so for the IDUs themselves.

Cora's current position is in a different agency. And the different client base—a much younger one now—seems to have a more positive outlook. "That clinic wasn't very successful," she says, "because a lot of the people were older and lived in the area of drugs and crime and they were taking methadone but still using drugs heavily. So I had a not sure feeling how that was going to be but here it seems it little more hopeful. They are younger people here and they could be a little more hopeful." Don plays it as a waiting game of sorts. He tries to create access with his clients through openness, by being non-judgmental and letting his IDU clients assert the agenda. He hopes his clients will reach out to him, when they feel compelled to seek a different life:

A lot of it's just like 'hey, how's it going?' The whole thing around that is hopefully, eventually they will come and have an HIV test, or want to engage in a conversation about their drug use. Maybe they might be at a point in their life where they've had enough, and you're a person that they've seen a billion times and they trust you so they might come to you and say 'I want some help. I want to get off heroin', or whatever they're using. I want out of the downtown East side.

These are the sorts of moments where Don can offer more than short-term harm reduction strategies like needle exchange and condoms. These critical opportunities are

better times to introduce serious discussion of longer-term approaches to addiction, such as total abstinence or methadone. Clients having expressed their own desire for change, these options are often given more serious consideration. That is, *if* the service is available when the IDU is willing, which unfortunately is not usually the case.

Sadly, for some IDUs the crush of hopelessness leads them to contemplate horrific choices. Farah has had clients tell her that they believe becoming HIV-positive would actually *improve* their circumstances:

I even have a lot of older people, mothers of, mothers and fathers of my clients that come in and say, 'I hope I get HIV so I can have a case manager like you.' Now that's not me they're talking about, it's the type of service. They say, 'we live in these senior's homes and they have nothing. We have no advocate, we have nobody telling us what we're entitled to or fighting on our behalf or putting things in place.' My client gets sick, I'm going to get things together within a day, they're going to have someone in their cleaning for them, they're going to have a care team in looking after them, they're going to have someone doing their personal care, their laundry, I'm going to have food delivered by the next morning and medications, everything's going to be perfect. These mothers will come in and say, 'we waited a month before the health unit came.' These [HIV-negative] people are sicker, you know, many times [sicker than some of my HIV-positive clients], it's very sad.

This is not an isolated story. For people living in dire poverty, the extra \$300 each month in disability benefits would nearly double their welfare cheques. IDUs are routinely treated disrespectfully by health care and social service workers, only to see their friends living with HIV being provided with additional services, and a more rigorous standard of medical care, thanks largely to a dedicated disability or AIDS case worker at a social service organization; to the clients these are the immediate, tangible benefits of HIV infection. Do they know that HIV leads to AIDS, which leads to death? Certainly, just as they know that injecting heroin can lead to overdose. But in a life characterized by difficulty, despair and hopelessness, long-term ramifications are sometimes not terribly

important. For people who feel devalued by society, in the here and now, more money, better services and being treated with respect are invaluable.

Social (In)Justice and IDU Vulnerability

Three questions that related to marginalization and social justice garnered a broad range of responses. Sixty-six percent of respondents disagreed with the statement, "racism has nothing to do with the number of Aboriginal IDUs." Two-to-one, the workers participating in this study see racism as a significant reason for the disproportionately high representation of Aboriginal persons, in particular, among Vancouver's IDU community. Several participants offer their experiences with Aboriginal clients; this is Farah's perspective about the over-representation of Aboriginal women in the downtown East side:

There's a lot, tons of Native women, loads of Native women that end up there, end up there from small communities. I think often times there is no where else to go, or they have a sister or a cousin or someone that lives in the downtown East side that might be able to find them a hotel, and they just end up staying there. Most of them are young, although there are some older Native women that maybe don't live down there but they come down there, they socialize there, they go to the women's centre they go for lunch, go in the bars.

A substantial number of Vancouver's urban Aboriginal population views the downtown East side as a geographic and social locus of community. One outreach worker whose clients include many young two-spirited (Aboriginal gay) men, sees them being drawn to this hub of their one identity (Aboriginal), often to seek relief from rejection in another (gay male):

[For] all minorities, when you run into people of your colour and things like that it is easier to bond. Because there is a lot of [injection drug use among] Aboriginal people around Main and Hastings, and things like that, a lot of the boys go there just to feel comfortable. Just to feel at

home. Then they go back to their gay lifestyle. So it's just like 'I'll go visit my culture at Main and Hastings and when I have to come back here to be with my gay world, that's when I'll do it.' So it's just like they go to Main and Hastings to sort of get that cultural connection which is really sort of sick but that's they're cultural connection.

For two-spirited IDUs, Main and Hastings is where they seek respite from racism in the gay community. For them, like for many urban Aboriginals in Vancouver, the downtown East side is where to go to find community. But in doing so, they trade in racism for homophobia or the closet. Asked whether there are 'out' gays at Main and Hastings, This worker responded:

Some of them are. Some of them aren't of course. I think once they get to this point, once they've hit the street working stage they really don't care who knows they're gay.

Many two-spirit males who become IDUs enter the sex trade (as "hustlers") to support their addiction.

Nearly 60 percent of the participants agreed or strongly agreed that "poverty is the problem, injection drug use is the symptom." Some workers saw injection drug use as a result of economic marginalization, others—who may agree IDUs are almost all poor—are unwilling to support the causality implied in the statement. Similarly, only 27 percent of respondents agreed that "injection drug use *causes* homelessness/unstable housing." This intriguing question—can we untangle the web of poverty, marginalization and addiction common to many IDU's lives, and attribute specific outcomes like homelessness to any one of these experiences?—is beyond the scope of this (or perhaps any) study. A more salient and answerable question would have been, "what changes could occur in an IDU's life, once stable and secure housing are made available?"

The lack of safe housing for IDUs—actively using, or pursuing abstinence—was one of the few areas where a clear consensus emerged: to address the challenge of

Vancouver's IDUs. Many include those who currently live in single-room occupancy hotel rooms (SROs) as being in unsafe accommodations. These hotels, which are notoriously unhygienic and have a reputation for violence, house many of Vancouver's IDUs. Janet recounts one client's experience with SRO living:

The last time I saw her she came in with, she was seeing one of our doctors cause she was feeling edgy. Why was she feeling edgy? Because the night before she'd been sitting on the sidewalk down on Hastings Street and someone drove by and shot her companion in the head. Sitting beside her! This is a woman who has a hotel room but doesn't stay in it very often because people keep coming into her room and I don't know what they do there but she says she gets a much better sleep down behind the hot dumpster than she does in her room.

Don sees users who suffer mental illness as in particularly dire need of safe housing, especially if they are pursuing abstinence. "Housing is an issue and you can provide them all the treatment and all the reasons in the world to stop but if they don't, if they see that they are going to go back into hell and then you add a mental illness on top of that. The chances of success are nil." Kate agrees:

I think that when there's no commitment to affordable housing, when there's not commitment to all the other things that are going really promote people's well being, I just don't see how that is going substantially change the situation.

She's also seen first-hand the difference finding safe, stable housing can make in an IDU's life—particular women IDUs:

A woman that I had known for probably six years and who had in that time been through several sexual assaults, and HIV positive diagnosis, I had been to every appointment with her, when dealing with cancer, it had been a nightmare and she had never had stable housing. It was always something that tried to get her like she was on every waiting list, she was, and it was never, I mean it was stable, she lived in the same hotel but it was never a safe environment. It was always a problem and she got into Bridge Housing and seeing her speak at the Open House, it was just incredible.

Finding a safe, supportive living environment for this woman has improved her life, according to Kate. But before this was available, the woman endured years of violence and was infected with HIV.

More alternatives are emerging for IDUs, the best known of which is the Portland Hotel Society ("the Portland"). The Portland's mandate is to house persons unable to maintain stable and safe housing for themselves, but who do not qualify for a supported living environment. In other words, anyone who cannot maintain basic accommodation, excluding disabled persons and mental health consumers who require some sort of institutional care (both groups have some facilities that serve them specifically), is eligible for the Portland. Not surprisingly, many of the Portland's residents are IDUs. It would be inaccurate to position the Portland as "the answer" to the question of stable and safe housing for IDUs, but for IDUs who find it a good fit, the Portland has made substantive improvements in their quality of life.

One of its unique features is that service providers offer satellite services to the residents of the Portland. Needle exchange, nurses and doctors, haircuts, and counseling are some of these services. Farah thinks that more facilities like the Portland are desperately needed in Vancouver:

The Portland Housing Society have a very, very clear policy, it seems, with their residents. If you're creating a disturbance and you're hurting somebody, or hurting yourself, they are going to call the police 'cause that's the police's job. The police are going to come and remove you and that's that. Well, when you do that in another hotel and if you're disruptive and you break something and you carry on like a lunatic you're going to be taken out and you're going to be served a eviction notice, right?

At the Portland what they did...my client, he trashed his room. He was very sad and he was very angry and he trashed the room and he trashed this and he went and yelled at that person, [and since] he was putting people at risk, they removed him. While he was gone sitting in a city cell

they cleaned his room. When he got back he had fruit in a bowl and bananas and oranges. That's harm reduction.

They are going to protect his housing until the point where he says, I don't want to live here any more and then they'll let him go. But until then, they will keep him as safe as they can, people around him as safe as they can and they will do anything they can to make sure that, in so far as their role is in this person's life, they are going to protect him and their housing. That's fundamental. That's good work.

## Legal Matters

The questionnaire contained five questions related to legal matters, including several that reflect proposed policy shifts. Nearly all participants (89 percent) support legal, monitored injection venues for IDUs to inject drugs more safely. Sixty-four percent disagree with the continued criminalization of heroin and cocaine. So some change in Canada's drug laws seems to have support—what is unclear is, whether some drugs be *legalized* (no longer against the law), or *decriminalized* (a modicum of individual use is tolerated, but users can be prosecuted under some circumstances). Don believes that:

If we were to legalize it we would get rid of the black market. If you get rid of the black market you get rid of the criminal element. If you provide it, people aren't going to steal to get it. It's a domino effect. You can take the money you're using on prosecuting and use it for treatment issues. For law enforcement, go chase the murderers, not somebody who's got a needle hanging out of their veins.

#### Janet sees the more than a domino effect:

People use drugs to feel better or to forget or to cope and then we turn them into criminals because of it, when all their trying to do is cope, so we add on a few more things to cope with and tell them that they are crap, which they already knew from the beginning.

Yet, 42 percent agreed that police should continue to prioritize the arrest and prosecution of drug dealers, though another 28 percent were unsure and 27 percent disagreed (3

percent did not answer). This is somewhat curious, since it is common knowledge that many addicts sell at least small quantities of drugs to maintain their own access to them. Dilemmas like these, arising out of a shift in approaches to addiction from a criminal to a health model while inhibiting the illegal channels through which most injectable drugs are distributed, were expressed by many of these workers. So on two of these three questions—regarding safe injecting venues and moving the problem of cocaine and heroin addiction further out of the criminal justice domain—substantial support does exist. However, only 47 percent agree with government dispensed drugs for registered addicts; most respondents either disagreed (25 percent) or were unsure (28 percent). As indicated in Table 8.1, social service workers are twice as likely to support some form of government distribution for some drugs. But even among those quite familiar with the ravages of injection drug use, no clear consensus has emerged on some of the legal implications of new approaches to IDU treatment. Loretta agrees:

[I'm] dealing with people like I said that don't want to be addicts and it's that entrenchment of having to be involved in the street and crime to get the shit [viz. drugs].

