

COMMUNITY BASED SERVICE PROVIDER PERSPECTIVES ON ART  
ADHERENCE AND HIV-POSTIVE INJECTION USERS ENROLLED IN  
METHADONE MAINTENANCE

by

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## **Abstract**

People living with HIV and who use injection drugs (IDUs) often face difficult life circumstances and comorbidities. Antiretroviral therapy (ART) is the only treatment available for HIV and long-term adherence is challenging. Methadone maintenance therapy (MMT) has been shown to improve health outcomes and medication adherence in IDUs living with HIV. The objective of this study was to gain an in-depth understanding of the barriers and facilitators that affect ART adherence from the perspective of service providers who work with HIV-positive IDUs. Eleven service providers were recruited from organizations in Halifax, Nova Scotia who work with people living with HIV and IDUs. They were interviewed about their perspectives on the structural and contextual facilitators and barriers that they and their clients encounter on a daily basis. Interviews were transcribed, coded, and analyzed using a grounded theory approach. Seven themes were identified: program support, resources, stigma, systemic barriers and IDU lifestyle, service availability, ART and MMT adherence, and policy. The organizations providing are generally underfunded and have limited resources. When these factors are combined with the clients' difficult life circumstances, they may not receive adequate support and therefore face worse health outcomes. This research suggests that the population of HIV-positive IDUs in Halifax needs more easily available access to services for housing, transportation, and addiction treatment.

## List of Abbreviations Used

AIDS .....	Acquired Immunodeficiency Syndrome
ART.....	Antiretroviral Therapy
ARVs.....	Antiretroviral Medications
HIV .....	Human Immunodeficiency Virus
IDU .....	Injection Drug Use
IDUs.....	Injection Drug Users
IIs .....	Integrase Inhibitors
MMT .....	Methadone Maintenance Therapy
MSM .....	Men who have Sex with Men
NEP .....	Needle Exchange Program
NNRTIs.....	Non-Nucleoside Reverse Transcriptase Inhibitors
NRTIs.....	Nucleoside/Nucleotide Reverse Transcriptase Inhibitors
PHAs.....	People Living with HIV/AIDS
PIs .....	Protease Inhibitors

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## **Chapter 1: Introduction**

### **1.1 Background**

The Human Immunodeficiency Virus (HIV) is a blood borne pathogen that directly attacks the host's immune system. Since 1985, it has affected over 69,000 Canadians (1), with 766 cases occurring in Nova Scotia to the end of 2011 (2). There is currently no cure for HIV infection but antiretroviral therapy (ART) can suppress the virus and aid the immune system to control the advancement of the infection, which if left untreated, can lead to full-blown AIDS (3). ART can be a demanding treatment regime because it often involves taking multiple oral medications daily, ideally for the rest of the individual's life. While such a regime can be arduous for any individual, it may be even more difficult for those who face additional challenges, such as injection drug use (IDU), to adhere to ART (4-7). Methadone maintenance therapy (MMT) is an opiate substitution therapy that can be used to address opiate addiction by providing people who use injection drugs (IDUs) with a safer drug to meet their body's physiological craving without causing the euphoric effects of other opioids (8). It has been shown to improve health outcomes and ART adherence in IDUs living with HIV (6, 9-13).

Injection drug using populations and people living with HIV/AIDS (PHAs) are both socially marginalized groups in their own respect (14, 15). Those who fall into both of these populations are therefore more likely to experience even further isolation, stigma, and social exclusion. This exclusion can create issues for utilizing and navigating within the healthcare system, especially if people are also coping with co-morbidities such as



mental illness or other life circumstances like unstable housing or poverty (5-7). Community-based programs and services, such as methadone clinics, needle exchanges, housing and social assistance, and specialized health clinics, are essential to providing support for both IDUs and PHAs. However, given the vulnerability of this subgroup of individuals who are living with both addiction and HIV, it is important to understand how the contextual factors associated with HIV or IDU interact with potential structural barriers within healthcare and social support systems and how that interaction impacts this population's health outcomes (16). The goal of this study was to identify structural and contextual barriers and facilitators to ART adherence based on the perspectives of community based service providers who work to support IDUs living with HIV in Halifax, Nova Scotia. For the purposes of this project, structural factors were defined as topics that had to do with how services are delivered to clients, as well as overarching policies and environmental factors like stigma. Contextual factors were defined as those affecting clients at a personal or individual level, such as being homeless or unstably housed, having limited education or employment, or any other life circumstances (16). It should be noted that although these factors are divided in this way for my research, they are in fact highly interrelated and can be difficult to separate. We were interested in service providers' perspectives because of their insight into their clients' day-to-day lives as well as the structure and function of the programs that serve IDUs and PHAs. We were particularly interested in how the delivery of services affects the clients and therefore felt that those who provided services were the best group of people to speak to that. The view of the service providers is only one of many and the perspectives of other groups, including clients or researchers, may differ and are not covered in this thesis.

## **1.2 Significance**

Compared to larger urban centres like Vancouver, Montreal, and Toronto, the number of people living with HIV in Halifax or Nova Scotia in general seems small, but among IDUs in Halifax those infected with HIV have a disproportionately high number of deaths. From its opening in 2001 until the end of 2011, Direction 180, a low threshold methadone clinic in Halifax, had 33 HIV-positive clients, 12 of whom died prematurely from related co-morbidities. These numbers are especially concerning considering that the Canadian mortality rates attributed to HIV have decreased dramatically since the introduction of ART in 1996 (17). At the end of 2013, Direction 180 had a total of 12 current clients who were HIV-positive (18). Local service providers are dedicated to lessening the contextual and structural barriers that IDUs living with HIV face, but this population continues to face worse health outcomes and death. The overarching purpose of this study was, therefore, to learn, based on service providers' perceptions and experiences, what they felt helped and hindered their ability to meet their clients' needs, and what changes to service provision they felt had the potential to improve the health outcomes of individuals living with HIV who have a history of IDU.

## **1.3 Objective**

The objective of this study was to gain a better understanding of the barriers and facilitators that service providers in Halifax, Nova Scotia encounter when working to provide services to HIV-positive IDUs, what barriers and facilitators they felt their clients encounter, and how those barriers and facilitators impact ART adherence in their clients.

These barriers and facilitators could be structural, including policies, mandates, or stigma, or contextual, including inadequate housing options, lack of education or employment, or addiction. Ultimately, our aim was to identify potential changes to service delivery that could be made to improve health outcomes for individuals living with HIV and a history of IDU.

## **Chapter 2: Literature Review**

In the following literature review I first report on the prevalence of HIV in Canada and Nova Scotia, the epidemiology of HIV, and treatment for the virus. Next, I examine injection drug use in Canada, harm reduction as it pertains to drug use and methadone maintenance treatment in particular, and the political environment that influences harm reduction and injection drug use. I then review the literature related to issues of medication adherence in injection drug users and community based programs that focus on supporting individuals living with HIV and/or injection drug addictions.

### **2.1 Etiology and Prevalence of HIV**

The Human Immunodeficiency Virus (HIV) is a blood borne retrovirus that attacks the body's immune system, which if left untreated results in Acquired Immunodeficiency Syndrome (AIDS) (19). The virus attacks and weakens the immune system by infecting CD4+ cells, an integral component of the immune system (20, 21). Since 1985 when reporting began in Canada, over 69,000 Canadians have tested positive for HIV (1). Between 1985 and 2011, 766 of those cases occurred in Nova Scotia (2). The annual incidence of infection in Nova Scotia continues to fluctuate slightly, with 16 new cases occurring in 2011, a slight increase from the previous two years. This corresponds to a rate of 1.7 per 100,000 population. The rate of HIV infection in Nova Scotia has been consistently lower than the rate in Canada as a whole, which was 7.2 per 100,000 population in 2009 (2).

Injection drug users (IDUs) are disproportionately affected by HIV, accounting for nearly one third of HIV infections outside of sub-Saharan Africa (22). In 2008, roughly 17% of new HIV infections in Canada were amongst IDUs (23). In Nova Scotia, injection drug use accounted for 15.4% of HIV exposures resulting in diagnosed infection from 2002 to 2011 (2). IDU as an exposure for HIV is much more common in women (29.4%) than men (12.5%). The leading route of transmission among men is men who have sex with men (MSM) (59.4%), and for women, heterosexual contact with an infected male partner (41.2%) (2).

Prior to 2001, IDU accounted for 5.6% of AIDS diagnoses in Nova Scotia but from 2002 to 2011 that proportion has risen to 9.4% (2). In 2009, there were 14 new cases of HIV in Nova Scotia and PEI (reported together due to small annual numbers), two of which were reported as IDU exposure (24).

In Halifax, Nova Scotia the low threshold methadone clinic, Direction 180, provides treatment and support for opioid addiction. From April 2010 to April 2011, 11 of the 171 active clients at the Direction 180 were HIV-positive. Of those 11 clients, 8 were receiving their ART medication on site (25). During that year 7 clients of the clinic died, 4 of whom were HIV-positive and died due to AIDS related conditions (25). Therefore, 2% of the HIV-negative population on methadone and 27% of the HIV-positive population on methadone died in a 12-month span.

## **2.2 Epidemiology of HIV**

The first diagnosed case of AIDS occurred in 1981 (26). The first case of AIDS in Canada occurred in 1982, and the year later was the first AIDS-related death. Since then, roughly 21,000 Canadians living with HIV or AIDS have died (26).

HIV attacks the immune system and can therefore be found in bodily fluids containing immune cells. For infection to occur, the virus must enter the bloodstream via an entry point containing mucosal membranes. The most common means of transmission are among MSM (for men only), heterosexual contact with someone at risk, and injection drug use (27). Those who inject drugs, especially if sharing needles, are at high risk for infection due to the direct blood-to-blood contact.

HIV can remain dormant and undetected in an infected individual for a long period of time (28). However, people are highly infectious immediately after transmission when the viral load spikes. This primary infection can be accompanied by flu like symptoms but can also be entirely asymptomatic. HIV itself is not fatal because the virus does not cause death directly. Rather, HIV weakens the immune system to the point that AIDS develops and the individual becomes highly susceptible to opportunistic infections that an otherwise healthy person would be able to fight off, such as tuberculosis or pneumonia. ARTs are designed to prevent those living with HIV from developing AIDS.

### **2.3 Antiretroviral Therapy**

To date, there is no cure for HIV infection or AIDS. Antiretroviral therapy (ART) is a treatment that suppresses the virus and supports the immune system (3). When taken as prescribed, ART is highly effective at keeping the viral load undetectable (29).

Adherence for ART is defined as >95% of the medication taken in the correct dosage and at the correct time (30, 31). Obviously such a high level of adherence can be challenging to maintain especially when considering that ART often involves the combination of multiple drugs to be taken multiple times daily, and is ideally a lifelong commitment once started.

There are four main types of antiretroviral medications (ARVs). They are nucleoside and nucleotide reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNRTIs), protease inhibitors (PIs), and integrase inhibitors (IIs) (32). Each one of these ARVs acts to inhibit a specific activity required for HIV to successfully infect the host cells. Modern ART involves a combination of several individual ARVs in order to best suppress viral replication (28).

Adherence to ART is crucial because once therapy is stopped or interrupted, viral replication resumes quickly (33). ART only acts to suppress the virus so people are still latently infected with the virus. Thus, when the medication is interrupted, those latent cell reservoirs can be rapidly reactivated. Discontinuation of treatment can also lead to the development of ART resistant HIV. It is not clear how many doses need to be missed

before resistance occurs but viral replication can resume quickly and with millions of viral copies made in just one day, resistance can easily develop (29).

## **2.4 Injection Drug Use of Opioids in Atlantic Canada**

In 2005, it was estimated that there were more than 80,000 regular illicit opioid users in Canada (34). Prescription opioids have become the predominant form of illicit opioid use (34). Based on the Profile of Injection Drug Use in Atlantic Canada, between 1996 and 1999 83% of clients newly admitted to an MMT program used prescription opioids, with or without heroin (35). In Atlantic Canada, dilaudid was more commonly used in New Brunswick and Nova Scotia than it was in the other two provinces (35). From 2000 to 2006, the number of people injecting prescription opioids, like oxycontin and dilaudid, continued to rise (34). This is likely because dilaudid was more readily available in Atlantic Canada and less expensive than other opioids such as heroin. Dilaudid and cocaine were the most injected drugs in Atlantic Canada in the early to mid 2000's (34). All of this information is based on an environmental scan from 2006 and a report from 2000. While this information is quite dated, no updated versions of these documents have been made.

In Atlantic Canada, IDU is more prevalent among males, but the incidence among females is rising (35). The estimated level of needle sharing amongst all IDUs in 2000 was between 25% and 50% and roughly 50% for the sharing of other injection equipment (35). The key informants from an environmental scan, who work with IDUs in eastern Canada, believed that the level of needle and equipment sharing amongst injection drug



users rose from 2000 to 2005. Needle sharing was estimated to be around 54% in 2005 (34). Additionally, in 2000, an estimated 25% of IDUs were involved in the sex trade (35). Therefore, transmission of blood borne pathogens, such as HIV, Hepatitis B, and Hepatitis C, is a significant risk among IDUs. Between 2000 and 2004, 11% of HIV-positive tests were reported as IDU exposure in Nova Scotia and Prince Edward Island (34). Again, this information is based on older data, but no new updates have been made.