Table 8.1: Views of Social Context of IDUs: Social Service & Health Care Workers

Probably / Definitely True	Social Service %	Health %	p‡
Poverty is the problem, injection drug use is a symptom	68.8	50.0	.16
Unstable housing/homelessness is the result; injection drug use is the cause	25.0	30.0	.72
Being high makes it difficult for IDUs to remember prevention techniques	43.8	75.0	.16
IDUs do not get enough emotional support from family or friends	68.8	90.0	.11
IDUs use drugs to avoid painful memories of physical, sexual &/or emotional at	81.3	90.0	.30
Racism has much to do with the number of Aboriginal persons who are IDUs	25.0	10.0	.40
There are already enough venues for needle exchange in Vancouver	12.5	10.0	.63
If there were better mental health Service available there would be less IDUs	62.5	65.0	.72
Despair or Hopelessnessa lack of motivation to avoid HIVis why most IDUs			
don't protect themselves from infection	50.0	55.0	.79

One other result of note with regards to the law was in response to the question as to whether the government should "quarantine HIV-positive IDUs who still share rigs." Though 92 percent disagreed with this position, 8 percent do believe that HIV-infected IDUs who do not refrain from sharing injecting equipment should be quarantined. One participant added, "Clients who are mentally unstable (with) HIV disease, street workers, sore infested clients, etc-all with HIV disease who cannot make safe plans for themselves or others must be quarantined as done with noncompliant tuberculosis (TB) clients." It should be noted that, even in its drug-resistant forms, tuberculosis has a terminus of treatment. When non-compliant persons with TB are detained for treatment, there is the likelihood of their eventual cure, allowing for their reintroduction to society; there are no comparable treatments for HIV infection. Since 1998 the knowing exposure of another person to HIV through anal or vaginal intercourse—without disclosure of being HIV positive, or without taking appropriate precautions such as using a condom—has been considered a physical assault (Supreme Court of Canada, 1998); one cannot, however, presume the act of sharing drug injecting equipment would fall within this same standard. According to the majority decision:

Where fraud is in issue, the impugned act is considered a non-consensual application of force if the Crown proves beyond a reasonable doubt that the accused acted dishonestly in a manner designed to induce the complainant to submit to a specific activity, and that absent the dishonesty, the complainant would not have submitted to the particular activity. The dishonesty of the submission-inducing act would be assessed based on the objective standard of the reasonable person. [Supreme Court of Canada, 1998, p. 6, emphasis added].

What is unclear is the extent to which an IDU's decision-making abilities, particularly one who is drug-sick and in severe withdrawal, would approximate "the

objective standard" referred to by the Court. To date, this interpretation of criminal law has only been applied to situations where HIV exposure occurred during sexual relations; but the tensions between society's interests and the rights of society's individuals is evident in this issue.

#### Abstinence and Harm Reduction

Eighty-six percent of the respondents saw their role as often or always one of helping IDUs reduce the potential harm around injecting drugs, rather than promoting abstinence. But any interest from IDUs for abstinence-based services (including but not limited to detox, residential treatment, and supportive living) are greatly impeded by a dearth of services. Virtually all respondents—94 percent—agree that abstinence can only work with more detox and treatment facilities being made available. Interestingly, non-addicts unanimously support this idea, while only 83 percent of addicts do (see Table 8.2). Perhaps those who disagree achieved abstinence before services of any sort were available, and thus don't see this as an absolute truth; regardless, the support for more detox and treatment beds is strong. Unsurprisingly, 83 percent often or always find that when they "refer clients to detox or treatment, but there's a severe lack of services." For these workers, the appropriateness of abstinence-based versus harm reduction approaches is moot: effectively abstinence-based services are not available when IDUs seek them.

Table 8.2: Views About The Social Context of IDUs: Addicts & Non-Addicts

probably/definitely true	Addict %	non-Addict %	p‡
Poverty is the problem, injection drug use is a symptom	41.7	66.7	.28
Unstable housing/homelessness is the result; injection drug use is the cause	41.7	20.8	.42
Being high makes it difficult for IDUs to remember prevention techniques	50.0	66.7	.51
IDUs do not get enough emotional support from family or friends	91.7	75.0	.23
IDUs use drugs to avoid painful memories of physical, sexual &/or emotional abu	83.3	87.5	.60
Racism has much to do with the number of Aboriginal persons who are IDUs	500	75.0	.23
There are already enough venues for needle exchange in Vancouver	8.3	12.5	.92
If there were better mental health services available there would be less IDUs	66.7	62.5	.20
Despair or Hopelessnessa lack of motivation to avoid HIVis why most IDUs			
don't protect themselves from infection	66.7	45.8	.65

### Methadone: Abstinence or Harm Reduction?

The importance of methadone in HIV prevention for IDUs was unanticipated.

Only the policy section of the questionnaire directly addressed methadone treatment for IDUs. "Methadone on demand" was supported somewhat by the participants, but ranked only 8th out of 10 proposals made. Five of 36 questionnaire respondents added additional comments on aspects of methadone therapy for IDUs addicted to heroin. Their concerns—from treatment access, access to methadone once it's prescribed (methadone distribution is highly controlled in BC), and fees charged for methadone (either by pharmacies or private methadone clinics licensed by the Ministry of Health)—demonstrated that methadone was a significantly contested issue regarding its role in treatment for heroin addiction. These comments led to the integration of methadone's role in treatment in to the subsequent interviews. All 16 interview

respondents expressed concerns about methadone therapy, making it an important emergent theme.

Methadone's role in treating heroin addiction is largely predicated on methadone's role in placating the addict's physical cravings for heroin, while not intoxicating the addict. Acquisition and dosage of methadone are monitored by medical professionals rather than black market sources. Also, since methadone is prescribed (for a fee, but much less expensive than equivalent prices of street heroin), dispensed professionally, and drunk rather than injected, it mitigates worries about IDU overdosing, drug-financing crime (i.e. robbery), and greatly reduces risk of HIV and hepatitis C transmission. Some methadone users (usually longer-term) are able to attend school, care for their families or work while on therapy.

Participation in Methadone Maintenance Therapy (MMT) was initially instigated as part of a long-term approach to achieving abstinence for heroin addicts. MMT is designed to help heroin addicts avoid the immediate and intense withdrawal experienced when an addict quits "cold turkey." Participants in MMT are expected to spend months or years on varying doses of methadone, based on their histories with heroin use (period of using, amount used daily prior to commencing MMT, and to what extent injection was the mode of delivery), with a gradual tapering off until MMT can end. Participation in MMT is coordinated by a physician, and sometimes includes required counselling; some clinics provide a limited number of counselling sessions, others none at all. And while most of MMT's proponents speak of methadone in terms of months or years, from this study it is clear too that some people have remained on MMT for *decades*. From the participants there is both support and concern about MMT, in terms of administering

treatment, and its role in both harm reduction and abstinence-based approaches to injection drug use. In Foucauldian terms, different knowledges—a knowledge regime (government policy) and local knowledges (social service and health workers) began to emerge from the data. These knowledges often represent competing perspectives about MMT, its value in treating addiction, and how MMT is delivered to clients.

MMT, though under the jurisdiction of the Federal government (methadone is an opiate, and thus a controlled substance), has been franchised to the College of Physicians and Surgeons of BC (CPSBC) for province-wide administration. Since physicians are the gatekeepers of access to MMT, and their professional society administers the program, the perspectives in policy matters are biased towards a behaviourist understanding of addiction. There are many instances in which the guidelines published by CPSBC are vague.

The following section details how one private MMT clinic operates; where appropriate, excerpts from the CPSBC <u>Policy Manual</u> (1999) are included. The integration of the reality of clinic operation and the policies created to direct MMT administration in BC shows significant inconsistencies between stated policy and regular practice. In addition, workers who are directly involved in MMT, and those whose clients access MMT (but do not administer any aspect of MMT themselves), have opinions about methadone based on their own practice—and their clients experiences with MMT. Their accounts, where relevant, are also included.

### The Methadone Clinic

One of my participants (whom, for this section, we'll call Pat) works in a private methadone clinic. I must admit, my presumptions about the private clinics were not

affirming; I saw them as a way for business people to profit on the misery of others. And while my visit to one clinic hasn't dissuaded me from believing that some clinic operators do priorize revenue over IDU care, this was not the case at the clinic I visited. While heroin addicts can access heroin through public health clinics, the waiting lists for public programs are often quite long. Private clinics charge a user fee (currently \$60 per month), in exchange for "one on one counselling and any sort of support and referral that clients may need," to coordinate care for heroin addicts considering MMT. Currently, several hundred clients are under the care of this clinic.

Clinics (both public and private) act as a point of contact between the College and those for whom MMT might be of benefit. Each clinic operates within definite rules regarding who is eligible, how MMT is initiated, the means by which methadone itself is acquired, and criteria for evaluating users' demonstrated commitment to MMT, usually through toxicological urine screens for substance use. Any change in an individual's therapy is vetted through the College, though determinations about individual client dosage are made by the prescribing physician.

For many IDUs, clinics of any sort are stark representations of mainstream society, something which few feel a part of. In acknowledgement of this, the clinic I visited has taken a different tack, to assuage their client's discomfort with visiting a clinical setting. Part of my interview with Pat went:

Pat: Most people, clinics or offices you go into or clients go into, people behind the counter are sort of suits and we're not that way. We're able to converse with them over the counter and B.S. with them and things like that and treat them like a normal person. It's not so much a clinical setting or an institutional setting. I think that is to our advantage in that I think that's one of the reasons why we sort of are the biggest in terms of numbers.

Interviewer: Do you mean because of your reputation with...

Pat: Because of our reputation amongst the clients themselves. People talk and we don't advertise or anything like that and we get almost every one of our patients through word of mouth. I think the impression, from what I gather talking to our clients is that we're relaxed, we're pretty cool about and we're pretty tolerant about where they're coming from and like we won't turn people away if they smell bad or they're just off the streets...

By changing the reception area, this clinic's operators have made an effort to create an environment geared toward the users' comfort, not merely the functionality of the clinic space. I asked Pat to describe the intake process for someone wanting to get on to MMT:

Interviewer: So let's say I come in and I'm off the street and I say I want to get on methadone. I'm just fed up. What process do I go through.

Pat: The way we do it is we take a urine sample, then we give an appointment for a doctor at the next available time. Usually, like say if you were to come in today to leave your urine sample, I have a doctor in tomorrow so we would wait, you'd leave your urine sample and then we'd give you an appointment time for tomorrow, we would have a preliminary urine result by the time you see the doctor tomorrow. As long as the urine result is positive for opiates then you've passed that first step and can see the doctor. The doctor will then do a medical assessment to see if you're appropriate for methadone treatment. If the doctor decides that you are appropriate, he or she will fax an application form to the College of Physicians and they will let us know whether we can start prescribing methadone to you. So the whole process takes from two to three working days.

Interviewer: From the time...

Pat:...from the time they step through the door to the time they get their first methadone prescription.

IDUs whose urinalysis confirms any use of opiates (heroin, codeine, morphine, opium) are able to consult with a physician, usually the next day. MMT is not appropriate for cocaine or speed addiction. Once opiate use is verified, the client and physician discuss their drug habits and history; addicts who use relatively small amounts of heroin—nascent heroin addicts—are rarely put on MMT. In other words, if minimum dosage of methadone (30ml per day, taken orally) is higher than their daily intake of

heroin, it makes more sense to try and detox them directly from heroin than to switch them to methadone. Few who come to Pat's clinic are ruled ineligible, but many are polyaddicted to heroin, cocaine, and perhaps other substances. In the last year he recalls only two potential clients whose level of opiate use was below the College-set standard; everyone was eligible for MMT. At this stage, the initial consultation with a physician occurs:

Interviewer: Okay I'm accepted, I'm put on a 'script, do you start with a standard base dosage for everyone how do you dose them?

Pat: Based on liver function tests that are done as size and weight of the individual, the amount of heroin that they're using...

Interviewer: Estimation of their habit size.

Pat: Yeah that sort of stuff goes into it. With the college now there's, they're reluctant to start people on higher doses even if their habit are enormous so the general thinking is to start them at a fairly low dose which is about 30 or 40ml per day and then they can up it up every couple of days to get them, like if their, if they have a massive habit and you can see the track marks everywhere and what not, 30ml is not going to work. We know that, the doctor knows that but it's a safety issue so they will titrate it up fairly quickly, so someone can go from 30 up to 80ml in a week based on incremental increase.

Interviewer: From my understanding, and average isn't the best word, but a common working dose for a lot of addicts is between 80 and 100. Is that right?

Pat: Yeah.

Interviewer: When you get above 100ml you're dealing with other issues like side affects from the meds...

Pat: That's pretty accurate. One of the things that the College of Physicians has issued to the doctors is what they call the golden rules. The golden rules are trying not to go past 80ml if you can, unless it's justified [and] everybody has to be ingesting the methadone daily in the pharmacy; [there are] other sorts of doctor things that they have to abide, but those are the two big things. Extenuating circumstances for when they don't have access to the pharmacy every day, like their working or

their ill or whatnot, but generally speaking 80ml or less and on a daily basis.

From Pat's description, both providing an adequate dosage of methadone to treat different users' daily heroin habit, and making sure no one's dosage is raised too quickly, are important considerations. If done as described here, addicts should experience a minimum of withdrawal-like side effects during this transitional phase. Done poorly, the addict will suffer immensely. But in a very real sense, the MMT prescribing physician becomes a dealer of sorts (in conjunction with the pharmacist who actually dispenses the methadone). However well (or badly) MMT is managed, the physician and pharmacist now hold an incredible amount of power over their clients.

Once an appropriate dosage is found, the program truly becomes one of maintenance. MMT is designed to stabilize the user's life by eliminating the need to seek drugs, and by satisfying the physical addiction while not giving users the same "high" that heroin does. On MMT, users use methadone rather than heroin, don't inject, don't get drug sick, and don't have to constantly source their drugs. Once this stability is achieved—and maintained for a sustained period—other strategies are addressable, such as education and work, or eventually pursuing total abstinence. But there is no "honour system" in MMT.

Interviewer: I'm now on the program and you've adjusted my dosage, what is my involvement with the clinic after that?

Pat: Weekly doctors visits. Once someone is stable and that is not using any other substances other than methadone...

Interviewer: So urine completely clean except for methadone.

Pat: Urine is completely clean except for methadone, then they can maybe come in every two weeks or every three weeks or every four weeks to see the doctor. In between that they can come in to see their counselor if they want and they will be called in for random urine sampling between prescriptions or between doctors visits.

Once enrolled in MMT, the user must submit to regular urine screens for substance use. Any opiate use is considered non-compliance, and can lead to removal from MMT. With other substances, the standards of what is "dirty" (i.e. what non-opiate substances should be treated as non-compliance) varies from clinic to clinic. According to CPSBC defines a positive urine test as the "presence of unacceptable drugs and/or unexplained absence of methadone" (CPSBC, 1999, p. 2). Deciding factors are often the prescribing physician's and clinic management's philosophy about the role of MMT in treating addiction:

Interviewer: Now what happens if someone's sample comes back dirty for something besides heroin?

Pat: The doctors are actually pretty liberal about dirty samples. It's sort of under, I guess, harm reduction. They are fairly liberal, I mean there has to be some consequences to someone constantly using cocaine or something like that. There is going to be consequences and that may be a withdrawal prescription because you decided that you don't want to use, stop using so there is no point on you being on methadone anymore, withdraw them.

But that's not as common now simply because everybody's using cocaine. If you throw them off methadone what are they going to do? They are going to use heroin and cocaine. They are sort of caught. What do they do? If they are only going to use maybe once or twice a week then they improve their life situation somewhat.

Interviewer: And reduce their risk for things like Hep C and HIV.

Pat: And [reduce] their risk. so that's how doctors are, our doctors anyway, I'm not sure about other [doctors at other clinics]...but our doctors are fairly liberal about that. They may increase the urine sampling or make them go, come in weekly to see the doctor or even twice weekly if the doctor is in twice a week. Things like that to make their lives a little more inconvenient but generally speaking...

Interviewer: To try to persuade them to...

Pat: Yeah,

Interviewer: What about things like alcohol and THC [i.e. marijuana]?

Pat: Alcohol, alcohol...doctors will occasionally test for it. It doesn't come as a standard test. Unless someone comes in here totally inebriated they probably won't test for it. That is something that isn't as important when it comes to the treatment here. THC was a routine test on the drug screen but it's now been taken off. The only test that we routinely test for are amphetamine [speed], cocaine, opiates and methadone, so just the four. Saves a bit of money for the taxpayers as well.

At Pat's clinic, the perceived role of methadone is as a form of harm reduction, though many of his clients hope to eventually get off all drugs, including methadone (about 10 percent of his clients have in the last several years). But the clinic's approach to methadone's specific ability to treat opiate addiction usually means focusing on opiate use during MMT as evidence of compliance, rather than all forms of substance use. Btu again, CPSBC policy is different:

Urine specimens should be screened for methadone and its metabolites, commonly abused drugs, and any other drugs known to be abused in the community. (1999, p. 2)

In effect, Pat's clinic is choosing an interpretation of the guidelines that doesn't strictly adhere to these rules. Here the interpretation lends itself to a local understanding of the lives of their IDU clients. But what happens to IDUs seeking MMT at clinics where the rules are enforced as written? The clinic's response should be, "Positive drug screening results should lead to the adjustment of the treatment plan," presumably an increase of methadone when a client's cravings for opiates are not being met. "Repeated positive urine tests require mandatory review or treatment and/or consideration of withdrawal of methadone" (p. 2). But these guidelines only explicate how to increase methadone dosage; they neglect to mention that MMT clients must be weaned off methadone, or they will experience severe withdrawal.

Unlike methadone clinics in other jurisdictions (most notably the US, as described by Bourgois (2000)), in BC they only prescribe methadone; clients must then take their prescription to a pharmacy. As in the case of syringes, pharmacies are encouraged to distribute methadone but are not compelled to do so; as a result, most pharmacies in BC do not fill methadone prescriptions. Pat doesn't think that access to pharmacies that fill methadone prescripts is much of a problem:

Interviewer: ...once they get the script here they go to a pharmacy to fill it. How many pharmacies fill methadone to your knowledge? How easy is it to get filled?

Pat: It's fairly easy.

Interviewer: In Vancouver probably...

Pat: ...in Vancouver it's easy. We've got a whole list of pharmacies for the Province of BC and it's about 20 pages long.

Interviewer: Really?

Pat: ...so even little communities have, like some small town like Chemanis on [Vancouver Island] has two pharmacies that dispense methadone. There's even one on Gabriola Island, places like that will have at least one pharmacy that does it. There's probably slimmer pickings the further north you go but it's actually fairly accessible, surprisingly.

Another concern is the cost. Participation in a private methadone clinic costs \$60—over 10 percent of a person on welfare's monthly cheque. And methadone itself costs about \$.20 per ml, meaning daily dosages cost between \$6 and \$20 per day.

Several other participants in the study told of clients who could not access MMT due to these costs. Pat has a different story:

Pat: People on social assistance don't pay for their medications, so it's free.

Interviewer: So for a lot of your clients probably it's free.

Pat: Yeah I would say about 75%...but these people aren't rich. Fortunately social assistance will reimburse \$41 of the \$60 [clinic] fee so they're out of pocket \$19 a month, which is, when you look at it that way it's not a lot of money but still...

Other study participants claimed that methadone clinic fees had to come out of their clients' social assistance cheque. This inconsistency is attributable to the difference between what Pat does, and what many of the other workers in this study do for their jobs. Pat only deals with the operations and issues around MMT, while his counselors may address broader issues with the clients during counseling,

Pat's job is to administer the clinic. As such, his familiarity with social assistance is focused on what's available in relation to private clinical drug treatment programs.

For the rest of the sample, how MMT is accessed and financed is one of many issues with which they are expected to be familiar. It makes sense that a methadone "specialist" would be more cognizant of how to maximize financial support from welfare. In fact, shouldn't welfare be offering the information regarding this support to their IDU clients (or their advocates) when appropriate?

### Surveillance

An integral part of MMT is surveillance of the IDUs. This primarily takes two forms: urinalysis for substance use and structured distribution of methadone itself, known as the "carries" system. Urine is checked regularly for signs of opiate use, and any number of substances, though testing for alcohol and marijuana is less common. Initially, clients on MMT are given daily carries, requiring them to go the pharmacy every morning to get that day's dosage. From Pat's description, it is clear that each of these aspects of MMT is designed to measure the effectiveness of the dosage of a client, and to

ensure adherence to therapy. Inherent in this system is the client's physical dependence on methadone (to avoid heroin-like withdrawal), and an incredible amount of power over the clients by their methadone-prescribing doctors. Nearly all of the study participants see methadone as an appropriate treatment for some IDUs, their experiences also demonstrated how methadone works as a system of surveillance of addicts. In this system, the potential for coercion is great. CPSBC guidelines also recommend that "collection of urine samples on a more frequent basis than they are tested has economic advantages and can be a deterrent to illicit drug use. Not knowing which urine sample will be tested may serve as a deterrent" (1999, p. 2). In other words, collect urine more often than required, and MMT clients will respond to the perceived increase in surveillance by adhering to the "no drugs" ideal.

## Dirty and Clean Urine

Urinalysis of substance use is an economical and rapid way of seeing to what extent MMT therapy is assuaging heroin cravings, and to evaluate a client's commitment to therapy. If an IDU on 60 ml daily dosage of methadone is still showing opiates use in their urine test (if it is "dirty"), perhaps the dosage is inadequate. Alternately, it could an indicator of a lack of willingness of the client to stop using heroin. Singular urinalysis results are no longer used to make these sorts of subjective decisions; test results over a period of time are compared to dosage changes and the client's current situation, to determine how best to proceed with treatment. So, if a client still tests dirty for opiates, but their levels are going down, incremental dosage adjustments and counseling are usually the response. Janet describes how things work in methadone programs that her clients have used:

Their urines are not clean they might have, they might have to see the doctor more often. He might, obviously they are still using so why are they still using? Is the methadone not holding you? Do you need a higher dose? Or what chaos is happening in your life? Did you work...you know...investigation.

Conversely, when someone on MMT's urine shows no *methadone*, they are presumed to be selling their methadone; this is not tolerated for long, and usually results in removal from the methadone component of the treatment program (some programs will encourage such clients to continue with counseling). "Not taking it," according to Janet, "that's going to lose you your carries pretty fast, if they're negative for methadone. You are not going to get carries because you should have some methadone in you somewhere."

How urinalyses that are dirty for non-opiates (usually cocaine or speed, though testing for things like marijuana and alcohol are sometimes still done) are handled seems to be quite inconsistent. Use of other substances does not result automatically in removal from the program, but physicians may decide that a client is "shifting" their addiction to another substance. This is a dilemma, since being on MMT can result in clients stopping injecting drugs altogether (smoking or snorting other drugs), a dramatic decrease in risk for HIV infection. Yet other harms related to drug use, such as overdose, remain. From the respondents in this study, it seems the reduction of harm from ceasing needle use is reason enough to keep clients on MMT. Pete explains his understanding work:

If you can show that their life is better and they are seeing you and accessing you for care but they are still using heroin and all of those thing then that's starting to be enough for the College of Physicians and Surgeons to say it's okay to be on methadone. The next step is okay, let's provide you some incentives for the group that is not using heroin, or even if they are, and you do want to stop, let's give you some incentives, so four clean urines or four clear urines in a row means that you get to carry your [methadone more liberally].