## **2.5 Harm Reduction**

Harm reduction is a compilation of policies, programs, and practices that have the goal of reducing adverse health, social, and economic impacts from the use of legal and illegal drugs without necessarily reducing the actual use of drugs (36). The focus on reducing harm associated with drug use, rather than drug use itself, is a critical feature of harm reduction. There is also a focus on working with people who actively continue to use drugs (36). Harm reduction practices include a practical yet compassionate approach designed to “meet people where they are at” (37). It recognizes that many IDUs are either unwilling or unable to stop using drugs but that many of the risks and harms associated with drug use can be reduced or mitigated (36, 38). Harm reduction is based on the best evidence available and is meant to complement other programs and approaches that aim to reduce drug use itself (36). Essentially, harm reduction is designed to serve IDUs by reducing the harm and risks associated with using drugs in order to benefit not only IDUs, but also their families and society as a whole (36). Examples of harm reduction strategies include needle exchange programs (NEPs), methadone maintenance treatment (MMT) programs, and safe injection sites.

NEPs not only reduce the risk of infections such as HIV and Hepatitis C, but have also been shown that those who regularly use NEPs are less likely to engage in high risk injection practices, like needle and equipment sharing (39-42). NEPs can have a profound impact as demonstrated by the closure of the only NEPs in Victoria, British Columbia in 2008. By 2010, the rate of needle sharing in Victoria had more than doubled to 20% (43). Another study done in Vancouver, British Columbia found that syringe exchange programs were effective at reducing syringe sharing and that widespread availability of syringes was more beneficial than limited access for reducing sharing (44). NEPs are also cost effective by reducing the spread of infection such as HIV and Hepatitis C, and therefore the additional burden to the health care system associated with treatment (45). A survey of Ontario NEPs has shown that they implement evidence based best practices based on empirical data that has been shown to be effective for decreasing infection transmission (46). Without NEPs many people who use drugs do not have access to clean needles and as a result share and reuse needles, increasing the risk of the spread of infections like HIV. They are a key component of mitigating adverse effects and for harm reduction.

MMT is another form of harm reduction and has been successful in improving adherence to ART amongst IDUs (6, 9-13). Daily oral ingestion of methadone alleviates the symptoms of opiate withdrawal and reduces the euphoric effects of other opioids. Through the management of the body's physiological opioid craving, MMT has been shown to reduce drug use, mortality, viral transmissions, and injection-related risk

behaviours while improving health, social functioning, and quality of life (47-50). When an individual's physiological need for opiates is safely met, there is potential for decreased drug seeking behaviour and injection. By eliminating these activities, the risks associated with both drug seeking and IDU, such as infection, overdose, or incarceration, are thereby reduced or eliminated. In a group of HIV-positive IDUs in British Columbia, MMT was positively associated with ART adherence and protection against rebounding viral spikes (6,7).

In addition, Pettes et al. studied MMT use in 353 HIV-positive IDUs in Vancouver (47). More than half of this group was on MMT at the start and over 30% of those not on MMT started during the study period. Amongst the study's participants, MMT use was significantly associated with ART use in this population and heroin use was associated with discontinuation of MMT (47). This demonstrates the importance of retention in MMT programs as well as the need to use harm reduction approaches to support IDUs.

Ward et al. found that MMT was effective for reducing illicit drug use and preventing the transmission of infectious diseases (49). This effectiveness was diminished though at low maintenance doses (<60mg) and if clients tried to become abstinent from methadone too soon. Adherence to ART is another key component of harm reduction because it is important for those individuals who are HIV-positive and continue to use drugs to have a low viral load if needle or equipment sharing is still occurring. As a means of harm reduction, MMT is regarded as effective and favorable for IDUs, especially among those living with HIV (6, 9-13).

In Canada, there is currently one stand-alone safe injection site, Insite, which is located in the downtown east side of Vancouver, British Columbia (51). While safe injection sites remain controversial in Canadian government, research has shown that these programs can help prevent overdose and reduce the onward transmission of HIV as well as improve uptake and retention of detox, while not increasing public disorder, crime, or drug use (52, 53). Wood et al. conducted an evaluation of several factors prior to and after the opening of Insite (52). In their measure of public order, they found a decrease in IDUs injecting in public, and a decrease in the amount of publicly discarded syringes and other injection related litter. They also found that IDUs had more education on safe injection practices and a decrease in syringe sharing by HIV-positive IDUs. There was no increase in drug related crimes and an increase in IDUs seeking out detox programs. Finally, 60% of overdoses that occurred on site could be handled by the nursing staff and did not require ambulances, trips to the emergency department, or hospitalization. In a review of Insite by Marshall et al., they found that the rate of overdoses in the area of Insite decreased by 35%, and by 9.3% in the rest of the city after the safe injection facility was opened. In the area around Insite, this corresponded to a decrease in overdose related deaths from 253.8 to 165.1 deaths per 100,000 person-years (53). By preventing adverse events such as overdoses and infections that can result in hospital stays, emergency room admissions, costly healthcare needs, or death, safe injection sites are also fiscally responsible. Despite the benefits of safe injection sites such as Insite, research evidence and knowledge translation are not always sufficient to enable policy change. The opening of Insite, and its continued existence, was the result of a concentrated and intense effort involving coalitions, lobbying, organization of public opinion, and political struggle (54).

Harm reduction includes abstinence from drug use as a desirable outcome on the spectrum, but it recognizes and accepts alternative options that can reduce the occurrence of adverse events or outcomes such as drug overdose or disease transmission through needle sharing (37). It is also a primarily “bottom-up” approach that focuses on advocacy and support rather than a “top-down” approach created by policy makers. However, harm reduction programs continue to be seen as controversial and associated with varying degrees of support from the public. Despite the research, the general population may view these programs negatively and as such education, lobbying, and mobilization of public opinion are also necessary.

## **2.6 Methadone Maintenance Treatment**

As discussed briefly above, methadone is a long-acting synthetic opioid that is ingested orally in liquid form (55). It is effective for treating opioid dependence and prevents withdrawal while reducing cravings and the euphoric effect of other opioids (8). Because of its long lasting effect, it only needs to be taken once a day.

MMT is a harm reduction approach to opioid addictions. By mitigating the immediate need for opioids, high-risk practices such as needle and equipment sharing are reduced because the addiction is being managed. MMT acknowledges that there is a need for a continuum of treatment options so programs vary in their rigidity, from low to high threshold (56). High threshold programs are largely focused on abstinence from drug use on the continuum of harm reduction. This approach can be beneficial for individuals who

can manage and desire structure and regulations in their treatment. High threshold programs do not allow continued drug use and will suspend or remove clients for missing appointments or for inappropriate behaviour, such as aggression. Low threshold MMT programs “meet the client where they are at” and are more lenient about continued drug use, behavioural issues and generally require a severe situation to remove a client from the program. Because of this, Health Canada has emphasized low threshold clinics as being a useful and necessary bridge to connect IDUs to other services and more comprehensive programs (56).

The approach to methadone treatment also varies based on longevity. Some programs are long-term, based on methadone maintenance, as described above with high and low-threshold, but other programs focus on a medically supervised withdrawal where the goal is to take clients off opioids entirely (57). In methadone maintenance, clients will start the program, be stabilized over several weeks while their methadone dose is increased, and then reach a maintenance dose (58). In all programs clients have to start off with daily witnessed ingestion of methadone, but as they progress they may be able to get “carries” so that they can have several days worth of methadone and do not have to go to a clinic or pharmacy everyday (57). Patients may be tapered off of methadone, but this is difficult and must be done slowly and carefully. As the methadone dose decreases to low levels, withdrawal symptoms can arise and there is a risk of people relapsing into drug use (58).

Low threshold methadone programs may help to alleviate problems encountered by IDUs that negatively impact their quality of life by encouraging them to attend or seek

treatment sooner (59). By removing the expectation of abstinence, users may be more willing and open to receiving treatment. When Millson et al. assessed health-related quality of life in 145 opiate users starting MMT they found that clients benefit from having psychiatric services on-site or having appropriate referrals to psychiatrists or psychologists. This study also found that clients needed access to primary medical services. Clients entering low-threshold MMT tend to have poor mental and physical health (59, 60). This poor health was also associated with lack of employment, chronic health issues, and hospitalization. Physical health issues may be a result of chronic health concerns and can negatively impact a person's ability to work. Additionally, the Millson study found that 26% of clients had overnight hospital stays in the year prior to initiation of MMT. Other studies have found opiate users to delay seeking help because of fear of stigmatization from health care professionals (61, 62).

There are many factors that contribute to IDUs desire or ability to access MMT and several social determinants of health that influence the level of MMT threshold most suited to them. A variety of program options, with a focus on low threshold, as well as environments free from stigma are needed in order to encourage and promote MMT among IDUs.

## **2.7 Policy and Political Environment Related to Injection Drug Use**

The criminalization of drugs, opioids in particular, dates back to the early 1900's in Canada (63). Under the Controlled Drug and Substances Act, it is a criminal offence to possess, import, export, or traffic drugs such as heroin, cocaine, barbiturates, and

amphetamines (64). Reports have shown that the legal status of these drugs hinders the care, support, and treatment provided to HIV-positive IDUs and also negatively affects efforts to prevent the spread of HIV amongst IDUs (65, 66). The illegality of these drugs also means that they are generally purchased in underground and potentially dangerous markets, their potency and composition are unknown, and the fear of criminal penalties can prevent IDUs from accessing the services they need.

Large amounts of funding are spent on law enforcement rather than prevention and treatment services for IDUs (63). IDUs are often pushed to the margins of society making them more difficult to reach. The current political environment condemns not only drugs but also the people who use them, and in doing so nurtures an anti-drug and anti-IDUs mentality in society. The laws support the general public's beliefs and attitudes that drugs are bad and therefore the people using them are less deserving of services, help, or support. The general public, along with health care providers and IDUs, do not receive adequate or accurate information about illegal drugs (63). There needs to be better and more complete education on drug use being provided by the government. This education should be unbiased, honest, and incorporate the harm reduction approach of being informative and realistic rather than judgemental.

Treatments such as MMT and other harm reduction services deviate from the current general concept that abstinence is the only acceptable outcome. Addiction is a complicated and intricate condition (67). For some IDUs, abstinence is unrealistic or unattainable and there are few IDUs willing or able to participate in abstinence-based



treatment programs (63). In order for service providers to be able to deliver the best possible care and for IDUs to be able to access the support or services they need, the political and societal environment around drugs and IDUs will need to shift. The policies and expectations around drug use need to become more realistic for the users being affected.

## **2.8 Medication Adherence in Injection Drug Users**

Much like therapies for other chronic conditions, long-term adherence to ART can be difficult (68). The barriers to treatment adherence for HIV are similar to other chronic condition and are generally due to regimen complexity, medication side effects, and lifestyle factors (69). Even among individuals with a highly structured or routine daily life, ART adherence can become demanding due to the rigidity of the therapy and the adverse side effects (4). Adverse side effects from long-term use of ART may include anemia, rashes, insomnia, depression, diarrhea, and many other unwanted effects on organs (70). There have also been neurologic and cognitive impairment associated with HIV and ART (71). This therapy is especially challenging because ART regimes can have different requirements including specific times for dosages and dietary needs for the medication to be effective. For IDUs, there are often various determinants of health that complicate adherence such as difficult life circumstances, including homelessness, and greater likelihood of participating in high-risk practices, which can create less stability in lifestyle and daily habits (5-7, 72-74). Among HIV-positive IDUs in British Columbia, homelessness was negatively associated with ART adherence (7). Homelessness challenges adherence because it can leave people with little structure or privacy, poor

access to food and water, and no fixed location to store their medications. In addition to the strict nature of the treatment, ART differs from other medication regimes in that if adherence is not met, the drugs may lose their effectiveness and those taking the medication can become resistant (29). When this occurs a new combination of ART must be started, which is often more difficult in terms of rigidity and side effects, and may be less effective (28). As there are a limited number of ARVs available, options for treatment can eventually be exhausted if a client defaults too often or becomes resistant to effective strains.

According to a review of 20 studies conducted by Ammassari et al., the contextual factors most likely to impede ART adherence are psychiatric co-morbidities, continued substance use, inadequate social support, and homelessness (4). There were also structural barriers including limited access to care (4). Of these factors, those that were consistently associated with poorer adherence were patient-reported symptoms, lack of social or family support, and complexity of the regime. The most common reasons for missing or skipping medication were complexity of the regime, fear of adverse side effects, and forgetting. They also found that former IDUs had similar rates of ART adherence to those without a history of drug use (4).

The impact of homelessness on ART adherence among IDUs living with HIV was examined by McNeil et al. who assessed doctors' and nurses' experiences providing care to homeless populations in six Canadian cities (75). Through interviews conducted with the participants, it was found that when first encountering patients or clients from the

homeless population, care providers often felt unprepared to address the social determinants of health that ultimately shaped the health of their clients. The providers did recognize the need to center care on the context of homelessness. This largely came through experiential learning by engaging with homeless people, evaluating treatments, and modifying practice based on those observations and experiences. This study clearly identifies the need for homelessness and other sociodemographic characteristics to be taken into consideration when working with this population because they create unique barriers to accessing support and services. The health care providers in this study improved service provision to IDUs facing homelessness by learning from their own experiences (75).

In addition to the individual level factors discussed above, it is well documented that structural barriers present a significant problem to accessing services for PHAs, especially when those individuals are also using injection drugs or experiencing other difficult life circumstances (16, 19, 76-78). A review of law and policy data found that 78 of 106 countries reported the existence of laws and policies that created obstacles for the key populations accessing HIV services, which included IDUs, MSM, and sex workers (79). For IDUs, the policies mostly created barriers for accessing harm reduction services. They suggested that a supportive legal environment has great potential to positively impact IDUs' access to care and therefore overall outcomes. Another review stated that reducing structural and system level barriers is needed to improve retention of patients receiving primary care for HIV (80). These structural factors included unstable housing, lack of childcare or transportation, and fragmented HIV services. In addition, Higa et al.

found that suggestions for system level barriers, such as appointment tracking systems, more flexible clinic hours, and reducing HIV-related stigma, were given little attention compared to individual level factors. Interventions that improved attendance at HIV-related medical appointments included providing transportation (81), having someone accompany clients to the appointments (16, 81-83), and providing support for navigating health care systems and locating additional services (16, 84). These interventions are making it easier for clients to access and utilize the services they need. As a socially marginalized population, lack of personal support and stigma are difficult barriers to prevail over so it is necessary to have interventions at the structural level to enable a supportive and non-judgmental environment.

Among homeless and unstably housed PHAs, not meeting nutritional, hygiene, and housing needs are strong indicators for poor overall health (85). Transportation needs can also present a significant barrier to clients following through with appointments or medication pick-ups. A study by Andersen et al. found that among HIV-positive women with no drug use or mental health issues, providing transportation was significant for improving retention in HIV-related care. Additionally, among HIV-positive women who used drugs and/or had mental health issues, providing transportation along with counseling services was effective for improving retention in HIV-related care (81). When MMT utilization is witnessed, clients are required to go to a clinic or pharmacy daily to receive their medication. If physically getting to that location is a struggle, then this creates a huge barrier in terms of being able to properly adhere. Finding adequate means of transportation to appointments is a critical component for attendance and adherence.

A common suggestion among researchers is better case management/counseling and better integration of services (16, 77, 82, 84, 86). Integrated services are more effective at reaching marginalized populations because it limits the number of facilities each individual needs to access. This, again, is affected by transportation. The less travelling a client has to do, the easier it is for them to attend appointments. By providing multiple services at one site, less navigation of the health care system is required from the client (16), and therefore less chance of losses to follow up. Having a central site also provides the opportunity for a client to build stronger relationships with service providers and reduces the potential for encountering stigma and discrimination.

The issue of ART adherence amongst IDUs is clearly complex and often interwoven with or exacerbated by the combination of social and contextual factors that are associated with IDU and the structural barriers that these individuals encounter when accessing care. These factors, such as homelessness or ongoing substance use, ultimately affect the stability of these individuals' daily lives thereby making adherence to a rigid medication regime or appointment schedule very difficult. Community-based programs aim to support these individuals and provide or improve stability in their lives, ideally leading to improved medication adherence and health outcomes. The main focus of many of these programs is harm reduction, which acknowledges that the elimination of these activities, such as recreational drug use, is difficult but that clients can benefit from reducing the risks associated these activities (87).

## **2.9 Community Based Supports for HIV-positive Injection Drug Users in Halifax**

There are several types of programs aimed at harm reduction and supporting IDUs and HIV-positive individuals in Halifax. This includes a methadone clinic, a needle exchange, an infectious diseases clinic, primary health care services, addiction services, and HIV/AIDS service organizations. A variety of community partners are involved in these programs to provide services to both IDUs and those living with HIV. For a list of such programs and services, see Appendix I.

## **2.10 Summary**

HIV infection continues to be a major risk among Canadian IDUs. ART, the only available treatment, has a strict regime and may have adverse side effects. Adherence among IDUs can be challenging because of difficult life circumstances that are often associated with addiction. These personal factors, coupled with structural or system level barriers faced by IDUs, make adherence even more difficult to maintain. Harm reduction focuses on mitigating the adverse outcomes associated with IDU, recognizing that addictions are difficult to overcome but there is benefit to lessening the risks and harms associated with them. MMT is one of a variety of harm reduction approaches to IDU, and has been shown to help improve ART adherence among IDUs.

## **Chapter 3: Methods**

### **3.1 Objectives**

As stated in Section 1.3, the objective of this study was to gain a better understanding of the barriers and facilitators that service providers in Halifax, Nova Scotia encounter when working to provide services to HIV-positive IDUs, what barriers and facilitators they feel their clients encounter, and how those barriers and facilitators impact ART adherence in their clients. These barriers and facilitators could be structural, including policies, mandates, or stigma, or contextual, including inadequate housing options, lack of education or employment, or addiction. The information obtained was used to identify which and what type of barriers most impact ART adherence and what potential changes could be made to improve health outcomes for individuals living with HIV and a history of IDU.

### **3.2 Reflexivity Statement**

This area and method of research were both new to me starting this project. I was however interested in marginalized populations and had some prior experience working with those affected by the HIV epidemic in Botswana. I am interested in marginalized populations because of the important relationship between health and social inequity. Greater disparities between the poorest and wealthiest populations in a society have been shown to have a significant impact on morbidity and mortality (88, 89). By examining service provision to marginalized populations, I hope to identify ways to improve morbidity and mortality amongst these populations.

Because of my interest in working with and supporting marginalized populations as a future healthcare provider, I know that I have a bias towards harm reduction practices and meeting clients where they are. However, having very little experience with marginalized populations in Canada and experiencing little marginalization myself, I have tried to maintain an open mind while conducting this research. HIV and IDU are still highly stigmatized and most harm reduction programs for these populations remain controversial. With that in mind, I have tried to consider all sides of the argument throughout my thesis.

### **3.3 Study Design**

The problem of poor health outcomes among HIV-positive IDUs in Halifax, Nova Scotia was identified by the service providers working with this population and demonstrated through the data from Direction 180 about their clients. While it was known that IDUs living with HIV have consistently had worse outcomes, there was little background information to suggest how it might be prevented. Most research in other locations has shown that MMT leads to improved health outcomes for HIV-positive IDUs. However, while MMT is providing support, the population in Halifax has continued to face high levels of morbidity and mortality. Therefore, an exploratory, qualitative approach was considered the most appropriate method to examine, from the service providers' perspectives, the structural and contextual barriers and facilitators that clients experience and what possible changes could be made to improve clients' outcomes.



Based on the objective of this study, we determined that the best approach was to collect qualitative data using semi-structured interviews. The interviews were conducted with service providers who work closely with PHAs and IDUs to elicit their insight into the structural and contextual facilitators and barriers that their clients encounter. There is a significant amount of quantitative research on service provision to PHAs and IDUs and some qualitative. We also aimed to develop a better understanding about the barriers and facilitators that service providers face when supporting their clients in Halifax and have them identify possible ways to mitigate the barriers and improve their capacity in supporting clients. While the interviews had a consistent set of questions/topics based on an interview guide, the questions were open-ended and the interviews flowed through the topics depending on how the information was brought up by the participants, which was more consistent with an unstructured interview process (90).

### **3.4 Theoretical Framework**

The theoretical framework for this study was based on the socio-ecological model. This model is rooted in the relationship between environmental conditions and human behaviour and well-being (91). Rather than the traditional approach to disease prevention, which emphasizes individual level modifications, the socio-ecological model supports the importance of linking individual behavioural change within an environment and community that promotes personal and collective well-being (Appendix II) (91-94). It was chosen because it applied to the study objectives of examining structural factors that influence an individual's environment as well as the contextual factors associated with their personal practices and well-being. This conceptual framework was helpful in this

study because it was important to consider the environment people occupy in order to better understand their actions and livelihoods. Looking at personal practices and factors without the context of overall social and community environments can lead to erroneous assumptions about why people do things and how they value their well-being. By using the socio-ecological model to look at individual factors within the larger scope of social, community, and societal environments, I had hoped to better contextualize the complex issue of service provision to HIV-positive IDUs and medication adherence.

This was also complemented by the grounded theory framework of analysis, which is a method used to derive theories from data as opposed to testing preexisting theories (94). As a methodology, grounded theory is based on systematic collection and analyzing of data (95). It can be used to generate new theories or elaborate on existing ones, when appropriate. Ultimately, I aimed to generate a theory about how the interaction of structural and contextual factors, based on the socio-ecological model, can help or hinder service providers' delivery of support and care to HIV-positive IDUs. Thus, grounded theory was the most appropriate methodological choice.

### **3.5 Interview Guide**

The interview guide was developed from information in the literature and areas of interest that had been identified by a committee of frontline workers and academic researchers in Halifax. All of the questions were opened ended and some had possible prompts if needed. The questions were intended to elicit information about the service providers' personal and professional experiences and thoughts around the structural and contextual

facilitators and barriers that HIV-positive IDUs encounter when accessing services as well as any facilitators and barriers that service providers encounter when trying to deliver services. The order of questions was fluid so the interviews were able to flow based on what the providers discussed.

### **3.6 Sample**

Study participants were community-based service providers in Halifax who provide front-line support to HIV-positive individuals with a history of injection drug use who have received both methadone therapy and ART. This work could have been through one-on-one, health-based work with clients or in an administrative capacity. Participants included program directors, nurses, counselors/therapists, and doctors employed by community-based programs in Halifax, Nova Scotia.

### **3.7 Participant Recruitment**

Eleven participants were recruited via direct solicitation from organizations known to serve HIV-positive and IDU populations. Based on the relatively small number of organizations and service providers working with this population in Halifax (40-50 individuals), this number was allowed us to capture a variety of perspectives and reach saturation (96). These organizations included Direction 180, Mainline Needle Exchange, the Infectious Diseases Clinic, North End Community Health Centre, Addiction Services, AIDS Coalition of Nova Scotia, Nova Scotia Advisory Commission on AIDS, housing services, and the Mobile Outreach Street Health Program. Those who agreed to

participate completed an interview that focused on their perceptions of the structural and contextual facilitators and barriers that HIV-positive IDUs face.

I did the recruitment myself by contacting the directors or administrative staff of the organizations to discuss their participation and, with their help, contacted other staff members that might be interested in participating. I did so by getting the work contact information of potential participants from the director or administrative staff and directly contacting those individuals to explain the study and ask if they were interested in participating. This contact was done in person, over the phone, or via email. If they expressed interest, an interview session was set up. The choice of participants that were included was made based on their position (e.g., nurse, doctor, administrative staff) so that there were a variety of perspectives.

### **3.8 Qualitative Interviews**

Participants were asked to speak about their experiences and opinions in the context of working with HIV-positive IDUs using a semi-structured interview guide (see Appendix III). The interview questions focused on the service providers' daily work with their clients, what challenges they face, whether they were contextual to their clients, systemic, or policy based, and any ideas they had as to how services could be more effectively delivered to their clients. The time involved was approximately one hour. Interviews were conducted between December 2012 and September 2013.

### **3.9 Data Collection**

Data collection was conducted at the interviewees' place of work. After consenting to be involved in the study, participants were asked open-ended questions about their experiences and opinions from working with HIV-positive IDUs. Interviews were recorded with an audio recorder with the participant's consent.

If a participant did not consent to being recorded but was still interested in completing the interview, the interview took place without being recorded. I would then take notes during the interview but there was no transcript from that participant. The notes were analyzed along with the other transcripts for dominant themes (97, 98). Characteristics such as workplace or position were removed from any quotes or presentation of the data to preserve the participants' anonymity.

### **3.10 Qualitative Analysis**

Interview data was first transcribed then input to NVivo for analysis using a grounded theory approach.

The interview data was coded into emerging themes using constant comparative analysis, which was based on a grounded theory analytical framework (97). Grounded theory is an analytic method used to focus data and build inductive theories through continued analysis and conceptual development (97). The method consists of simultaneous data collection and analysis and constant comparison of codes and data (98). Grounded theory was chosen because we aimed to build theories that emerge from the data that is available

rather than test an already existing theory about service provision. The codes were not preexisting but rather developed from the data. Initially, the interviews were analyzed with open coding whereby a code was assigned to phrases, paragraphs, or sections of the interview. These initial codes were then categorized into overarching themes.

Analysis for each transcript was an iterative process. Analysis began with the first data collected and was constantly reviewed and compared to new data as the theory developed (98). As data from each interview was coded, previous interviews were reviewed to consider any new codes or themes that emerged from other transcripts (96, 98).

Once all the transcripts were coded, a document was made for each of the themes, containing sections of the interviews that pertained to the theme. A summary was then written for each theme. Using these summaries and NVivo, axial coding was done, which examines how the themes are connected. Each theme was assigned a final name with a narrative describing the findings and direct quotes to support them. All identifying information was removed from the transcripts and quotes.