A dirty test for opiates, particularly after several clean ones, does not automatically result in any sort of punitive action. According to Pete:

It might mean a prolapse or a prelapse or whatever, it doesn't necessarily mean a relapse depending on what else is happening in their life. Urine should not be connected to whether you have a house or not, it's more about them and where their goals are, where they're setting their goals.

Given what most of the workers in this study say, having a house makes adherence to any addiction treatment program—including MMT—more feasible.

#### Carries

When an appropriate dosage is found for a client and they become consistent adherers to their MMT, physicians can offer less frequent carries, every two or three days, or once a week. But this is a matter decided by the prescribing physician; depending on the relationship between the clients and their physician (is it their family doctor, a health clinic doctor, or a methadone clinic doctor?), some MMT clients are put on daily carries for *years*. Loretta finds that her IDUs clients who have tried MMT have done much better with their own family doctors than any other approach:

To hook up on methadone, the best route to go is to get it through your doctor, not have to be involved in the clinic. Through your doctor then you are immediately referred, [it] doesn't cost you anything...if you have a doctor. Any of the clinics on the downtown Eastside now will not accept anymore people on their waitlist to see GPs to get on methadone, if that is their only issue. If they have other issues as well, and methadone comes up then it's a possibility.

For downtown East side IDUs who "merely" want medical help with their addiction to heroin, access to a family doctor is difficult. Ironically, the CPSBC claims that "patients seeking Methadone maintenance treatment for narcotic dependence will be assessed by the Methadone prescriber of their choice" (1999, p. 2; emphasis added). In reality, IDUs

have little choice in how to access MMT; for most IDUs, the quickest access to MMT is via private methadone clinic, like Pat's.

Suzanne, the only active IDU interviewed, had stopped MMT the week before I interviewed her, *after ten years*:

Well I was on, I just quit. In fact I was kind of sick right now, believe me it's hard not to ask for \$10 bucks, let me tell you right now. I am honestly that sick. It was my last prescription last week and I got off because the system is disgusting, degrading and shameful. Not only that it's using a synthetic narcotic that very few people truly prefer. It's just...it's a continuation of degradation of being a user. It does not re-enter you into society, at least not until you quit methadone and go straight. It's a system designed to imprison users.

After many years on MMT, Suzanne has decided that the price paid in terms of her own dignity, was not worth the benefits of the therapy. Janet, though she's never been an addict herself, has concerns about MMT for her clients. "I think it's a worse drug than heroin," she believes. "It's harder to get off. It's easier to get off heroin than it is to get off methadone. But for reducing chaos in lives, it's the drug of choice." In her view, MMT has significant flaws. Her suggestion, legalize heroin.

Kate has her own concerns about MMT:

I have had a number of clients on methadone and nobody really pays attention to what other drugs they're doing. I think it's really great when you've got a person who maybe, for lack of a better word, high functioning, maybe like a functioning addict who has a job and somehow and I'm making probably value judgments but none the less it's taped, who is somewhat responsible like that was their addiction. They wanted to stop, they're getting on methadone, they're still functioning, they're not doing a whole bunch of other drugs, they are living their life.

But a lot of the [clients] that we work with, they take the methadone but then they're still doing other street drugs, they're still taking prescription drugs, there's nobody there ensuring that really they're just doing the methadone like they're suppose to be. They are really using it as another drug. As a form of a drug that's easier to get then the drugs that they were getting before.

It would be unfair to paint a wholly unflattering picture of MMT. Several participants did recount stories of clients whose lives have been improved by methadone, though none spoke of any clients who had been weaned off methadone and "gone straight," as Suzanne describes it. No one offered stories of clients going on MMT, eventually getting off methadone, and becoming a part of mainstream society. MMT was usually described in terms of its potential to help achieve abstinence, but effectively used as a means of harm reduction.

### Power and Its Abuses

The authority of the prescribing physician (and the College of Physicians and Surgeons) over MMT clients is daunting. Some workers think that physicians don't always put their clients' best interests ahead of their own agenda. One counselor believes that, "I don't think it's watched closely enough. I think there's some doctors who make a hell of a lot of money because they've got a good patient load of methadone people."

Linking the proffering of MMT to heroin addicts to physician revenues is a strong allegation. Meg finds the requirement of *any* fees related to MMT to be quite paradoxical:

It is so bizarre and if they don't pay they get cut back. Now who does that sound like? That sounds like your local dealer to me. I just think that that is just appalling.

Other participants spoke of concerns about using continued access to MMT to manipulate their clients with regards to other health related questions. From Suzanne's experience,

Oh there is various forms of punishment, and it depends on your doctor and how you get along with your doctor and their bias etc. but usually the first time [your urine is dirty] you get a warning, your second or third time you get put on, if you're not already on daily [carries], you're put back on daily then your threatened with random piss tests. I know a poor fellow who could barely walk, had to go twice a day to get his methadone. But they're seeing him twice a day. So they have ways of punishing you. There is also in many clinics there's counselling. [If] you don't go [to counseling] you're up shit creek.

Should MMT clients be required to participate in counselling? If so, how does this system make a value judgment that accepts a certain amount of non-opiate substance use during MMT, but asserts greater control over clients' bodies when they decline counseling?

Caitlin found her clients' methadone physicians were prone to leveraging certain "choices" in care, with their patients' methadone prescriptions:

There were providers in the downtown East side that we felt that were being coercive in their prescribing practices with women. Women would come to us and say, in the course of doing outreach with women, they would identify like, 'my doc's a total asshole. He's, he told me I need to move out of the neighbourhood or he's cutting me off methadone.' You know, those kinds of concerns would be identified, and then in our little network we would strategize among the workers about how to take that forward beyond the individual women.

Loretta's clients have had the same experience:

The amount of control, I've heard horror stories from women around doctors using, using it as a control thing, whether the woman may have other health issues going on the doctor will say 'I'm cutting you off methadone unless you get in here and get tested for this and that and this.' Personally it like that's too much control if methadone is used a money.

For Caitlin, Loretta, and their colleagues to bring these allegation forward in any official forum means putting their clients at risk. Instead, they have strategized about how to bring the larger issues of power and coercion up with methadone-prescribing physicians in the neighbourhood. Had they intervened with the individual women's physicians, their clients could have lost their access to MMT, the equivalent of quitting

heroin "cold turkey." Many would also need to find a new doctor, a rarified commodity in the downtown East side. The imbalance of power is striking.

Tino thinks the entire system of carries needs to be rethought. He sees too many hoops for IDUs to jump through, in order to get access to MMT:

I think there's the whole process, the dispensing thing is a big chaotic and messy, people having to cross town to go to a pharmacy to get their daily dispensing of methadone, that's, how do people do that who don't have a penny to their names, are on welfare that don't have a bus pass, whatever. So that needs fixing, and still I've tried to get folks into methadone clinics, [only to be told] 'well we're only taking drop ins and the best option for you is to come show up on Monday morning at 9:00 and you wait with everybody else to see if there's a cancellation.' It doesn't work. It doesn't work.

From Tino's experience, the material barriers (distance, transportation, money) to MMT make it difficult for IDUs to access methadone.

But some workers are finding ways for methadone to work *based on their clients'* needs rather than requiring clients to adapt to the current delivery system. Farah tries to do the following for all her clients:

I try very, very hard to put back some of the dignity in their lives. The first thing I do with a client who comes in who's got methadone, and I ask them of course, but what I hope and they all do, allow me, I switch them over to a pharmacy that I know will deliver and I have the medication delivered to them instead of them getting up and going sick out to a pharmacy where they're antsy, where they don't behave in a way that their proud of after because their waiting. I know and the methadone doctors will say to me 'Farah, for the first two months I want this person coming in.' I agree with that. I fully agree with that, but when I've got a client who's been on methadone 5 years plus, that's enough.

So now they get it delivered every morning. They can relax until that happens, and [I] make sure it's before eight, I think that's very, very important, and they have their medication, they can lie down again for a little bit, they get up their feeling good. That's the way you start a day. I get up out of bed, I feel good. I cannot imagine getting up every morning with my stomach upset, sweating, feeling sick, no way. It's horrible.

Of course, Farah's clients need to be established MMT patients who are considered "adherent" under the "carries" system. But, Farah's success in making MMT work better for her clients who are on methadone gives hope for continued improvement to methadone distribution systems in Vancouver.

# Competing Knowledges Regarding Methadone

These accounts delineate three distinct knowledges: that which represents the institutional interests of Health Canada and the College of Physicians and Surgeons, health workers, and social service workers. Policy clearly frames MMT as an abstinencebased approach to treating opiate addiction, only to be proffered when other treatment options (detox and residential treatment) have failed. MMT clients are to be abstinent from all substance use, particularly once an appropriate dosage of methadone has been determined. The over-arching goal of MMT is to disengage the client from all aspects of their drug using lifestyle (including criminality, intoxication, and unemployability), eventually to be weaned off methadone. Once fully abstinent, clients should be able to participate actively in society. Though cursory attention is given to harm reduction benefits of MMT, the goal of therapy is clearly abstinence, and MMT clients who transgress this principle can be denied therapy. This positioning of MMT as an abstinence-based approach to addiction treatment, with total abstinence from all substance use, is the cornerstone of society's knowledge regime regarding methadone: used properly, it changes drug addicts to productive members of society.

Yet health workers directly involved in MMT (prescribing physicians, nursing and administrative staff in clinics), don't agree. They consistently employ MMT as a means of harm reduction. Many of their clients continue to use other drugs, ranging from

alcohol and marijuana to injecting cocaine and speed. Pat, Pete and Janet all accept that few of their MMT clients will achieve abstinence from anything except opiates. They value the lowered risks of overdose and disease transmission (particularly HIV and hepatitis C) achieved by eliminating one of the injectable drugs, heroin. Very few of their clients ever achieve long-term abstinence from drugs other than heroin. For these health workers, MMT is harm reduction in liquid form; they value MMT because of its potential to mitigate ancillary harms related to heroin addiction. They do not view methadone as a means to achieve total abstinence. Their position, a local, transgressive knowledge in relation to the knowledge regime's view of methadone, stands as refutation of official MMT policy.

Social service workers also view MMT as a harm reduction strategy, rather than an abstinence-based approach. But they view the mechanisms by which MMT is administered—the very nature of the system set up by Health Canada and the College of Physicians and Surgeons of BC—as inequitable and frequently exploitative. Despite the policies in place, there is no equitable access to MMT in Vancouver; few primary care physicians are sufficiently credentialed to prescribe methadone, and those who are rarely take on new patients. IDUs wanting to access MMT can usually only do so via public clinics (which are also over-subscribed), or private, fee-based methadone clinics. Thus, there is no genuine "choice" available to IDUs seeking MMT. Once MMT is accessed, the power dynamics between the prescribing physicians and the clients are wholly imbalanced. The physician has now taken the place of the local drug dealer. Those who cannot pay are taken off treatment; those who don't adhere to their individual physician's idea of adherence to the treatment (somewhere between total abstinence and abstinence

from heroin) also are subject to removal. IDUs have reported physicians who use continued access to methadone as a means of coercion regarding unrelated matters. Alternately, the surveillance system of urinalysis can be increased, priorizing quantitative adherence to therapy goals (viz. Urine test results) over qualitative changes in lifestyle for the IDU. And these forms of power are enforced inconsistently between different physicians. For these workers, a transgressive local knowledge frames MMT as a potential means to reduce harm related to heroin addiction, but whose system of administration is ripe with potential for abuse. They view the inconsistencies of surveillance and administration as very problematic.