### **3.11 Ethics, Consent, and Confidentiality**

Informed oral consent was obtained and recorded by me so that participants' names were not recorded or retained on any documents. Oral consent was used because there is a small population of service providers working with HIV-positive IDUs and having consent documents free from names is an additional way to ensure the participants' anonymity as well as their clients' anonymity. All identifying information was removed

from the interview transcripts. This information included names, locations, and job positions. The audio recordings will be saved for 7 years then destroyed. Consent was obtained for use of quotes and any quotes that were used were stripped of identifying information to maintain confidentiality. Ethics approval was obtained through the Dalhousie University Research Ethics Board.

### **3.12 Strengths**

The primary strength of conducting qualitative research using open-ended interviews is gaining in-depth insight on a topic from those who experience it firsthand (99). The open-ended structure allows the participants to answer questions based on their experiences and observations rather than having to mold their answer to fit the researcher's predetermined hypotheses. The data also goes into much greater detail about social phenomena, is validated through common themes between participants, and provides a holistic perspective of observed phenomena (100). This methodology is well suited to this study because the purpose of this project is to gain an in depth understanding of the intricacies of service provision to HIV-positive IDUs.

Having the interviews conducted by the same person lessens potential bias, such as interviewer bias, and promotes consistency between the interviewees' experience. There is also less risk of participants answering questions in a way that is socially desirable because there are no possible answer choices for them to choose from with open-ended questions. They are simply describing their experiences as a service provider.

Finally, although this research is specific to Halifax, Nova Scotia and may not be generalizable to other areas, it does provide detailed information for this area and can be beneficial to these specific service providers.

### **3.13 Limitations**

The data for this project is based on the experiences and perceptions of the participants. As we are not able to interview all individuals that work with HIV-positive IDUs, such as correctional facilities and certain organizations, some viewpoints may be omitted. Additionally, service providers were the only people interviewed and other groups, such as clients or researchers, may have a different perspective.

Because of the nature of the project, there is the risk that my personal biases may come across in the interviews or analysis. I tried to remain objective during both data collection and analysis by asking open questions that did not lead the participants in a particular way and coded the data based on what the participants said and not what I feel that major themes should be. As previously mentioned, my personal bias is towards harm reduction practices and making services accessible to clients. However, I was always aware of my personal biases and position while conducting this research so as to mitigate their potential impacts on interviewing and analysis. This was also a new form of research for me, so I tried to be more cognizant of my personal biases while approaching the research with an open mind.



There is a risk that knowledge of other studies from the literature review influenced my view but the open-ended questions and my conscious effort not to lead the participants should mitigate this bias. A personal bias based on the literature may have also come through in the analysis but this should have been minimized by my being limited to only what the providers already said and not being able to adjust or manipulate the data. Additionally, a committee member reviewed my work to check the codes and themes.

As was previously mentioned, this project was looking at structural and contextual factors that affected ART adherence. For the purposes of this project, structural factors were defined as topics that had to do with how services are delivered to clients, as well as overarching policies and environmental factors like stigma and contextual factors were defined as those affecting clients at a personal or individual level, such as being homeless or unstably housed, having limited education or employment, or any other difficult life circumstances (16). These distinctions were made to simplify the analysis and presentation of data. Other researchers may have chosen to define them differently but for this project's purposes they were appropriate and I feel that the distinction does not diminish the quality of the results.

Finally, although the grounded theory approach was employed for analysis, which is meant to generate a theory based on the data, a full theory was not actually developed. A rich amount of data was accumulated that provides insight and knowledge into an area that previously had limited research, but due to the complex nature of this issue a complete theory could not be generated at this time.

## **Chapter 4: Results**

A total of 11 (two male and nine female) service providers were interviewed using the semi-structured interview guide. A total of 51 codes and sub-codes (32 codes, 19 sub-codes) were identified through constant comparative analysis (Appendix VI). Seven major themes were identified through coordination of the codes such that they complimented each other or worked together in a rational way. The themes that were identified were program support, resources, stigma, systemic barriers and lifestyle, service availability, HIV medication adherence, and policy. Each theme was defined and supported with direct quotes from the transcripts. Quotes are given with a pseudonym to represent the service provider. These pseudonyms are made up and do not reflective of the gender of the participant in order to maintain anonymity.

### **4.1 Program Support**

The Program Support theme includes advocacy, communication (between service providers and their clients), programs, between program relationships, and program support codes. Every service provider mentioned one or more of these topics. This theme encompasses the many ways that service providers and community-based programs already work to support their service users and the services that they offer for the population.

Many community-based programs have strong working relationships with one another that improve care provision to their clients. One such partnership is between the

methadone clinic and the infectious disease clinic, which allows for patients to get their medication with greater ease:

“(The methadone clinic collaborates) with the Infectious Disease Clinic to have their medications (there) because, you know, it’s, it’s reducing those barriers (...) but there’s still another piece missing (...) rather than, you know, the person coming to (the clinic) maybe there’s a way (to) bring it to them, you know, whatever their situation is.”

*-Sam*

One provider touched on the fact that these inter-program relationships are important in order to provide clients with all the support and services they need:

“(...) it’s not just relationship based care with the clients that we serve it’s also the relationships that we have with the agencies that allow us to provide more of a- I think a, I hate using jargon but more of a wraparound support to people.”

*-Meghan*

Another relationship that exists is between outreach and emergency services. By working together they can more readily access their patients to meet their health care needs and ideally prevent extreme events that require emergency care:

“(There is) a partnership through (outreach services) and the uh emergency department to kind of try and provide the best possible care for patients, um, that are inadequately housed or have addictions issues in the community to prevent them from coming back to emergency and not having their (...) health care needs met.”

*-Jeff*

Service providers also play an important role as advocates for their clients. They are dedicated and determined to help their clients in whatever way they can and, whenever possible, find them the resources they need:

“(…) so to date there’s nothing that’s ever really stopped me from helping somebody, (…) through the years like I would call and call and call and call till I got an answer, and where I could you know send somebody (…) we never say no without an explanation (…) not that we’re not allowed, we don’t, we never say no without an explanation, and why we can’t so.”

*-Sam*

*Sarah* mentioned that for some service providers it can be a challenge to find or contact their clients to come in for appointments but by collaborating with other services, like outreach services, they are able to find and support their clients:

“(…) sometimes it hard to get people to come in and it’s just because you know we can’t get in touch with them or they forgot or they have been using and again that’s where (outreach services) is really really helpful ‘cause they can often find the patient and bring them in to us and then to come up with a mechanism about you know how w- they’re gonna help with adherence (…)”

*-Sarah*

In some instances, confidentiality rules can make it more difficult to support clients across various services. While service providers recognize that confidentiality is there to protect

the clients and the programs, they might be able to provide better support if there was a way for more open communication between programs:

“Uh I think some of the confidentiality rules um- although they’re based to protect facilities, protect- ultimately protect the clients but also protect the facilities and organizations, um I think there could be increased information sharing between facilities uh not just between homeless shelters or between uh CSC and uh the shelter system or- but I think between venues like the (methadone clinic) um- you know, checks and balances because we’re- we’re talking about a population of people who do struggle with consistency.”

*-Jill*

Health and wellness is a personal experience and how one person interprets being “healthy” may be very different from others. *Jill* discusses the need to remove personal expectations about health goals when working with this population in order to help clients achieve the goals they feel are necessary and important, rather than imposing perceived goals on them.

“Um, I think it’s challenging- you know the ways in which you work with uh IDU community uh you need to change your own goals (...) you can’t kind of have your own perceived goals about what achieving wellness is for them, they have to define what that is and (...) you have to be happy and supportive uh in allowing them to do that because it’s not our job to define what is health for them.”

*-Jill*

## 4.2 Resources

All service providers also talked about resources in some form. The types of resources were split into income assistance, food or nutrition, funding, housing, limited space, staff or hours, and transportation. Housing and funding were the most frequently mentioned resources, followed by transportation, staff or hours, and limited space in programs.

### 4.2.1 Housing

As mentioned, almost every provider discussed the issue of the lack of adequate housing. IDUs tend to be a transient population and many are homeless or living out of shelters. In these sorts of living environments there is often ongoing drug use occurring so people trying to address their addiction and adhere to MMT may be faced daily with other people using drugs. This environment can make addiction recovery especially difficult, as one provider discussed:

“(…) we don’t have affordable housing in areas where peop- where it’s void of some of that activity you know a lot, a lot of the (drug) activity is in the places where people can afford to get um apartments and people have poor rental history sometimes so the only place they can get it is in places where there’s active use going in the building so so trying to be on a methadone maintenance and be in recovery is really difficult and- but that’s all you can afford.”

*-Kayla*

Another provider discussed a similar point saying that people trying to recover from addiction with MMT not only have to live in an environment where there is

ongoing drug use, but may even still be living with or near the same people they formerly used drugs with:

“(…) sleeping in an environment where there are many, many other users, a lot of them not trying to get well (….) um, is a- is a huge obstacle and a huge challenge so not only contending with the desperation or isolation of being homeless and living in a large population in a large room, um you’re dealing with physical withdrawal (….) some of the same guys I see uh who are trying to stick with their- their methadone program uh are stuck in the same place with uh the same guys that they used to score pills with ”

*-Jill*

The same provider discussed the need for more housing options including transitional housing for people recovering from addictions and abstinence houses for people without addiction or substance use who also require housing:

“(…) the things that could happen in between are wet houses, so places where it is okay for alcoholics to have a drink, that’s managed. (….) Um, wet houses so not just for alcohol, for some drug use, um and I know that’s really difficult to manage, um also uh abstinence-based transitional housing, so some places where it is just not access- acceptable to use in any form uh because there are homeless who are sick, who need to get between the two.”

*-Jill*

## 4.2.2 Funding

Again, funding was a topic brought up by nearly all the providers. Nine of the interviewees discussed funding and had similar feelings about it. Below *Kayla* is the only provider quoted because they articulated the issue most clearly. Funding essentially determines what services organizations can and cannot provide. Even with willing individuals, if you do not have the money to pay employees or for facilities then there is a finite amount of work that can be done. *Kayla* describes how even though these organizations want to do more, they are financially hindered:

“(…) there’s just so many things that need to be (done) and when you’re grossly unfunded and resourced to do just the basic, it’s really hard to go above and beyond to do those other extra things. (…) ‘Cause you kinda have to draw a line, as hard as that is sometimes”

-*Kayla*

Below, *Kayla* discusses the disparities in funding allocation. They talk about non-harm reduction programs getting a larger portion of funding but having higher failure rates because they are not meeting clients at a level that they need:

“(…) if you look at the programs that are funded in Nova Scotia (…) um (needle exchanges and methadone clinic) who are the leaders in that work, get pittance (…) compared to what those other programs are getting and yet they have a 97% failure rate”

-*Kayla*



Finally, *Kayla* mentions the reason they feel these sorts of harm reduction programs cannot support more people. Without more funding there is a limited amount of space and therefore limited amount of people that can be seen:

“I think money probably limits accessibility, um, you know, or lack of funding means lack of beds, means lack of accessibility”

*-Kayla*

### **4.2.3 Transportation**

Transportation is a necessary resource for clients to attend appointments and pick up medications but can be difficult for them to access. Clients often live away from the services they use and need taxis or buses to be able to attend appointments and get to clinics. *Luke* described how difficult it was to get a bus pass for transportation from social assistance:

“(…) if you think about community services for example, to get a bus pass you need to have a doctor’s note listing the 15 appointments you need to go to every freaking month. (…) That is a huge barrier for someone who is IDU. (…) To go to the doctor, to come up with 15 places they’re supposed to go, get the doctor to fill it out, then bring it back to the worker, then get the worker to sign off on it and call the places that you’re gonna have the appointments, like it’s just not gonna happen (…) they’re just not gonna get a bus pass.”

*-Luke*

*Kayla* also described how difficult it can be to get transportation coverage for clients and how difficult that in turn can make it for the clients to attend appointments:

“(…) in terms of people who are not well and getting, you know, whether it be, you know, transportation via taxi (…) um, to and from, you know and dealing with those battles. I mean we have one worker and one client, oh my God I don’t know how many meetings we had with, with them about their, you know, taxi coverage um, and the challenges around that.”

*-Kayla*

#### **4.2.4 Limited Space in Programs**

A lack of space in treatment programs was identified as a major resource issue and was also brought up under funding as being a result of programs having limited funding. *Sam* discussed the issue of waitlists because of limited space and what happens to some people while they are waiting for MMT. They also mentioned the number of people currently being seen at the clinic:

“(…) there’s almost like 300 people on the waiting list (at the methadone clinic) although that may fluctuate, (…) this is not just - oh my God, some people have died, that’s truth, waiting for help, and then you’ve got people that’ve gone to jail (…) you know they’ve been waiting for help, people that finally said I’m outta here because I can’t take it anymore and have left. (…) I think there’s 240 people on the program, 70 of them are daily, so that go there daily, everyday, so they want to keep it- they think they’re somewhat managing it at 70 people a day.”

*-Sam*

It should, however, be noted that people living with HIV who want to access MMT do not have to be waitlisted and will be able to start the program immediately. Another provider talked about adherence to MMT and that most clients do actually adhere but the barrier of waitlists can be very off putting for those trying to access the service:

“I believe that if there were more space for methadone programs then we would see- like people are going to adhere to that because (...) it’s a very small percentage that starts, stops, starts, stops, starts, stop. (...) Umm, the larger percentage adheres to methadone maintenance. (...) and people don’t bother sometimes applying or putting their name in for an intake for methadone because they know what the waitlists are like and they just think why bother.”

*-Meghan*

#### **4.2.5 Staff or Hours**

Limited number of staff and hours of operation were identified as a resource limitation. Ultimately both are also affected by funding because organizations can only hire so many people and be open for a limited amount of time based on their available funding. *Kayla* discussed services that it would be nice to have for further support but are simply not feasible for organizations at this time because they would need more staff members:

“(Ideally) I would love to see case management, peer support happen whereby, you know, we had two people and, everyday their role was to just go visit people, take them for coffee, you know, rally them up, you know, link them to recovery supports or appointments and those kinds of things and, (until they’ve) put some healthy structure in their lives or made the links and

experiences it because I think for the most part (...) I believe they want a better life”

*-Kayla*

They also discuss the fact that the methadone clinic is only open to clients in the morning and that it would be beneficial to the population to have more flexible hours of operation:

“(The methadone clinic is) not 9 to 5, (it’s) 8:30 to 12 (...) um, it’s, it’s even that much more challenging with, when they’re using so we need to put our energy into finding something that’s still more um, flexible.”

*-Kayla*

#### **4.2.6 Food or nutrition**

Accessing food is an important resource especially for the population being served because their medication may be dependent on food. Additionally proper nutrition is important for any one with health concerns, particularly those with co-morbidities. Different ART regimes have different dietary restrictions and within a population that may already find adherence difficult, it is important to make the medication regime as manageable as possible. Here *Sarah* talks about finding regimes that are appropriate for each person:

“(There are) certain medications that are not just dependent on food but the amount of food so that’s something (that’s discussed) with the patient and you know if they’re not having a regular meal, they’re sort of you know having

little things then that would not be something that (would be prescribed) because that's not gonna fit with their day (...)"

*-Sarah*

#### **4.2.7 Income Assistance**

Many of the clients being served rely on support from income assistance. Income assistance has strict policies to ensure that money is being allocated appropriately but sometimes these policies create a substantial barrier and prevent those who need the service from being able to access it. Below, a service provider describes how the protocols around income assistance are affecting a client's ability to access treatment for their addiction because of their lack of stable housing:

"I can give you an example of a woman right now who is couch surfing, she works in the sex trade, she has an opiate addiction and she can't get on methadone because she doesn't have an address which means that if she doesn't have an address, she can't get on uh income assistance and if she can't get on income assistance she can't get pharmacare, and if she can't get pharmacare she can't pay for methadone so therefore she can't go on methadone when there's a methadone bus that pulls up to a block from where she's couch surfing everyday. (...) now one could argue she just needs to go to a shelter (...) but, she does not want to go to a shelter um and she actually feels safer and um more settled in the place that that the person who's letting her sleep on the couch right now. (...) so she can't apply as a no fixed address."

*-Meghan*

### 4.3 Stigma

Stigma is still a major issue for both IDUs and people living with HIV. Every service provider mentioned stigma and most talked about stigma as a result of the perception of HIV and IDU. Not only are the clients that access these services being stigmatized but the service providers themselves can also be stigmatized when they are perceived as “enabling” drug use. Here, *Sam* talks about the perception that harm reduction programs are promoting drug use:

“So I don’t know what, like, I really feel that for as many people that come in here and say thank you to us, you do a fantastic job, then we have all the ones that say all you’re doing is promoting drug use, all you’re doing is continuing to allow people to use. If you would stop giving them needles and crack pipes, then they would stop using.”

-*Sam*

*Kayla* describes the societal perception of addiction and drug use as a choice and moral deficiency and explains that this idea makes it difficult for IDUs to reach out and access help when they need or want it:

“I think you know, we have a long way to go to tag (addiction) as a health issue, um, it’s still deemed as a moral deficiency, it’s still deemed as, you know, people are choosing to do that (...) it’s the kind of thing that when somebody reaches out for help, um, you know if the helps not there then you know their situation is just going to continue to (...) get worse, and that’s what happens.”

*-Kayla*

Similar to *Kayla*, *Jeff* discusses the perception of people who use drugs and how that creates stigma in hospital emergency departments when these people come in for medical care:

“(…) there’s multiple, multiple issues- obviously overcrowding in the emergency department’s a big issue, um, and people that have a- issues with addiction, you know, often aren’t treated well when they come to the emergency department and so I think there’s some judging that goes on by health care providers that, you know, think that this is a life that they’ve chosen you know, and that they, you know, have a lot of control over and that kind of thing.”

*-Jeff*

When asked about why changes are not being made to the service delivery system to better support PHAs and IDUs, *Luke* identified stigma and perception as the biggest issue:

“It’s pretty simple, it’s the stigmatization and the perception people have about people who use drugs.”

*-Luke*

Finally, one service provider discussed the issue that some programs may be promoting rather than mitigating stigma. The prognosis for HIV infection is radically different than

it was 10 or 20 years ago and with proper medication it is a manageable chronic condition. The idea of anonymous testing, while beneficial years ago, may now be promoting the stigma around HIV because it gives the notion that this is still something that people should be hiding:

“Uh interestingly with HIV, it’s my opinion and it has been for a while that um that some of the programs (have) negative impact at this point. Like um the whole concept of uh anonymous testing for me now stigmatizes more than it gets around stigma. Um it is now n- not a terminal disease as you know, it’s a chronic disease that’s treatable and people do very well and by separating it out in this kind of way uh I think is more um stigmatizing.”

*-Larry*

#### **4.4 Systemic Barriers and IDU Lifestyle**

This theme is a combination between the systemic problem code and codes that represent the difficulties involved in IDUs’ day-to-day life. The codes included that represent lived experiences are addiction, autonomy, chaotic lifestyle, corrections, drug use, medication regime and defaulting, and familial support and relations. These two topics were combined because they were related in causing a similar barrier and also aggravated by each other. The systemic barriers are issues within the delivery of service that make access to services more difficult for clients whereas the lifestyle factors are aspects of clients’ life that makes accessing services more difficult. Both factors impact access to services and when combined exacerbate the situation and make accessibility harder.



Below, *Meghan* talks about the difficulty of medication adherence and that if we are to expect people to adhere to their regimes then we should be creating an environment that fosters and supports that adherence:

“I think that we blame people for not adhering because we’ve created a system that is pretty much maybe impossible for them to adhere to. (...) so we talk about adherence in the sense of that people aren’t adhering but but we don’t create the the milieu, we don’t create the the venues whatever you want to call it um for them to be able to adhere.”

*-Meghan*

*Kayla* further discussed the way in which services are delivered and how, especially for people in active addiction, the constraints of specific times and schedules may not always be feasible. The “9 to 5” design that much of our society uses is practical for most people but for people who are dealing with chaotic events in their life that restriction may be a significant barrier and could be alleviated by more flexible options:

“(...) our mainstream society’s services and support are designed in a way that would, you know, meet the needs of you or I, you know 9 to 5, you know. (...) When you’re on a crack run you don’t, you don’t have 9 to 5. (...) You know, things are pretty chaotic and so, I think there’s opportunity there, you know, to keep people engaged, um, and you know, have some flexibility. (...) You know, about how we’re meeting them.”

*-Kayla*

*Luke* shared a similar perspective on the policies that currently exist and how they limit IDUs access to services that they should be able to use like all other citizens:

“I think there are lots of policies and practices that impact the capacity for people who are using drugs, whether it be injection or even any other type of drug (...) which all place people at risk for various things- um that limit them, and limit their uh rights and limit their access to services that they full well should be able to make use of like any other citizen.”

*-Luke*

*Meghan* mentioned another issue in that our current system of healthcare delivery has a difficult time providing services in a way that deviates from its model. Outreach health services do exist but the model is mostly based around people coming to appointments and facilities to receive services. It can be difficult for providers to reach people “where they’re at” when they have to work based on appointments from fixed sites:

“So there’s system barriers in that we do not have a health care system that is able to deliver health care outside of the model that it’s presently in (...) we have a health care system that is set up on people going to where health care is offered and it’s set up in in a few ways it’s set up by appointments, by referrals, all of those kinds of things. For the individuals (that outreach services) works with, that level of um structure or that form of structure doesn’t work for them so you know I believe that there’s other forms of structure (...) that um allow people to access health care kind of where they are (...)”

*-Meghan*

*Meghan* further added to this explaining the importance of not only of looking at adherence but also exploring why it might be difficult for people to adhere and make scheduled appointments. By having service providers that are aware of these difficulties, they can hopefully work with the clients to overcome them:

“(…) so how can we understand why you’re missing, you know is it hard to get here, is it that you know you’ve slept in, is it that in fact you actually like the opiates that you take during the day, like that that gives you better coverage somehow or (…) is it the lifestyle, is it um is it the the energy or the relationships that come with that lifestyle? So all of those things sometimes can be hard to give up or hard to step away from or because the- that’s my normal (…)”

*-Meghan*

One of the major influences in lifestyle is having appropriate and adequate personal supports. Health care professionals can help and support their clients but that does not make up for the lack of support from friends and family that many face. This limited support can impact PHAs and IDUs well-being and ability to cope with navigating the health care system:

“(…) unfortunately one of the biggest things that they have you know very few sort of personal supports I think (…) we certainly try from a health care professional point of view but it’s not like they’re in this stable house that they have friends and family that can help them take their medication.”

*-Sarah*

#### **4.5 Service Availability**

This theme encompassed four codes, which were accessibility, detox, health services, and the service availability sub-code of resources. It describes what services are available for HIV-positive IDU and how readily accessible they are for the population as well as other services that the providers would like to see made available.

*Kayla* discussed the difficulty of providing services to people in active addiction because they often have erratic schedules and only brief windows to actually access services. When programs and support are not available during those times, the IDUs cannot access any services and continue with their pattern of use. By having a wider range of time and program availability, IDUs could be more easily reached:

“(…) so for example somebody with HIV, um, on methadone, poly-substance use, they’re using cocaine, they’re using benzos, they’re using everything basically, you get little windows of opportunity where you can intervene and support them and help them, um, but you know, (the methadone clinic dispenses) from 8:30 in the morning till noon. So if you’ve been up for 48 hours, you know, 8:30 till noon means nothing”

*-Kayla*

They further expanded on this by saying they would like to see a wider range of time that methadone services can be available to clients. They also mentioned that by having other medications available at methadone clinics, clients are more able to adhere:

“I think I, you know I, I would like to see um, broader, broader availability of times when they can access, you know, their meds and their methadone. Like, by having their meds (at Direction 180), we’ve helped (...) people adhere.”

*-Kayla*

*Meghan* discussed the need for different types of methadone programs, some that are strict and some that are lenient. Every client is different and their treatment should be based on what works for them:

“(...) for some people the restrictions of not being able to use others substances is too much for them to kind of take on at once (...) and then for others the restriction of not using substances is exactly what they want (...) in their lives so having programs that really um vary in terms of their criteria (...) for intake, their criteria for being maintained, and the way in which they offer their program is really (...) important for adherence. And that people can actually go to a program that fits for them versus one that doesn’t fit for them. Um so that’s really important.”

*-Meghan*

*Jill* mentioned the need for high and low threshold methadone clinics to work more parallel to each other, rather than as distinct programs. This sort of relationship would allow clients to move between programs and find a level of structure that works for them. Currently this sort of arrangement is not available:

“I’d like to see uh, not complete separation but I’d like to see some abstinence-based and some um harm reduction running more parallel.”

*-Jill*

Another service provider felt that service availability could be improved by providing more centralized care. Offering multiple services at one site limits the number of appointments and amount of travel that clients have to do. This can improve retention and adherence by reducing those barriers:

“(…) the most important i- issue with respect to people with addiction in treatment is to offer as many services as you can on site. So the more that things happen here, the more likely you are to get a good outcome, and in fact there’s literature to support that um that concept of having a centralized primary care services and addiction unit. So in other words what you want is not places that just offer addiction treatment but places that offer addiction treatment as well as mental health services, primary care services, Hepatitis C services, um chronic pain services (…) and uh HIV treatment services ”

*-Larry*

Services tend to be lacking for clients who are in active addiction and do not wish to address their addiction or drug use. They do still need to have services available for them to access but, as discussed with stigma, many people do not want to work with those in active addiction because of how they are perceived:

“(…) programs don’t also focus on the need to continue health care even when people are in active addiction. Right, like (…) that’s a huge gap, right. There’s

no interest in working with you unless your- your journey is ready to stop using drugs.”

*-Luke*

#### **4.6 HIV Medication and MMT Adherence**

Clearly adherence to HIV medication and MMT was a prominent theme because of the population this study is interested in and the clients these service providers are working with. The theme of HIV Medication and MMT Adherence includes the adherence, co-morbidities, HIV treatment, and MMT codes. This theme covers the difficulties of adhering to these regimes as well as things that have helped clients with adherence.