While some workers (like Farah) have found ways to give their MMT clients a greater level of dignity (by having methadone delivered to the client's home each morning), they are a lucky few. Most IDUs on MMT must navigate treacherous waters between policy and individual physician's perspectives. In areas outside Vancouver, these challenges loom even larger. Consider how IDUs in smaller towns manage, when there might be only pharmacy that dispenses methadone, and only one MMT-credentialed physicians—what alternatives do they have, if they curry the disfavour of those given so much power over them? The guidelines which govern MMT in BC (and Canada) must be adapted. A more nuanced articulation of the means by which MMT can be proffered—with different approaches available to IDUs with different using patterns—needs to be incorporated into policy. Without this, prescribing physicians who use MMT access to manipulate or abuse their still-using clients, can claim adherence to College guidelines.

### Access to Services

If the commonly held belief of these workers is that there are not nearly enough detox and treatment beds for those willing to pursue abstinence, why is there a continued discourse in our public sphere about "abstinence versus harm reduction"? In reality, there is no alternative to harm reduction available to most IDUs in Vancouver, since there are virtually no in-patient services available to addicts, be they IDUs or not. Since IDUs characteristically have difficulty maintaining stable housing, their need for inpatient programs is particularly stark. This makes the local knowledge that an advocacy approach is more appropriate (among many workers, as delineated in Chapter Seven), quite logical: if all that is consistently available for your IDU clients are stop-gap, shortterm harm reduction techniques, what other approach is tenable? These two local knowledges—that abstinence-based treatment is not accessible, and that without abstinence as a *genuine* choice for their clients makes harm reduction the only reasonable strategy—confound the alleged tension between harm reduction and abstinence. And the continued positioning by medical officials of MMT as an abstinence-based approach, is yet more evidence that the knowledge regime perpetuates a discourse of choice and competition between these two paradigms, while reality shows only one genuine option for the vast majority of IDUs in Vancouver: harm reduction.

Currently in Vancouver, there are less than fifty detox beds, and approximately 200 residential treatment beds, to serve *all persons* with substance abuse problems (not only IDUs). On average, a client "graduates" from detox after 7-10 days. Estimating conservatively, that would allow for 53 clients per bed per year, serving a total of about 2,500 clients in a given year. Similarly, with a minimum 28 days in residential treatment programs (some are for as long as 90 days), this would allow for 13 clients per bed per

year: a total of 2,600 residential treatment places. These are the current capacities in Vancouver, for *all* addicts, not just IDUs. Few of these facilities allow for methadone therapy to be administered concurrently with their programs; fewer still allow persons taking medications for mental illness to participate. Vancouver's estimated active IDU population is between 6,000 and 10,000 people (Strathdee et al., 1997a, p. F59).

We can assume there are many more non-injecting addicts (drug addicts or alcoholics or multiply addicted) who are seeking access to these same services. We also know that recidivism is high for those who try to achieve abstinence the first time, making these numbers even more disturbing. There is simply no way our current abstinence-based treatment system can serve even a minority of the IDUs in Vancouver—presuming they would be willing to give abstinence a try. Janet expressed her frustration with trying to help her clients:

What needs to be done I've always said is you have to throw as much at it as possible. Not just methadone. Absolutely methadone, you have to throw as many different things at the problem as possible because for each person something might work, might make the difference to get them over to the next stage and maybe going over the next stage they'll still fall back but you just have to try everything because it's such a big problem.

The abstinence versus harm reduction dichotomy is specious. Injection drug users cannot be blamed for not pursuing abstinence when no services are available to help them do so.

#### Summary

The workers in this study support the notion that persons with mental illness,
Aboriginal persons, and women IDUs experience particular vulnerabilities to HIV.

Current services for addiction tend not to embrace a holistic view of their clients: the

lived experiences of IDUs, when related to their marginalization for these other reasons, are often ignored or silenced. In the case of mental illness, both the mental health and addiction service systems tend to exclude dual diagnosis clients from care. These workers see margins within the already marginalized community of IDUs.

Many participants also saw a dichotomous harm reduction *or* abstinence approach as being dangerously exclusionary. In most instances, a continuum of services, articulated for individual client needs, was preferred. Unfortunately, with the exception of MMT, services available related to injection drug addiction are based on the either/or equation.

The final chapter of this dissertation integrates the findings of the previous chapters, and their broad implications. Strategies for shifts in policy regarding IDUs in Vancouver are discussed, as are the limitations of this study, areas for future research, and a brief reflection on my experience conducting this research.

### Chapter Nine: Conclusions

This study demonstrates that, while the prevention techniques proffered by those involved in HIV prevention programmes do not vary dramatically, the values and beliefs between sub-groups of workers do, representing several distinct sets of local knowledges. Government-delivered health programme workers and their NGO social service counterparts, had different lived experiences with substance use, access to education, and street involvement. In policy matters, women and men, Aboriginal and non-Aboriginal persons, those who have attained baccalaureate degrees versus those who have not, and addict and non-addict sub-samples each held significantly different views on matters of policy. In particular, methadone maintenance therapy (MMT) in its proscribed form is substantially different in its actual use—a gap that ostensibly is more flexible and forgiving for IDUs, but also leaves some IDUs more vulnerable to exploitation or abuse. Clearly these workers also view themselves as "successful" at this work, but their successes are often based on what their IDU clients see as success. These workers operate within a complex web of power relations, and use local knowledges both in terms of practice and beliefs.

Workers who participated in this study have a variety of ways of working. Some individuals use both harm reduction and abstinence-based approaches within their own practice, based on each client's needs. As the community of IDUs is not homogenous, neither is the community of practitioners. But one area in which there is near unanimity is in the belief that the current system of delivering services to IDUs, with respect to harm reduction and especially abstinence, is woefully inadequate. It offers, as one participant noted, "band aid" solutions.

It is evident that the knowledge regime of medicine, the dominant voice in policy discussions regarding IDUs and HIV, offers a deceptive discourse about "choices" for IDU HIV prevention endeavours. Among the practitioners in this study, local knowledges that challenge this binarization assert a reality that the more common choice available is between harm reduction, or no prevention strategy at all.

### Power

Concern about how power operates in these practices is a critical issue. Any tack chosen by educated, somewhat mainstream workers, to some extent disempowers IDUs; society has demarcated a disempowered role for IDUs, a dynamic towards which workers and IDUs are drawn. By working for agencies that provide services—and which are, in turn, funded by donors who have their own agendas—the question of power is unavoidable. Foucault's theory of power doesn't accept a strictly hierarchical notion of power, where it is asserted only through overt channels and pathways; power is often diffused or subverted (1990a, pp.11-12). These workers have been subverting much of the knowledge held by medicine about injection drug use, in terms of their practices regarding methadone distribution and how MMT is administered as a harm reduction strategy. But, in choosing to work for government run or government-funded (in the case of social service workers) agencies, they are ostensibly placed in a hierarchy. Yet their practices and beliefs betray a willingness to transgress this regime of knowledge, when it doesn't undermine the power and authority of their organization, and when it's in their clients' interests to do so. That some of them are concerned about the distinct yet complementary strategies of advocacy and mentorship reflects an acute awareness of the critical role power has in their work, and in the lives of their clients.

This understanding of power dynamics to some extent confounds Foucault's notion of power. He views power as most often being diffused through systems and institutions, a view that presumes all people are affiliated with some sort of institution or entity when questions of power are relevant. But for IDUs, their level of disempowerment supercedes Foucault's ideals—at least for these workers. The degree to which IDUs are excluded from mainstream society, not merely marginalized, means their resistance to power is often about being acknowledged by institutions (like health care). Seeking services from institutions cannot be construed as membership or substantive affiliation with them. Likewise, since IDUs are not "inside" the health care system, their interests in relevant programs and strategies are often misrepresented. This probably accounts for the differences of perspective between the educators in this study who have been IDUs and those who have not.

But sometimes, when working with extremely marginalized clients (like most IDUs), it is necessary to de-emphasize an absolutist notion of empowerment, and focus instead on the identification and implementation of strategies which serve to engender clients' welfare, particularly in the longer term. If in doing this workers acknowledge the local pertinent knowledges, they can help their clients out of the mire, and facilitate their accessing their own power. Injection drug users need not be subjugated to IDU workers; but it must be acknowledged that most are already subjugated to their addictions. For many addicts, the ability to make informed, self-caring decisions about themselves has either never been in place, or is long past. An idealistic commitment to solely advocacy-or mentor-based service provision would be misplaced. Workers on either end of the spectrum, who always follow their own or their clients' own agendas, are equally remiss.

The more responsible tack seems to be an interweaving of both ideals—presuming there exists a network of services that will give IDUs genuine options to consider. Currently, there is not.

Thus, there are three areas where substantive change could occur. First, we should acknowledge for many IDUs, becoming more empowered is not possible without some *directed*, *outside* intervention. The client-centered approach now holding sway in the downtown East side has worked better than previous strategies where IDUs were considered objects rather than people; still, the successes found are not enough. The realities of IDU HIV prevention practice, as articulated by the participants in this study, should be acknowledged. Second, a dramatic increase in addiction services—harm reduction and abstinence-based, with a continuum of care between these two paradigms—seems needed. Finally, until we examine why some members of society are particularly vulnerable to becoming IDUs, and make concerted efforts to help them before they become IDUs, today's challenges will be perpetuated. For society, this means expenses from crime and increased health care costs; for IDUs and their families, this means heartbreak and suffering.

Foucault's articulation of power/knowledge relations, particularly his descriptions of how resistance is often local in nature and obscured from the purview of society atlarge, does describe how several of the study participants practice HIV prevention education with their IDU clients. Workers articulated needing to adapt their practices to their IDU clients' circumstances, even when "the rules" said otherwise. Janet's distributing syringes on-demand is a good example of how a worker's local knowledge supercedes the regime of truth's articulation of how practice "should" be. In her

description—and those of other health workers—such acts of resistance are leading to changes in policy (from an "even-exchange" NEP program towards "on-demand"), in other words, changes to the knowledge regime. Yet workers like Tino support broader harm reduction initiatives like safe injection venues, but do not allow their clients to inject drugs in their presence—in such instances, his understanding of the knowledge regime's power to exclude them from working with IDUs, makes the risks of that particular form of resistance too great. But he—and many of his health and social service colleagues—support safe injection venues. Policy, and the knowledge regime, have yet to catch up with some practitioners see as the logical next step.

# Understanding the Realities of IDU HIV Prevention Practice

As a broad group of practitioners, the workers who participated in this study certainly share a unique understanding of the challenges in helping IDUs avoid HIV.

Truly, HIV prevention targeting IDUs foments a local, "subjugated knowledge"

(Foucault, 1980b, p. 82). Within sub-groups of practitioners—women, gays, Aboriginals, IDUs and non-injecting addicts—even more localized knowledges can be uncovered.

Between and among these workers, these knowledges interact with the knowledge-regime of medicine, in endeavouring to integrate these knowledges into their practices, workers are routinely required to make decisions based on competing sets of knowledge.

Social service workers seem more comfortable with articulating a willingness to priorize the local, when the dissonance found between the competing knowledges requires them to do so. Similarly, practitioners who work with clients whose oppression is not limited to their being IDUs (again, women, gays, Aboriginals, other people of colour, particularly when the workers themselves are a member of one of these communities) delineated

specifics of practice for the unique needs of individual clients. Among such IDU workers, there is ample evidence of broad mistrust of any institutional responses that will put IDU needs ahead of populist, mainstream ones. Overall, these workers are using aspects of the knowledge regime (needles for exchange, an understanding of the pathology of HIV) to complement the local knowledges used in their context-specific efforts to reduce HIV among IDUs.