*Kayla* talked about how having other medications, including ART, available for clients to take with their methadone has been beneficial to adherence. Allowing them to have all their medications in one location makes adherence simpler and by combining things with methadone, which manages their addiction, they are more likely to come for their daily witnessed dose:

“You know, it’s helped with mental health, it’s helped with diabetes, it’s helped with depression, anxiety, it’s helped with you know, Hep C when (there’s been) treatment on site, and it’s helped with HIV. (...) Right, because their medications are managed and they’re able to get them (...)”

*-Kayla*

One service provider commented on an interesting phenomenon of clients being compliant with their HIV-medication but not with methadone. This is likely occurring because people understand their infection and that they need to manage it but are not ready to address their addiction:

“(Interestingly there are) people that are non-compliant with methadone but compliant with HAART. (...) Um, so you have probably the majority of people who if they’re compliant with methadone, will also be compliant with HAART right- (...) So they take their HIV meds, but they don’t come for their methadone. (There’s) a few people like that, so it’s an interesting twist so (...) um you don’t get that many people that’ll come for their methadone and not take their HIV meds, it happens but it’s not as common right. ”

*-Larry*

*Sarah* talked about the importance of adhering to ART and drugs failing if people do default from the medication. They also mentioned ways that community programs can remind people to take their medications:

“If you take the medications they’re gonna work (...) but if people can’t be adherent and there’s a reason- there’s this many reasons long why they can’t, then the drugs are gonna fail. So yeah, so we try to develop mechanisms and tools as well to help them be adherent so whether that’s a you know it’s a pill box, it’s a beeper, there’s reminders, or contacting people like (outreach services) or getting the community pharmacists involved.”

*-Sarah*



The same provider went on to talk about what happens if people do default from ART in terms of the new medication regimes they will have to use:

“More complicated, more pills, more multiple times during the day and then that gets really hard, that hard for very uh stable individuals (...) to you know to even do especially on a long term basis, so then it gets even more challenging (...)”

*-Sarah*

Because there are negative side effects associated with the HIV medication, one service provider described why it is important to educate HIV-positive individuals on what the drugs are and why they need to be taking them. It can be difficult if a person’s HIV infection is asymptomatic for them to appreciate why they still need to take ART, especially if the medications are giving them negative side effects:

“It’s a medication that either you know, makes you feel lousy and you don’t understand why you’re taking it (...) because (...) your HIV is just been this thing that you’ve had but you know, you didn’t know you had it or sorry, you knew you had it but you didn’t really feel quite effected by it (...) and so you’re taking this medication to continue to not feel affected by it but it’s giving you all this grief (...) You know, so I need education, I need real appreciation of what this- how this medication will in the long run help me (...)”

*-Meghan*

Several service providers talked about the benefits of ART. *Luke* talked about why it is important for PHAs to be on ART, not only for themselves but also for public health if they are participating in high-risk practices. They also talked about the risk of becoming resistant to certain classes of drugs:

“(…) we all want people to be on treatment, for a variety of reasons (…) one, because we want to keep people alive, two we know it’s a good- good measure for prevention, um and what happens is, when each drug class is burned, the options get fewer and fewer. (…) So people can get a point within a 5 year span if this happens 3 or 4 times, by being limited to one class of drugs.”

*-Luke*

#### **4.7 Policy**

I was interested in policy and how it impacts the delivery of services to HIV-positive and IDU populations. There were four codes in this theme; policy in general, organizational policy, provincial policy, and government policy. Organizational policy had to do with the different programs’ rules and regulations whereas provincial and government were higher level policies that dictate how programs can operate.

The service providers that were interviewed frequently said they did not feel they had enough knowledge of higher-level policies to comment on them. Here is an example of *Jill* commenting on provincial policies:

“I don’t think I can speak to that, I don’t think I have a (...) I don’t think I have a solid enough uh base to understand it.”

*-Jill*

Some providers stated that they felt frontline workers and clients need to be more engaged in making policies rather than the top-down approach that is being used. Policies made at higher levels have direct impacts on people’s health and access to social services but when people working on the front lines or being affected by the policies are not involved in the process, the policies may not be as effective as they could be:

“The problem is is that these policies are being made from the top (...) not from the ground up where the issues occur. That’s a problem, so that’s what needs to change. Anytime a policy is being made that impacts upon a person’s health or social, (...) their housing, their health, whatever it is, people should be engaged and I don’t think people are involved enough in those, those processes, when these policies are made.”

*-Kayla*

*Luke* also talked about the top-down approach of policymaking and how policies are based on what the government perceives health and wellness should look like. They also mentioned that policy makers are largely driven by the great need to respond to what voters want:

“I mean it goes all the way to where the government sits and the government’s values about something and then how that trickles down to the government funded agencies and then how they perceive what health and wellness looks

like and (...) you know, and I do think it's not necessarily those working in health and wellness 'cause I actually think they all get it (...) I think it's coming from uh a top-down which is constantly in kind of the need to uh respond to the voter, right."

*-Luke*

One provider also discussed not only the importance of having policies but the need to support policies with actions. Policies may outline what can be done but that does not always mean that is what will be done. Policy can also help to shape the environment around things like addiction but stigma remains as a significant issue:

"Policies don't mean much because (...) it's just a piece of paper and it's what's important is what you do not what the policy says because very frequently as you know people don't follow policies. (...) So you can have something very nice on paper that says very nice things but if you don't back it up with action then it's of no relevance. (...) So what policies sometimes do is they define overall environment that might push uh systems in one direction or another right. (...) So if a government develops policies that are pro um addiction treatment then that might have an impact on where things go (...) Stigma um for addiction is still huge wherever you talk about it, it's big in the healthcare system, it's big in the community, it's in politics. (...) that's the biggest issue. That's not really policy but (...) it has more of an impact than the policy."

*-Luke*

Some providers had different opinions on the government's support of programs for IDUs and PHAs. *Larry* talked about how it might not necessarily be a lack of support for harm reduction and addiction treatment but limited resources and funding to distribute:

“I don’t get the sense that the government is not willing or even on board to to fund places like this. (...) I think it’s more that the the resource isn’t there um for them. I mean the money’s not there. I don’t get a strong sense from the current government that they’re- they’re um, you know, not willing to help. (...) they’re certainly willing to support (the methadone program) and they’ve been willing in a number of ways to be helpful that I think there’s- the money isn’t there.”

*-Larry*

Each program has their own set of policies about how they operate, some of which help clients and some that make access more difficult. The methadone clinic in Halifax is very low threshold and lenient about their clients’ drug use:

“I think (...) in terms of you know, access and retention for methadone, I think (the methadone clinic is probably) the most liberal in the province, um. That, you know, (the methadone clinic has) the highest tolerance for other drug use, behaviours, um, you know it’s, discharge does not come easy-”

*-Kayla*

Some programs, including addiction programs and shelter houses, have strict rules when it comes to accessing them. These sorts of restriction can be difficult or unrealistic for people who need the services:

“So I think generally there are numerous types of policies and practices- or you know, even shelters that you have to be sober at (...) you know, or uh addiction

programs where you have to be sober for this many days and you have to jump through these 7 hoops just to get access to care.”

*-Luke*

Another organizational policy that can make adherence difficult for people is not being able to hold onto personal medications while staying in a shelter. This rule is obviously in place for the protection of employees and people using the shelter but it still means that individual people have reduced access to or control over their medications. This service provider recommended transitional housing as a way to bridge this gap:

“(…) it’s for protection of the facility, you can’t have uh everyone in the general population holding on to their own medications (…) um, but at the same time I think a step could be taken further to- I guess you couldn’t do it in a big shelter, it would have to be transitional housing. It would have to be a different arrangement. So they (…) I guess that’s what I’m getting at, that’s the- the piece that’s missing, transitional housing.”

*-Jill*

#### **4.8 Summary**

From the analysis conducted, I identified seven major themes from the data that were collected. Many of these themes are interrelated and influence each other, which is to be expected when looking at a complex issue such as medication adherence and service provision to HIV-positive IDUs. The service providers working with HIV-positive IDUs in Halifax do their best to deliver programs and care but are limited by the funding and resources available to them. Their clients are also faced with stigma, difficult life circumstances, and systemic barriers to accessing services. Overarching this are the

policies that dictate how these sorts or programs are funded, thereby limiting everything beneath it. I will now examine these themes in further detail in my discussion section.

## **Chapter 5: Discussion**

In the following discussion, I will further examine each of the main themes identified in the results and relate it back to what the literature and other studies have found. I will then examine the complex interconnectedness of this issue using the socio-ecological approach. I finish by offering concluding thoughts and recommendations based on the findings of this research. The one point that stands out, without question, is that service provision to marginalized populations such as HIV-positive IDUs is a highly complex and complicated issue. Much of what was said by the service providers involved in this study is corroborated by the literature.

### **5.1 Program Support**

The interview data clearly showed that the service providers who work with HIV-positive IDUs in Halifax are working tirelessly to provide the best support they can for their clients. They are frequently faced with issues of limited staff and funding but continue to go above and beyond to help the people they work with. Having committed, compassionate, and open-minded service providers is crucial to engaging and retaining individuals such as IDUs and PHAs that are frequently faced with stigma and social exclusion. However, it is unfair to rely on the goodwill of providers to go above and beyond what is expected of them when they are working in a system that does not adequately support them or their clients.



Organizations such as Direction 180, Mainline Needle Exchange, the Mobile Outreach Street Health program (MOSH), and the Infectious Diseases clinic are currently working together to provide care. They work collaboratively to help clients adhere to medication regimes and attend appointments. Examples of these partnerships are Direction 180 working with the Infectious Disease clinic to provide ART alongside methadone and MOSH working with the Infectious Disease clinic to accompany patients to their appointments and check on them within the community.

When these community based organizations work together and focus on ways to meet clients where they are at to make services more accessible, clients are more able to follow through with their health care needs and, in turn, have improved health outcomes. MOSH is a huge resource for other programs because they are able to locate clients and either take them to appointments or bring necessary health services right to the individual.

Providing this support is still challenging though and requires service providers to re-evaluate their own perceptions and judgements. It was evident from the service providers that participated in this study that they understand the importance of working with people on their own goals and accepting clients as they are. However these providers are more familiar with marginalized populations such as IDUs and PHAs. Not all service providers that individuals in this population encounter have that level of experience and understanding and stigma remains a significant issue which will be discussed below.

## 5.2 Resources

In both the literature and our data, resources were a significant limiting factor to service provision. I divided them into seven separate categories of resources for simplification. While funding is one of the resource categories, it does affect all of the others. With increased funding, organizations would be able to serve more people, pay more staff, be open longer hours, and possibly offer extra services like assistance with housing, transportation, and dietary needs.

Limited resources present a structural barrier to clients receiving services. Higa (2012) found that these sorts of system level barriers tend to be given little attention (81). However, intervening at this structural level has been shown to improve attendance for HIV-related medical appointments (16, 81-84). Transportation, for example, can be a huge barrier for someone who takes daily witnessed methadone. They may have to travel a significant distance each day to receive their medication and without the support of a bus pass or taxi allowance that transportation may not be feasible. As one service provider discussed, obtaining a bus pass requires a lot of doctor's notes and explanations. Some organizations will provide clients with taxi chits. While this does help it is not a practical daily transportation solution. Since the data was collected for this project, Direction 180 has implemented a mobile bus program to bring methadone to certain areas for clients and, to date, it has been very successful for reaching a wider group of IDUs (18).

Other basic resources that could improve adherence are more staff, longer hours of operation, and more space in methadone programs. As mentioned, most of these are limited by funding. When the interviews were conducted, Direction 180 had a very long waitlist. That meant that there were people who wanted help but simply could not get it because there was not space at the clinic for them. However, the mobile bus program has largely helped to alleviate this problem, making wait times a matter of days or weeks, compared to the months people used to have to wait (18). Unfortunately, some people still slip through the cracks due to loss to follow-up for appointments. Being able to offer help to all those who seek it is a huge benefit among the IDU and HIV communities. More staff could, again, mean that more clients could be seen each day at the clinic and that organizations and clinics could be open longer hours. Longer hours give clients the freedom to work appointments into their schedule rather than creating their schedule around an appointment. As some of the providers mentioned, strict schedules and limited time frames can be difficult for IDUs to function within so more flexible hours would also help alleviate this issue. Direction 180 is only able to see clients in the morning, and even the mobile unit has set hours. While these changes would be beneficial, they may not be feasible given the current government and finite amount of resources. I will discuss this further in Section 5.4, but for people with instability in their daily lives, getting to a clinic every morning can be a significant challenge.

Housing and nutrition are also issues that need to be considered when working with HIV-positive IDUs. For ART, some regimes may have specific dietary needs about what and when to eat while taking the medications. The service providers are diligent about finding

the most compatible line of ART but if a client defaults and needs a new regime the subsequent ones tend to be stricter. Housing continues to be a significant issue and was consistently mentioned by service providers. While it has less of a direct impact, for clients that have difficulty finding housing and have to use shelters, they may be trying to adhere to methadone and ART while living with current IDUs. It can also have a direct impact like in the case a service provider discussed with a client who was staying with a friend rather than in a shelter. Because this person had no address to list as his or her own, they could not access social assistance and therefore could not receive pharmacare or afford to be on MMT. In this case, lack of housing has a direct effect on the services a person can utilize.

Many shelters also require those staying there to turn their medications in at the desk which means people have to relinquish some of their control over medications in order to have a place to stay. One service provider discussed how difficult it is for people who are in recovery but still have to see people they used to use drugs with, who continue to use, on a regular basis. Understandably that could make recovery and adherence much more challenging.

As mentioned before, all of the resources essentially come down to limited funding. More funding could mean more transitional and low-income housing, the ability to offer bus passes or other forms of transportation, and longer hours with more staff to be able to serve more people.

### 5.3 Stigma

IDUs and PHAs are both marginalized groups that face social stigma and discrimination from individuals and systems within mainstream society (14, 15). IDUs living with HIV therefore encounter further stigmatization. The people and organizations providing services to these populations can also be scrutinized and judged by the public, in particular harm reduction programs. There is a perception about harm reduction that it allows and encourages people to continue using drugs, rather than its true goal of mitigating the side effects of high risk practices such as drug use.

One particular point about stigma that was brought up by several providers was that IDU is seen as a conscious choice that IDUs continue to make and people see it as a “moral deficiency”. Society tends to blame and outcast these people rather than recognize them as worthy members of our society who are struggling with addiction and should be helped rather than judged (63). Many providers also talked about their clients’ apprehensiveness towards accessing services for fear of how they will be treated or because of how they have been treated in the past (61, 62). There were a few stories about services users trying to access health care services and receiving subpar care because of how the health care providers perceived them. Rather than seeing them as a patient with health concerns that needed help, they saw them as a drug user who caused the damage themselves and therefore did not deserve the same level of care as other people.

The issue of stigma largely comes back to education. The general public and many providers may not know enough about IDU and HIV and therefore stigmatize these

populations based on their own perceptions. The service providers discussed how many people think that IDUs are causing their own situation by continuing to use drugs without realizing that many IDUs continue to use drugs to avoid horrible effects from withdrawal. This is especially an issue when there are people on waitlists for methadone who are reaching out for help but, due to limited resources, cannot be helped and continue to use drugs because of their withdrawal symptoms and physiological addiction. IDU, particularly among those who are sharing needles or equipment, can significantly increase the risk of contracting HIV, or spreading it if they are already HIV-positive.

Essentially, stigma and societal perceptions around IDU and HIV creates a barrier for individuals trying to access services because they either feel unwelcome at certain organizations or those perceptions limit the number of services that can be provided based on resources. Greater education about addiction, drug use, and HIV for healthcare providers and the general public are needed if the stigmatization of IDUs and PHAs is going to change significantly.

#### **5.4 Systemic Barriers and IDU Lifestyle**

There are several factors associated with IDU that can make navigating within the existing service delivery model difficult. These factors include homelessness, limited social support, lack of education or employment, and continued drug use (4-7, 72-74). When they are combined with rigid service delivery structure and limited resources, adherence can be worsened. Our health care system operates in a structured, appointment-based manner. This generally works for the wider population but for

individuals such as IDUs living with HIV attending scheduled appointments can be challenging. This is especially true when they are faced with homelessness or are living in shelters, have little family or social support, or continue to use drugs. As mentioned in the previous section, some people may also not want to attend appointments because of the stigma they encounter at some health care services. At Direction 180, methadone is only dispensed in the morning because the limited staff and funding prevent them from being open longer. As one service provider described, many of the clients there rely on the shelter system and do not have alarm clocks so sleeping through appointments can be a real issue.

Another systemic barrier that was also discussed as a resource is transportation. HIV-positive IDUs living on assistance or in shelters have limited options in terms of where they can live but still need to be able to access places like the Infectious Disease Clinic, Emergency Services, methadone clinics, and other health clinics. If their only option for housing is located long distances from these services, the systemic restraints discussed above for accessing transportation affect their ability to attend appointments and receive the care they need.

Because this issue is a combination of both structural and individual factors, there are two approaches to mitigating it. From the systemic perspective, by offering more flexible hours or mobile outreach, such as MOSH, clients would be able to attend appointments more easily and adhere to their treatment plans. Creating more housing options, in particular low-income and transitional housing, could improve individual-level factors.

Organizations such as MOSH, Direction 180, and the AIDS Coalition of Nova Scotia will also support clients by attending appointments with them. Because many of their clients have limited familial or social support, having a community or organization member attend for support can have a huge impact. The most effective option would of course be to lessen the systemic barriers that are present and improve individual-level factors by offering more resources and supports for clients.

### **5.5 Service Availability**

Service availability is another factor in which both resources and funding come into play, but it also entails what services are available and how they are being delivered.

Methadone programs vary from high to low threshold. This determines their leniency in terms of behavioural issues or continued drug use. Some of the service providers discussed the need for more spots for new clients in both high and low threshold programs because the same type of program does not work for every individual. Some people will do better with a strict, abstinence-based program and prefer the structure whereas other people require low threshold because a high level of structure does not work for them. The other important piece is to have transition between the two and, as one provider mentioned, high and low threshold programs running in parallel so that there is more interaction and coordination between the programs. Currently in Halifax there is Direction 180, which is low threshold and lenient with its clients, and there is also the Detox Program, which is high threshold and has strict rules. There is still a missing piece for people who perhaps want a middle ground and there is also no transition if people want to start low threshold and then switch as their therapy progresses. All of



these types of services would of course require more facilities, more staff, and more funding.

Integrated or centralized services was discussed in the literature (16, 77, 82, 84, 86) and by the providers interviewed as a way to improve service availability. Centralized facilities provide multiple services, for example MMT, infectious disease services, mental health services, and primary health care, all at one site. This limits the amount that clients have to travel for appointments and requires less navigation within the health care system. In doing so there is less opportunity for loss to follow up (16). Currently in Halifax, these types of services are fragmented. Direction 180 clients can receive ART with the methadone, but they will still have to attend appointments at the Infectious Disease Clinic. If they have additional needs such as mental health counselling or appointments with primary care physicians the demands can accumulate quickly. Again, these demands can be exacerbated by transportation issues, limited social support, and stigma, as previously discussed. In Halifax, the North End Community Health Centre and MOSH help to alleviate many of these issues by supporting clients, attending appointments with them, or bring services to them through the mobile unit.

A final issue with respect to service availability is simply that there are a limited number of services available for both IDUs and PHAs. One provider brought up the issue that there are a limited number of programs that focus on working with people in active addiction. The emphasis is still on abstinence from drug use and telling people they need to stop using drugs. Not all IDUs are ready or willing to give up drug use and it could be

for any reason such as the relationships and peers they have in the IDU community, that they enjoy IDU and want to continue to use, or that they are not ready at that point in their life to focus on their addiction. Regardless of the reason, programs that work with people in active addiction can have a huge impact on reducing overdoses and fatalities, reducing the transmission of viruses like HIV and Hepatitis C, and improving the quality of life of the clients they serve.

Based on the data from this study there needs to be an expansion of the services currently available as well as a linkage between them to create smoother transitions for clients. It would also be beneficial to have centralized, integrated service delivery and an increase in the number of services that work with people in active addiction. However, these changes are likely not feasible given the current fiscal constraints in public health funding.

## **5.6 ART and MMT Adherence**

Medication adherence was one of the primary topics in this project. As discussed in the literature, ART adherence is difficult because of the rigidity of the regime and the high level of adherence required (95%) (30, 31). Defaulting is also a major concern as resistance can develop (29). A key point from both the literature and from the service providers is that offering medications such as methadone and ART alongside each other can greatly improve adherence. This can also be true for other medications like Hepatitis C treatment and medications for depression and anxiety. Direction 180 can provide these medications for people if they are getting them prescribed and dispense them when

clients receive their methadone. As one of the providers described, methadone is a treatment that makes IDU feel better and helps to manage their cravings and addiction so adherence to methadone is easier for them to maintain than adherence to ART. Therefore by delivering the other medications, like ART, with methadone we can improve adherence for it as well, and many studies have supported this finding (6, 9-13).

One occurrence that a service provider discussed that is not largely found in the literature is that they will encounter clients who, as far as they know, adhere to their ART but have no interest in treating their addiction so choose not to take methadone. It does not seem to be as common as clients who attempt to adhere to both medications but it may be a topic worth exploring in future research.

A major concern about defaulting from ART is that resistance can develop (29) and new, more difficult lines of therapy will need to be used. Some of the service providers talked about having serious conversations with clients about the realities of ART and educating them about why they need these medications. The first line of ART that a person is prescribed is generally the easiest in term of side effects and rigidity, but if they develop resistance subsequent medications lines can be more stringent and difficult to handle. This is why providers seek to ensure that their clients understand the seriousness of the medications that they are taking and help them to decide when is the best time to start them. One provider talked about having patients say that they are not ready to start yet, that they feel that their lives are too chaotic at the present and choose to wait until they are at a place where they can handle taking ART. Not all HIV-positive individuals have

this option if their health is too poor but this shows that these service providers are educating their patients and making sure they provide care that best fits with the patient's circumstances. Another provider brought up the point that it can be difficult to admit that you are not ready for the medication yet. It takes a lot of self-evaluation and awareness to decide when you are ready to start a difficult medication regime like ART so it is important for service providers to be supportive, but also frank about the realities of the treatment.

There are two main reasons a provider brought up that ART is important, particularly for IDUs living with HIV. The first reason obviously is to keep these individuals healthy. IDU is already associated with comorbidities (4) so maintaining health is crucial. The second reason is to prevent the further spread of HIV. If HIV-positive IDUs continue to engage in high-risk practices like needle and equipment sharing, there is a significant risk of passing HIV to other people. ART acts to suppress the viral load, to an undetectable level when taken properly, so that the virus will not be passed on.

Because of its long-term regime, ART will always be a challenge but MMT has repeatedly been shown to help IDUs with adherence. With more education for clients and support from programs, hopefully an environment that facilitates adherence for HIV-positive IDUs will be fostered and the individuals that want treatment will be able to access it.

## **5.7 Policy**

Policy was an interesting topic because service providers were well informed about their own organizational policies but had little knowledge about any provincial or government level policies that impact their work. They did know the constraints that they have to work within, but not the overarching policies that impact this. In general, organizational policies were made with the clients best interests in mind while ensuring that services were delivered in a safe manner. The service providers' commitment is, first and foremost, to the people with whom they work. One problem that was brought up was that larger provincial or governmental policies are made in a top-down approach without engaging the frontline workers. As one provider discussed, frontline workers are so busy trying to provide support and services to their clients that becoming engaged at a higher level is often difficult and requires even more time. Ideally there would be a way to engage these workers with firsthand experience to better inform policy so that services could be delivered in a manner that is more appropriate and accessible for the clients.

As I discussed in the literature review, the political environment in Canada promotes abstinence from drug use as the best and sometimes only option through the Controlled Drug and Substances Act (61). While harm reduction programs are available, the 'war on drugs' makes the programs scarcer and limit the funding that they receive. Additionally, these policies influence the public view of IDU and can lead to stigmatization because it makes IDUs "criminals" since they are using illegal substances. As one interviewee discussed, policies and politicians are influenced by what the general population, their

voters, want. There is limited advocacy for or by IDUs because of the stigma and marginalization around drug use. The people who do advocate for better services for IDUs, such as service providers, are small in number compared to the general population and often overworked trying provide support and act as an advocate. This lack of advocacy worsens the stigma, and the more stigma there is, the more difficult it is for those people who do advocate for IDUs, creating a cycle that is difficult to break. If IDU continues to be stigmatized and abstinence remains the only acceptable choice for the general public, there is little to no motivation for policy-makers to make any changes. Changing this unfortunately requires a radical re-education and change in how addiction and IDUs are viewed. Policies that have more acceptance of harm reduction and engaging individuals in active addiction would hopefully help to create more acceptance in society and encourage more funding for these types of programs.

## **5.8 Socio-ecological Model**

The socio-ecological model examines how both individual and environment level factors interact and influence a person's health (91). This model was utilized in this research as we examined the contextual factors, which are individual to each client, and structural factors, which encompass the ecological or environmental factors. Despite presenting the themes separately, they are all in fact connected and influencing each other. In this case, the individual level factors that were associated with HIV-positive IDUs that had an impact on health and service access were, for example, homelessness and drug use. Although they are good indicators, these factors alone cannot predict an individual's health. These factors are influenced by the individual's social networks, relationships,

and support systems (91). Without adequate support networks, the individual level factors can be worsened. The next level of influence in the socio-ecological model is community. This encompasses the services available to people, which in this study includes programs such as MMT, needle exchange, and community health centres. Finally, affecting all the other levels is society (91). In this study, this was largely covered through stigma and policy. These factors ultimately shape the socio-ecological environment because they influence all levels below them (See Appendix II). The societal environment affects the mentality and perceptions of the community as a whole, which determines how each individual's traits or characteristics are received. At the individual level, HIV-positive IDUs in Halifax are actually quite a small population but they are continually slipping through the cracks in the system and facing high rates of morbidity and mortality. This shows clearly that it is not sufficient or efficient to focus on changing people's individual-level factors without also looking at how the social, community, and societal environments also need to change.