These workers, in a very real sense, have very few options for their injection drug user (IDU) clients. In terms of harm reduction, needle exchange services in Vancouver are comprehensive, and continue to improve as NEPs expand into more street-level intervention (i.e. the handing out of needles in various areas around the downtown East side, especially its alleys and doorways, and other places IDUs congregate to fix their drugs after purchase). Thus, these workers' reliance on NEPs as a primary means of harm reduction is understandable. Similarly, workers frequently encourage their clients to use condoms (and about half actually hand out condoms) during anal or vaginal intercourse. It is also clear that IDUs—like most people—make value judgments with regards to the nature of their relationship with different sexual partners, which mitigate their decisions about condom use. From these workers' experience, street-involved women IDUs often work in the sex trade, and are expected to eschew condoms with their regular male partners (who are often their pimps), as "proof" of their trustworthiness. IDUs with lovers, girlfriends, boyfriends or life partners probably use condoms as frequently as do non-IDUs in similar relationships—not very. So these workers continue to include sexual harm reduction in their prevention messages.

Despite having one of the busiest, most comprehensive needle exchange programs in the world, IDUs in Vancouver have accounted for almost half the new infections of HIV in British Columbia since 1995 (BCCDC, 2000). Needle exchange, outreach work, crisis counselling and other services delivered to Vancouver's IDU community have made a difference, but the harsh reality is that Vancouver still offers a limited range of harm reduction options for IDUs. As Strathdee et al. challenged in 1996, "Needle exchange is not enough" (p. F59). Fischer, Rehm and Blitz-Miller (2000) compared harm reduction strategies in Canada with those in the Netherlands, Germany and Switzerland, and found that the rates of drug overdose deaths and HIV infection among IDUs correlate with the lack of comprehensive harm reduction strategies. Each of the European countries offers needle exchange, safe injection venues, and prescribed opiates—and has largely eliminated overdoses and HIV infection. A commentary from Kerr and Palepu in the Canadian Medical Association Journal (2001), and a recent Health Canada report (Elliot, 2002), both called for the establishment of safe injecting venues in Vancouver and other cities in Canada with significant IDU populations. Based on the experiences of Germany, the Netherlands, Switzerland and Australia, such venues have been viewed as effective in reducing injection-related harm, and increased participation in MMT and abstinence-based treatment programs by program attenders. But such innovative (at least for Canada) harm reduction strategies—safe injection venues or government-dispensed heroin (and other injectable drugs)—still face barriers, legally, politically, and in terms of consensus among those who work with IDUs. The College of Physicians and Surgeons of BC has a resolution from 1977, which states "it shall be deemed to be unprofessional or, in appropriate circumstances, infamous conduct for a member of the College to

administer, prescribe, give, sell or furnish a narcotic, or a medication containing a narcotic, except for recognized and acceptable reasons; AND THAT drug addiction shall not qualify as an 'acceptable medical reason'" (1999, p. 4). This constitutes a significant barrier to any proposal for the distribution of prescribed heroin to IDUs in BC.

Harm reduction isn't the only way for IDUs to avoid HIV. Other approaches do exist regarding HIV prevention, most notably the pursuit of abstinence. But it is clearly evident that the *dearth* of abstinence-based programs in Vancouver (detox centres and residential treatment centres) makes the likelihood of any significant number of IDUs achieving abstinence very small: indeed remote. And these workers also made it clear that the short-term, 10 day detox and 28 day residential treatment program (which are most commonly employed by abstinence-based addiction services in BC) are woefully inadequate for treating IDUs, whose lives are most often characterized by chaos. Once treatment has ended, IDUs must wholly uproot their lives to have any chance of remaining abstinent. Unable to negotiate through such a process on their own, many IDUs return to injecting.

Significantly longer-term facilities, a sort of managed care where former IDUs can get emotional support and acquire life skills (and attend school or job training, if appropriate), are needed. Based on these workers' accounts, most of their IDU clients have survived brutal physical, sexual and emotional abuse, which began before they became IDUs. To come to terms with their histories sustained, long-term therapy also needs to be made accessible, to give IDUs pursuing abstinence any chance of integrating into society.

A substantial number of Vancouver's IDUs lives were traumatic and marginal, before picking up a needle for the first time: they have little reason to value life without being high—or, more accurately—numb. If we are to provide services that make abstinence an option for them, what can society offer them after treatment ends? Also, there will always be some IDUs who suffer mental illness; taking away the addiction means still living with a chronic condition whose challenges are often exacerbated by the inability of health care and society to give them the dignity they deserve. Other IDUs will not be able to attain levels of education or training that will allow them to earn a living wage in our decreasingly resource-based economy; the loss of jobs related to challenges to BC's resource sector have already had a deleterious impact on the downtown East side, according to Suzanne. Such jobs helped many IDUs in Vancouver achieve some sort of stability:

There [was] an economic loss here big time. Resource work, this is what most people worked at, resource or physical labour. Those jobs are really gone. They're gone. That was the backbone of this community. That was the economy.

For former IDUs who are unable to adequately participate in education and training in the current economy, the proposition of living on welfare benefits of less than \$600 per month cannot be appealing.

Methadone maintenance therapy (MMT) fits somewhat between the abstinence and harm reduction approaches, as it's currently used in Vancouver. The workers see MMT as one means to stop heroin use for some IDUs; MMT can also connect IDUs to counseling, so they address their broader substance abuse and life issues. But, it is only since MMT in British Columbia has de-prioritized total abstinence that this approach has been tenable; initially MMT was designed to help heroin addicts avoid severe

withdrawal, but not become intoxicated. By slowly weaning them off methadone, they became drug-free. While an approach that doesn't expect IDUs to linearly move from injecting heroin to methadone to abstinence (in any particular time frame, or without some missteps along the way), why are so few of these workers' clients getting off methadone without returning to injection drug use?

# Beyond the Abstinence/Harm Reduction Dichotomy

We need to overhaul the current system of services for IDUs, incorporating the ideas presented in this study. These workers' experiences suggest the need for a broader spectrum of services than is currently available to IDUs in Vancouver.

- 1. An immediate—and dramatic—increase in abstinence-based services. The pathetic number of detox and treatment beds in Vancouver is an embarrassment to our city, province and country. Hundreds of more beds are needed—now!
- 2. "Damp" programs, which value the pursuit of abstinence, but do not rigidly enforced strict adherence. Such programs should have guidelines that reward efforts towards abstinence, but do not exclude participants who use drugs or alcohol *at all* from access to treatment. Most programs are currently geared toward the pursuit of total abstinence ("dry"), or short-term harm reduction while still actively using substances ("wet").
- 3. A mediated level of abstinence-based programs that differentiates between alcohol and marijuana, and other drugs. Most participants agreed—and demonstrated from their own experiences with substance use—that all substance use should not be equated. Often, helping their clients to get off injectable drugs seemed more likely to occur if their clients' use of alcohol and marijuana were

treated as a separate—and less immediately critical—issue. Hence, methadone programs generally don't test for evidence of use of either of these substances. Treatment options that look at stopping use of "hard" drugs as an important step in harm reduction—a sort of transitional kind of abstinence—should be built into any broad substance abuse treatment strategies. From my own work with substance abusers, those IDUs who did eventually "get clean" almost always stopped using hard drugs, but continued to use marijuana and alcohol for some time. The "all or nothing" abstinence approach seems an unrealistic (and cruel) yardstick by which to measure success for IDUs.

- 4. The establishment of long-term (up to two years, as suggested by several participants), residential, supportive living centres for IDUs who pursue abstinence. Instead of sending newly abstinent IDUs back to SROs or the streets, facilitate their transition towards a more stable life. Key components of these facilities should include regular meal services ("when you're really hungry and you want food and you have to figure out where you're going to get food from and you don't have anywhere to live, probably somewhere way down the line is HIV"), high standards for maintenance and hygiene (in private and common areas), counseling, and flexible life skills building programs. Residents could be taught how to do basic housework and maintenance, organize, plan and cook meals, and how to improve their self-advocacy skills. If appropriate, job skills and educational upgrading could also be offered on-site
- 5. Recognition of different types of IDUs. Suzanne's experiences seem atypical to the clients described by many of the workers in this study. And in many ways she

is. Suzanne and some of her peers—older IDUs—seem to have better access to stable housing (usually outside the downtown East side) and are not street-entrenched. The more "hard core" users that make up the respondents' case loads live moment-to-moment and injection-to-injection; the two groups (and many IDUs that do not fit either of these brief descriptions) have little in common except their being drug injectors—and society's viewing them as unimportant or a nuisance. Rather than debate whether programs should or should not target "Suzanne-like" users, the reality is that different sorts of IDUs exist. As Meg wrote in her questionnaire,

I believe that people use drugs for a reason, their own unique, individual reason. At some point, for some reason, a person gets to the place where they have had enough (hopefully). If there are services available at that time/moment-great. They may avail themselves of the service for long-term or short-term. That experience can be a turning point. If no services are available they may go back 'out' until they are at a 'place' where they are ready to try again.

But every time an IDU cannot access such services, there is a risk they will overdose or become ill with HIV, hepatitis C, or some other infection. And it will be too late.

- 6. Programs that target youth. The workers believed their younger clients who have injected for a shorter period of time had better chances of stopping. If ingénue IDUs can be offered treatment earlier, in specific services targeting them, many of the workers believe these younger IDUs will be able to stop injecting.
- 7. Re-examination of the ways in which methadone maintenance therapy (MMT) can be used to treat injection drug use. These workers clearly see MMT's role as having shifted from a strictly abstinence-based approach to one of harm reduction. For different clients, varying notions of "adherence" to MMT can apply. For

example, an IDU might start with a "no opiates" goal until he reaches a stable dosage of methadone. His adherence could then be adapted to be measured in terms of all hard drugs. Eventually, he may choose to pursue total abstinence, and possibly end MMT. Conversely, another IDU might want to cease all hard drugs (not merely opiates). She might not pursue abstinence from alcohol, but could still be weaned off MMT. A more articulated and transparent MMT system would allow IDUs to negotiate the terms of their own treatment, and let them set measurable, realistic goals.

8. Establishment of an IDU "ombudsman" for Vancouver/British Columbia. This would allow IDUs and those working with IDUs, a mechanism for voicing their experiences and concerns. Currently some care providers appear to be abusing their power over their clients, particularly with regards to MMT. And the field of IDU HIV prevention is so political, committed and dutiful workers cannot speak of their concerns without risking their jobs or their organization's funding.

Until a much broader spectrum of IDU services are available, the rate of IDU HIV infections in Vancouver will continue to be high. And for the IDUs themselves, their lives will continue to be extremely marginal. Particularly for street-entrenched users, violence, fear and depression—with origins both in past and current circumstances—will continue, unless we as a society do better.

For most there are no services to offer, which is also probably why so few workers in this study spoke of many of their clients achieving abstinence. And if the spectrum of choices to proffer is so marginal, workers will be reticent to inculcate any

sort of hope in their clients. They know on some level the system of services can't adequately serve most IDUs. Without confidence in the services available—often even their own—many are priorizing client-driven advocacy, which often focuses on short-term issues.

When working with IDUs in Vancouver, the most viable strategies to lower risk for HIV infection are via (limited in scope) harm reduction services (more limited in availability), abstinence-based services, or MMT for an indefinite period of time. Few would argue that these services are comprehensive enough to stem HIV infection among IDUs in the short (or long) term. These limited services have reduced the number of new infections, but hundreds of infections still are occurring annually. And in a broader sense, we as a society are not offering substantive changes to IDUs, to make a life without injection drugs plausible or appealing.

## Social Determinants

Based on the responses of the participants in this study, the final area where substantive change could occur is also the most daunting. In their eyes, very few of their IDU clients began injecting drugs by happenstance. Most became IDUs due to lives characterized by poverty and abuse, long before they ever injected drugs. A disproportionate number of their IDU clients are Aboriginal; several workers in this study see Vancouver's injection drug use challenge as a legacy of Canadian colonialism towards indigenous peoples. And nearly all of their clients—Aboriginal and not—experienced brutal childhoods.

Until we address the extremes of social and economic inequities in Canada—and particularly their manifestations as child poverty and violence—we will continue to

produce "IDUs-in-training." Researchers like Strathdee et al. (1997a) and Harvey et al. (1998) have come to similar conclusions: if we as a society pay attention to the social determinants that predict injection drug use, we can prevent today's potential IDUs from becoming tomorrow's IDUs. People inject drugs due to a sense of disenfranchisement and the concomitant pain, both physical and emotional. Ameliorate their standards of living, and less will choose oblivion. According to these workers, the best strategy for treating injection drug users is to preclude any need to inject drugs—or to abuse any substances.

This is not to imply that those who have already become IDUs should not be a priority too. For today's IDUs, whom we as society have failed by not addressing these injustices, we cannot undo the damage of their childhoods. But we can, as Loretta suggests, "make new offers": a dramatically improved standard of living is a great incentive to practice self-care. For street entrenched users, many of whom who have no familiarity with the idea of caring for one's self, only such an extrinsic motivation will have any meaning. This could explain clients "hoping they get HIV," to access better housing, food and dignity. According to these workers for those who are already injectors, while offering a full spectrum of treatment options is important, we need to improve the standard of living for all IDUs. Central to this end would be a dramatic increase in stable and affordable housing—regardless of whether one is pursuing treatment or not. Farah's clients' experiences with the Portland and Kate's clients' experiences with Bridge Housing demonstrate how accessing stable housing makes being an IDU less demoralizing, which then allows IDUs to more seriously consider ways to reduce their risks for HIV exposure. These are not the ideas of an isolated group of

activists—workers in this study from a variety of settings including most of the physicians and nurses who participated, endorsed the importance of stable housing for actively using IDUs.

The work in which these women and men are engaged is challenging. Yet those who participated in the interviews all expressed a genuine joy in their work, despite sometimes daunting challenges. Many are at times dubious of the stances made by politicians regarding their IDU clients; still, their hope for change in their clients' lives rings through. And, while many of the stories told were harrowing, even horrible, I got a strong sense that their work is purposeful and successful. So I share their hope.

### Limitations

The findings of this study describe the experience of a relatively small sample of practitioners. Their approaches are certainly more complex than could be articulated in a 12 page questionnaire or during a 90 minute interview. But this study gives us important insights into what these workers face, and how they navigate between different sets of interests. This study is not generalizable, but many of the experiences of these workers should resonate with other HIV prevention workers whose clients include IDUs. In particular, this could include Western, social democratic contexts where healthcare is an explicit entitlement and there are codified principles of social justice as part of the rule of law (including the rest of Canada, the European Union, Australia, New Zealand, and the non-EU Scandinavian countries, but excluding the United States). Workers there can evaluate the degree of transferability for themselves.

For those concerned with health entitlement issues for other marginalized communities—queers, indigenous peoples, women, persons of colour—there are also

lessons to be learned from this study. These workers' experiences and perspectives (nor my analysis of them) offer comprehensive, foolproof solutions to the complex web of social injustice and addiction that has rendered IDUs so vulnerable to HIV. But we can now at least begin to understand the challenges these workers face in serving their IDU clients. So too can we see areas where gaps are in existing services.

# Implications for Adult Education

As adult educators, these workers endeavour to help their IDU clients avoid HIV infection. From their experiences, achieving this goal is more complex than proffering prevention techniques and tools; their accounts articulate the challenges of doing adult education of any sort with adults who are extremely marginalized. Most (69%) see their work as part of their personal commitment to social justice—an ideal lionized in much adult education literature.

For those interested in how adult educators from disparate professional and personal backgrounds approach helping marginalized men and women access their entitlements as human beings—primarily wellness, but also dignity. Adult educators whose practices also include a strong social justice orientation—in adult basic education, social movements, and health and social services—should find resonance in these workers' perspectives, even when the some of the particulars of practice differ. Adult educators doing social justice work are too often isolated by the particulars of their practices to network and share experiences with others doing this work in other contexts. Their stories of navigating between the local knowledges and the knowledge regime demonstrate that resistance, reasoned and purposeful resistance, is often a critical

component of working with those excluded from mainstream society. Such stories need to be shared more often; adult education literature is a natural place to share them.

For adult educators concerned with other areas of practice—particularly work in social justice—these workers' accounts give testament to how different practitioners can accomplish different things, based on how they are situated in terms of context. Both social service and health educators found appropriate strategies to find success; that there were substantive differences between sub-groups of practitioners validates the idea that adult education practices that are extra-institutional differ from their formal counterparts. In its examination of an adult education practice not bounded by a shared institutional setting (not a classroom), this study demonstrates that a broader range of adult education practitioners' experiences can be studied. As such fields of practice gain their rightful place in adult education literature, the gap between our discipline's espoused commitment to social justice and the complex practices in which this commitment is pursued, will be better understood.

### Future Research

Our understanding of the pragmatic and theoretical concerns of doing HIV prevention work with injection drug users is still sparse. Similar studies in other contexts where IDU targeted HIV prevention work is being carried out are needed. The study of HIV prevention as a field of adult education practice offers an inherent interdisciplinarity that encourages deep and broad inquiry into complex issues like this. We need also encourage researchers in other disciplines—particularly epidemiology, to continue to broaden the areas of inquiry for their studies. In particular, emergent qualitative inquiries need to be brought into the centre of epidemiological research, not merely as an add-on

component of much larger quantitative research plans. Quantitative and qualitative approaches both bring particular orientations, with concomitant capabilities and limitations. They should be viewed as oppositional or competing paradigms, rather as complementary ones.

A larger study using similar questions and themes would also inform matters of practice and policy, here in Canada and internationally. The work being done by adult educators in Montréal, Amsterdam, Zurich, Sydney and other cities with large IDU communities would yield a broader data set, from which more generalizable conclusions could be drawn.

## Final Words

I began preparing to do this study several years before commencing graduate work. My many years of activism, where local experiences were devalued or ignored by researchers and policy makers, necessitated that any research project with which I was involved placed local knowledges on an equal footing with the knowledge regime. Any extent to which I have succeeded to this end is for all who read this thesis to decide. But embedded within the claims made here is a much larger one—we as a society need to put greater value on those whose work is on the margins of society. This dissertation would not have been written, did I not believe this was possible, specifically within the university-based research enterprise.

If we continue to narrowly define substance treatment programs in terms of abstinence or harm reduction, without considering the contexts in which the clients live (and to which they will presumably return), relapse is inevitable for most. A newly abstinent IDU, who successfully accesses and completes detox and residential treatment,

will still be marginal, still be likely unemployable, still be poor, but will now be wholly present for their marginalization. This is a powerful disincentive for change. If we as a society address the social inequities that lead many to become IDUs, less will do so. If we create a system where a true continuum of care exists between abstinence, methadone, and harm reduction, many IDUs will become healthier. Some will avoid HIV, hepatitis C and other lethal infections; others who become infected will be able to adhere to the demanding treatments for infection, and live happily for many years. Some IDUs will even achieve total abstinence, and find lives for themselves, which they could not have imagined previously. But with our current services, and despite the dedication of workers like those who participated in this study, most IDUs in Vancouver will be infected with hepatitis C, and over one-third will get HIV. And still these workers do what they can.

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THE UNIVERSITY OF BRITISH COLUMBIA

# Examining *Practice*,

Understanding

Experience:

**AIDS Prevention** 

& Injection Drug

**Users** 

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We're aware that your work involves many unique challenges, and would like to better understand your practice, as well as your opinions about a variety of issues related to injection drug use and AIDS.

When completing this questionnaire, please consider the following definitions, for consistency's sake:

Injection Drug User (IDU), addict, user or substance abuser: For this study we use these terms interchangeably.

Abstinence: Also described as "getting clean, abstinence is used here to mean programs which emphasizes helping IDUs to <u>stop using all mood or mind-altering substances</u>, including alcohol.

Harm reduction: Harm (or risk) reduction is used to describe HIV/AIDS prevention programs which seek to help IDUs to avoid contracting HIV/AIDS by emphasizing <u>safer using practices</u>.

Thank you for your assistance with this project!

Staff use only	# ]	DOE	BY	

## Section A: AIDS, drugs & addiction

Disagree

**Strongly** 

For each of the following statements circle the number which best represents your opinion, based on the following scale:

Not sure/no opinion

	disagree	Disagree	Not suite/no opinion	Agree	agree
	1	2		4	5
1.	Addiction is a m	nedical condition	on, not a criminal problem		
	1	2	3	4	5
2.	Injection drug u	sers (IDUs) co	uld quit using drugs if they	really want	t to
	1	2	3	4	5
3.	Heroin and coc	aine use shoul	d remain criminalized		
	1	2	3	4	5
4.	To stop the spre	ead of AIDS, w	e must quarantine HIV+ I	DUs who st	ill share needles
	1	2	3	4	5
5.	IDUs should ge	t access to leg	al, monitored injecting site	s to promot	e harm reduction
	1	2	3	4	5
6.	IDUs should be	able to get the	eir drugs dispensed to ther	n by the go	vernment
	1	2	3	4	5
7.	To get IDUS to	use less risky	ways of using, is a good s	trategy for A	AIDS prevention
	1	2	3	4	5
8.	Most IDUs don'	t want to "get o	clean"—become abstinent		
	1	2	3	4	5
9.	For abstinence	to work, detox	and treatment services m	ust be avail	able on demand
	1	2	3	4	5
10.	Arresting and p	rosecuting dru	g dealers should be a poli	ce priority	
	1	2	3	4	5

Staff use only	#	DOE I	BY

**Strongly** 

Agree

#### **Section B: Prevention Practices**

For each of the following statements circle the number which best represents your opinion, based on the following scale:

#### \*Note that the scale for this section is different

	Never 1	Rarely 2	Sometimes 3	Often 4	Always 5	Does no 0	t apply
1.	I encourage h	arm reduction	techniques (ove	er abstinence)	with my IDU o	lients	
	1	2	3		4	5	0
2.	I distribute cor	ndoms to my II	OU clients				
3.	1 I demonstrate bleach/bleach		3 syringes/needle:	s/rigs/other eq	4 uipment, usin	5 g	0
4.	1 I advise client	2 s to use condo	3 oms for vaginal s		4	5	0
	1	2	3		4	5	0
5.	When I excha basis (even ex		needles/rigs/othe	er equipment, i	t is on a "one	-to-one"	
	1	2	3		4	5	0
6.	I advise client	s to use condo	oms for anal sex				
	1	2	3		4	5	0
7.	I advise client	s to use condo	oms for oral sex				
	1	2	3		4	5	0
8.	I refer clients to	for detox or tre	atment services	s, but find a sev	vere lack of se	ervices	
	1	2	3		4	5	0
9.	I distribute syr	ringes/needles	/rigs without exc	changing them	for used one	s	
	1	2	3		4	5	0
_							
	Staff use only #	#	DOE	BY			216

### **Section C: Social Context**

For each of the following statements circle the number which best represents your opinion, based on the following scale:

#### \*Note that the scale for this section is different

	False	Probably false	Possibly true or false	Probably true	Definitely true
	1	2	3	4	5
1.	Poverty is the pr	roblem; injectio	n drug use is a sym	ptom	
	1	2	3	4	5
2.	Unstable housin	g/homelessnes	ss is the result; injec	tion drug use	is the cause
	1	2	3	4	5
3.	Being high make	es it difficult for	IDUs to remember	prevention te	chniques
	1	2	3	4	5
4.	IDUs do not get	enough emotion	onal support from far	mily or friends	3
	1	2	3	4	5
5.	IDUs use drugs abuse	to avoid painfu	I memories of physi	cal, sexual ar	nd/or emotional
	1	2	3	4	5
6.	Racism has not	hing to do with	the number of Abori	iginal persons	who are IDUs
	1	2	3	4	5
7.	There are alread	dy enough venu	ues for needle excha	ange in Vanc	ouver
	1	2	3	4	5
8.	If there were be	tter mental hea	lth services availabl	e there would	l be less IDUs
	1	2	3	4	5
9.	Despair or hope IDUs don't prote		ck of motivation to a from infection	avoid HIV/AIC	S—is why most
	· 1	2	3	4	5

## **Section D: Additional Feedback**

What did we miss? Are there any perspectives or beliefs related to AIDS, prevention, or substance use that were not covered in these questions? Are there other issues that you think are important that could help us better understand your work?  Use the space below to tell us.

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### **Section E: Policy Issues**

As an expert in IDU-related health issues, you have been asked to provide feedback to a Royal Commission on substance use. What sorts of programmes and activities would you prioritize?

Step One: Add any additional ideas in the additional space at the bottom of the list.

Step Two: Place an X next to any activities that you think should NOT be funded.

Step Three: Rank the activities, placing a "1" next the most important item, then a "2" next the second most important, etc. Include in your rankings any ideas you added to the list.

Rank	Strategy
	Detox on demand (more detox beds)
	Treatment on demand (more treatment beds)
	Free housing
	Unlimited needle exchange
	Government-distributed drugs
	Safe injection venues
	Methadone on demand
	Decriminalization of drug use
	Decriminalization of petty drug dealing
	Improved (non-addiction) mental health resources
	Other:

Staff use only	#	DOE	BY
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# Tell us about yourself.

### **Section F: Substance Use**

Place a  $\int$  in column 1 next to each item you've **EVER** tried/used

Place a  $\boldsymbol{J}$  in column 2 next to each item you've tried/used in the past 6 months

	Column 1	Column 2	
I have used:	Ever in my life	In the past 6 months	1
Alcohol			<b>,</b>
Hash/marijuana			I
Cocaine - snorted			ı
Cocaine - smoked (crack)			ļ
Cocaine - injected			
Ecstasy			
Acid/LSD			
"magic" mushrooms			
Heroin - snorted			
Heroin - smoked (chase the dragon)	0		
Heroin - injected			
Crystal meth/speed - snorted			
Crystal meth/speed - smoked			
Crystal meth/speed - injected			
Benzos (valium, tranqs, sleeping pills, ativan)			
Other (specify)			
Which of the following statement addiction, including alcoholism. Pl	lace a√next to t	·	
- rama recovered/reco	Janing addition		
☐ I have been addicted problems	I have been addicted to drugs, but now use without		
I am currently (active	ly) addicted to		
☐ I have never experier	nced addiction		
Other - please explain	n below		

DOE [

Staff use only

BY [

# Tell us about *yourself*

## **Section G: Work and Community**

1.		t are the first three digits of your all code?	6.	desci which preve	th ONE of the following best ribes the primary organization for you participate in HIV/AIDS ention activities which include tion drug users? Check one only
2.		u are not sure, in what abourhood do you live?			Detox Drop-in centre
3.	What	t is your gender Check one only			Telephone information hotline Treatment centre Ministry of Children / Families
	☐ fe	male 🛘 male 🕽 transgender MTF			Needle exchange
		nsgender FTM 🗆 Other:			Food bank
		efer not to answer			Temporary/emergency shelter Church
4.	What	t is your age: Check one only			Street youth
					Health Clinic
		Less than 19 years			Police
		20 - 24 years			Community Centre
		25-29 years			Ant-poverty organization
		30-34 years			Aboriginal organization
		35-39 years			Hospital emergency room
		40-44 years			Other:
		45-49 years			
		50 54 years	7.		th ONE of the following job titles
		55-59 years			describes your position in this
		60 years or more		orgai	nization? <b>Check one only</b>
		Not sure			
		Prefer not to answer			Outreach worker
					Case manager
5.		t is your estimate of the average			Receptionist
		unt of time <u>per month</u> you			Telephone hotline operator
		cipate in HIV/AIDS prevention			Nurse
	activities which include injection drug				Physician
	users? Check one only				Front desk/counter
					Social worker
		Less than 10 hours per month			Youth worker
		11- 20 hours per month			Supervisor
		21-30 hours per month			Executive Director
		31-40 hours per month			Research Assistant
		41-50 hours per month			Researcher
		More than 50 hours per month			Other:
		Not sure			
		Prefer not to answer			

|--|

# Tell us about yourself

## **Section G: Work and Community (continued)**

Н	Ihy have you become involved in IV/AIDS prevention activities with OUs? Check ALL that apply:	11. My HIV/AIDS prevention work is: Check one only			
	☐ I am/was street-involved☐ Know/knew someone street-involved☐ I am/was an IDU		paid voluntary (unpaid work) Both paid and voluntary		
	☐ Know/knew an IDU ☐ I am/was a non-injecting addict ☐ Know/knew a non-injecting addict		religion I was raised in was arrily: Check ALL that apply		
	☐ Commitment to social justice		Aboriginal:		
	A required part of my job		Judaism		
	Religious or spiritual commitment		Roman Catholicism		
	☐ Other:		Ukrainian, Greek, or other Orthodox United Church of Canada		
			Other Christian:		
9. T	he <b>highest level of education</b> I have		None		
	ompleted is: Check one only		Other:		
	☐ Graduate degree (masters, doctorate)☐ Some graduate study☐ 4	13. The religion I currently practice is: Check ALL that apply:			
	<ul><li>4 year university degree</li><li>Some college/university/CEGEP</li></ul>	п	Aboriginal:		
	☐ 2 year post-secondary training		Judaism		
	☐ 1 year post-secondary training		Roman Catholicism		
	☐ Some post-secondary training		Ukrainian, Greek, or other Orthodox		
	☐ High school diploma		United Church of Canada		
	☐ Some high school (grade 9-13)		Anglican/Presbyterian		
	☐ Some junior high school (grades 5-8)		Other Christian:		
	☐ Some elementary school		None		
	□ No formal education		Other:		
10. I consider my cultural identity to be: Check ALL that apply			current annual income is roximately: <b>Check one only</b>		
	☐ Canadian		Less than \$10,000 per year		
	☐ European				
	☐ African		\$20,000 - 29,999 per year		
	☐ East Indian		* <b>,</b>		
	☐ Other Asian		+ · · · , · · · · · · · · · · · · · · ·		
	Aboriginal		\$50,000 or more		
	Mixed:		Prefer not to answer		
	Other:				

Staff use only # DOL B1
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# Tell us about yourself

### **Section H: What comes next**

1.	Would you be interested in participating in a follow-up interview?  The interview will be based on themes that emerge from the					
	•	•	articipants <sup>.</sup> ill not includ	•		Your responses
	io any qui		m nor meida	ca. comm	dennanny is	, assurea
		Yes				
		No				
		Not su	ire			
	Ple	ase copy	y your partic	cipant ID	number fro	m the cover of
	thi	is questi	onnaire in th	ne space b	elow:	
			p			
			Enter Part	ticipant II	<b>D</b>	

Thank you for participating in the <u>Examining Practice</u>, <u>Understanding Experience</u>: <u>AIDS Prevention & Injection</u> <u>Drug Users</u> Study!

#### Appendix B: Letter of Invitation to Participate in Study

September 25, 2002

Dear AIDS prevention worker:

While there have been many studies of AIDS and injection drug use, to date the experiences of those helping injection drug users (IDUs) avoid contracting AIDS has not been studied. As part of my doctoral studies in Education Studies at UBC, I would greatly appreciate your sharing your knowledge and perspectives related to this important work. The purpose of the Examining Practice, Understanding Experience: AIDS Prevention and Injection Drug Users study is to examine the technical matters of AIDS prevention for IDUs, and the context in which your practice occurs. This study will shed light on your work, its challenges, and your ideas on how best to slow the spread of AIDS among Vancouver's IDU community.

As a participant you will complete a self-administered questionnaire which takes approximately 30 minutes. As each questionnaire only uses an identification number, your identity will be kept confidential; names of participants will not be used in any reports from this study. Upon receipt of a signed Consent Form (enclosed), you will receive your questionnaire some time in February/March 2001. A limited number of participants will be asked to participate in private, one-hour interviews to expand upon their answers from the questionnaire. Once the project is completed, a summary of the results will be sent to you either by mail, fax or e-mail, depending on your preference.

The following is a list of questions which will be asked of participants. Demographic questions asked include - name; gender; age; postal code (or neighbourhood of residence); hours per month in AIDS prevention work; nature of your organization's work; whether your work is paid or unpaid (volunteer); level of formal education; ethnic/cultural identity; religious background; current job title; motivation for involvement in AIDS prevention; personal experiences with licit and illicit drugs; and estimated annual income. Questions about the specifics of your practice—what strategies you include or exclude from your work—and your opinions about AIDS, drug use, and related health, social and legal issues will also be requested. Finally, you will have an opportunity to give your opinions on what priorities should be set in regards to government policies related to AIDS and injection drug use. Generous space for comments not covered by the questionnaire will also be provided.

If I have any concerns about my treatment or rights as a research subject, I may contact the Director of Research Services at the University of British Columbia, Dr. Richard Spratley, at 822-8598.

#### **Consent:**

I understand that my participation in this study is entirely voluntary and that I may refuse to participate or withdraw from the study at any time without jeopardy to my employment.

I have received a copy of thi	s consent form for my own records.
I consent to participate in thi	s study.
Subject Signature	Date
Witness Signature	Date

#### Appendix D: Participant Information Sheet



**Faculty of Education** 

2125 Main Mall

Vancouver, BC Canada V6T 1Z4

### Participant Contact information:

Name					
Organization					***************************************
Address					
City			Provi	nce	
Postal Code					
Phone		)			
Fax					
E-mail					
□ business,	OR		☐ home add	lress	

Don't forget to sign the Consent Form and mail it back with this form in the attached postage-paid envelope. Thank you!

#### Appendix E: Interview Questions

Dr. Jean Barman, Principal Investigator Department of Educational Studies Mr. John Egan, Co-Investigator/Doctoral Candidate 24 October 2000

#### **Qualitative Interview questions**

Explain to me how you became involved in AIDS prevention with injection drug users

How does your (having experienced/not having experienced) drug addiction shape your approach to this work?

How does your organization's objectives impact your work?

What sorts of strategies do you offer to IDUs to decrease the likelihood of transmitting HIV?

Who are the IDUs that you work with?

What are some of the barriers you encounter—or your see your clients encountering—to avoiding AIDS?

How do you define "success" in your work? FOLLOW-UP: How do you define "failure"?

Help me to understand why you prioritize (harm reduction/abstinence) in your prevention work.

What is missing from current strategies to fight the IDU AIDS epidemic in Vancouver?

Tell me a bit about how sexually-transmitted HIV risks are discussed in your practice?

Why do you think people become injection drug users? FOLLOW-UP: How then, can we prevent people from becoming IDUs?