In the case of HIV-positive IDUs in Halifax, there were a number of structural and environmental factors influencing their health. These included limited resources in the programs supporting them, limited access to necessary services, and a political and social environment that stigmatizes them. This can in part be explained by looking at harm reduction and its place in the socio-ecological model. Harm reduction programs, such as MMT, are delivered at the community level and can act as a supportive social network, but ultimately are determined by the societal view of them. As many of the providers discussed, there is still a negative societal perception that harm reduction enables drug

use as opposed to its intended purpose of lessening the harms and risks that are associated with drug use. Therefore, harm reduction within the socio-ecological model is being significantly affected at the societal level, which impacts its ability to work at the community, social network, and even individual levels.

When considering all levels together it is clear that while an individual's personal factors affect their health, these aspects can be greatly affected and exacerbated by a community or societal environment in which they can only receive limited support and services, or which is hostile because of stigma. Truly addressing the issue of poor health outcomes in HIV-positive IDUs will require both individual and environmental factors to be assessed and improved. People need to be given support for individual factors in an environment that fosters and maintains their health.

## **5.9 Conclusions**

Much of what this study found is similar to what is happening for other HIV-positive IDUs in Canada. So although this research was done in one specific city, the overarching themes of stigma and policy, as well as their impact on harm reduction, are applicable to many other places in Canada as it is our government and policies that are setting the tone at the societal level.

The service providers are working vigorously with what they have to provide the best possible care they can for their clients. There is still however the issue that they are working with limited funding and resources and therefore are unable to provide all the



support and services that they would like to. Government and policy, which is driven by voters, determine the funding allocation for programs and services. Unfortunately, there is still a significant amount of societal stigma around IDU, HIV, and harm reduction, and this ultimately shapes the community and environment in which people have to access and receive services. In the current conditions, this stigma makes accessing services difficult for IDUs either by making them feel unwelcome or making the services, such as harm reduction, scarce. There is a societal perception that IDUs do not deserve services and help because they are deciding to use drugs. There needs to be more education around addiction and IDU, as well as HIV, in order for the greater population to understand not only what these “labels” truly mean, but also why it is necessary that we as a society provide services for them. Because they are, indeed, members of our society and deserve support, services, and respect as much as anyone else. Ideally, this research will add to existing literature about HIV-positive IDUs by giving voice to these populations and those who work with them. Alongside this research, HIV-positive clients on MMT were also interviewed. Those interviews were beyond the scope of this thesis but will also add to the literature and give those people directly affected by the system and policy a chance for their voice and opinions to be heard when they otherwise might not. It is important to iterate again that this thesis includes only the perspectives of service providers and may be different from those of clients, policy-makers, or researchers.

If these views were to be changed, it would ideally result in more funding that could lead to more facilities with flexible hours, integrated healthcare centers, more transitional

services, such as MMT and housing, and more accessible transportation. All of these, as the literature review indicates and as the service providers involved in the study have said, would result in better adherence for HIV-positive IDUs, better health outcomes, and more clients retained in the programs.

### **5.10 Recommendations**

There is no doubt that this is a complicated issue with no simple answer. Based on the data from the service providers in Halifax, there are no easy recommendations that I can make because the changes need to come from addressing and reducing stigma and reevaluating the policies that dictate funding for harm reduction programs. All of the programs are already providing the most support they can with the funding and resources that they have. There are services however that I think would benefit with HIV-positive IDUs, and IDUs in general, in Halifax:

- i. More low income and transitional housing options
- ii. Multiple MMT sites with low and high threshold programs working in a coordinated fashion
- iii. Bus passes and other forms of transportation be made more accessible for people with multiple appointments
- iv. HIV, Hepatitis C, mental health, and basic healthcare needs be made accessible in a centralized, integrated way for drug using populations, as well as more outreach services for these populations

- v. Educational campaigns for healthcare workers and the general public to raise awareness about HIV and IDU to help reduce the stigma around them

These changes would ideally improve clients' individual ability to navigate within the system and would also help to change the community and societal perceptions of HIV, IDU, and harm reduction; thus addressing all levels within the socio-ecological model. HIV-positive IDUs are a small subset of the IDU population and therefore may need more targeted interventions to improve health outcomes, such as more outreach services. To achieve this, community organizations like Mobile Outreach Street Health and Direction 180 are best positioned to respond, given the current reach of their services, but expansion requires resources. The most effective way to address this would be to reduce the stigma around harm reduction and allow it to be more widely accepted, but that is a change that will require a significant shift in the societal perception of IDUs. The Canadian Public Health Association has recently begun a campaign to improve the prevention of sexually transmitted and other blood-borne infections, which includes HIV (101). The campaign includes improving service providers' relationship with individuals who are at high risk of infection, such as IDUs. Hopefully through the work of initiatives like this the stigma towards harm reduction and IDU will decline.

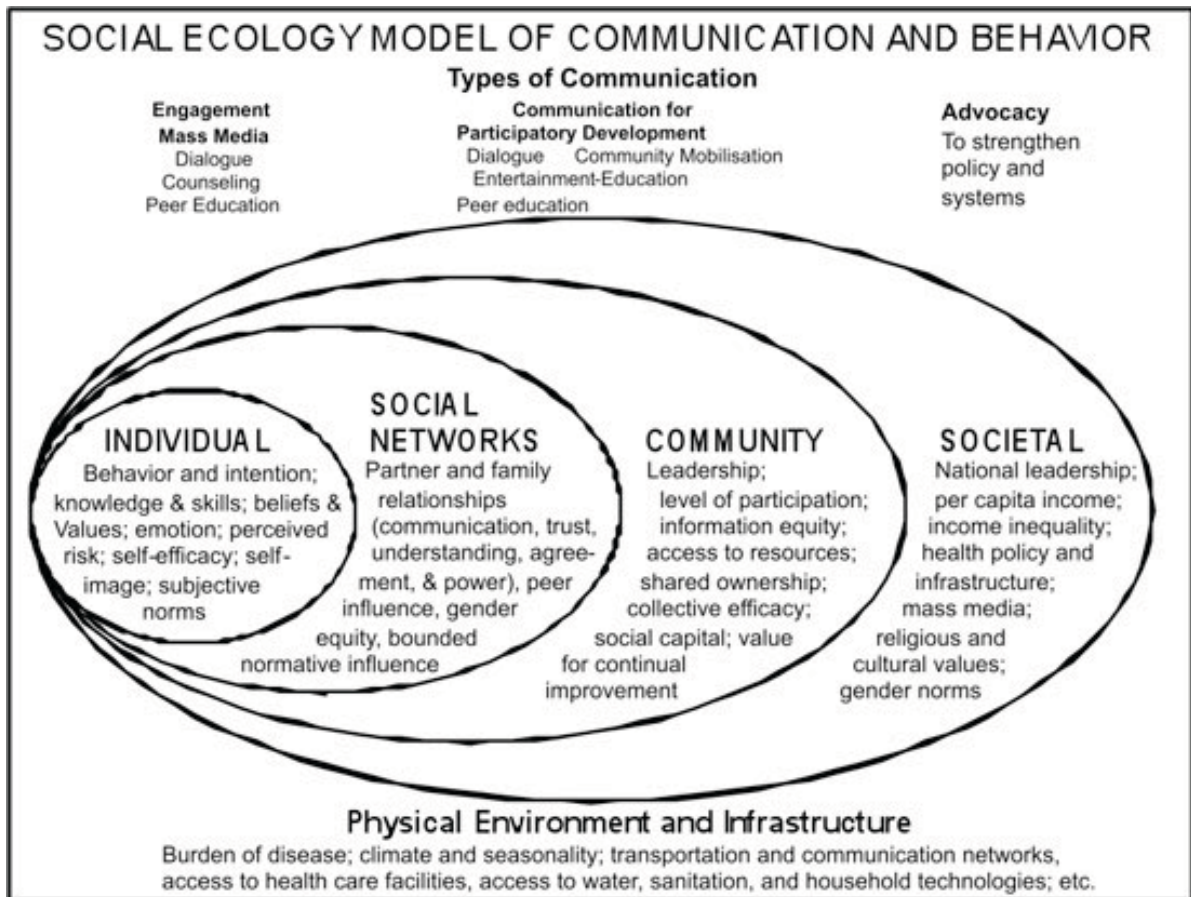
## Appendix I: Services and Programs in Halifax, Nova Scotia

Service/Organization	Contact	Services Provided
Direction 180 (102, 103)	2164 Gottingen St. Halifax, NS B3K 3B4 902-420-0566	<ul style="list-style-type: none"> <li>- Filling and dispensing methadone prescriptions</li> <li>- Nutrition and lifestyle counseling</li> <li>- Disease prevention</li> <li>- Help locating other resources such as food and housing services.</li> </ul>
Mainline Needle Exchange (104)	5511 Cornwallis Street Halifax, Nova Scotia B3K 3B4 Office: 423.9991 Outreach: 830.3853 Toll Free: 1.877.904.4555	<ul style="list-style-type: none"> <li>- Free needles and injecting equipment</li> <li>- Free condoms</li> <li>- Site for safe needle disposal</li> <li>- Raise awareness and education about harm reduction and safer injecting practices</li> <li>- Peer support available</li> <li>- Daily over the counter nutrition and coffee</li> </ul>
North End Community Health Centre (105)	2165 Gottingen St. Halifax, NS B3K 3B5 (902) 420-0303 comms@nechc.com	<ul style="list-style-type: none"> <li>- Medical clinic offering appointments for acute and chronic care</li> <li>- Disease management</li> <li>- Walk-in services for emergencies</li> <li>- Outreach services</li> <li>- Blood collection</li> <li>- Counseling</li> <li>- Nutrition programs</li> <li>- Community initiatives</li> <li>- Addiction and mental health services</li> </ul>
Mobile Outreach Street Health (106)	MOSH Team: <u>Rick Swaine, RN</u>	<ul style="list-style-type: none"> <li>- nursing assessments</li> <li>- Blood work and testing</li> </ul>

	<p>(902) 802-3332 rickthenurse@nehc.com <u>Monica Flinn, RN</u> (902) 802-1919 mflinn@nehc.com <u>Patti Melanson, RN</u> (902) 802-9696 pmelanson@nehc.com <u>Rebecca Marval, OT</u> (902) 802-7785 rmarval@nehc.com <u>Heather Nicholson, Admin</u> (902) 429-5290 hnicolson@nehc.com</p>	<ul style="list-style-type: none"> <li>- Harm reduction supplies</li> <li>- Chronic condition management</li> <li>- Addiction-related support</li> <li>- Services provided in outreach capacity</li> <li>- Referrals to other health care specialists</li> </ul>
Addiction Services (107)	<p>Room 187, The Purdy Building The Nova Scotia Hospital 300 Pleasant Street Dartmouth, NS B2Y 3Z6 (902) 424-8866</p>	<ul style="list-style-type: none"> <li>- Counselling and support groups</li> <li>- Inpatient treatment</li> <li>- Day treatment</li> <li>- Opioid treatment programs, including methadone</li> </ul>
Infectious Disease Clinic (108)	<p>Dr. B. Lynn Johnston, Head Division of Infectious Diseases Room 5014 Dickson Building 1276 South Park Street Halifax, Nova Scotia B3H 2Y9 (902) 473-5553</p>	<ul style="list-style-type: none"> <li>- Variety of services for those living with an infectious disease</li> <li>- Inpatient consultations</li> <li>- Outpatient care from a interdisciplinary team</li> </ul>
AIDS Coalition of Nova Scotia (109)	<p>1668 Barrington Street, Suite 401 Halifax NS B3J 2A2 (902) 425 4882 or (902) 429 7922 Toll-free: (800) 566 2437</p>	<ul style="list-style-type: none"> <li>- Support to those living with and affected by HIV/AIDS in Nova Scotia</li> <li>- Provide information about treatment, adherence, nutrition, and mental health</li> <li>- Offer a space for PHAs to interact and gain support from the staff</li> </ul>

		<p>and each other</p> <ul style="list-style-type: none"> <li>- Counselling services</li> <li>- Financial assistance</li> </ul>
Halifax Housing Help (110)	<p>75 Primrose Street, #101, Dartmouth B3A 4C9 (902) 466-8714</p>	<ul style="list-style-type: none"> <li>- Help with apartment maintenance</li> <li>- Help locating housing</li> <li>- Trusteeship</li> <li>- Moving assistance, and</li> <li>- Help locating other services like income assistance and medical or legal help</li> <li>- Aid those with a history of rental arrears</li> </ul>
Nova Scotia Advisory Commission on AIDS (111)	<p>PO Box 31 6th Floor, Dennis Building 1740 Granville Street Halifax, NS B3J 2L4 (902) 424-5730 AIDS@gov.ns.ca</p>	<ul style="list-style-type: none"> <li>- Focuses on preventing the spread of HIV/AIDS</li> <li>- Providing support for PHAs</li> <li>- Work with AIDS Service Organizations, government and non-government community groups, and those most impacted by HIV/AIDS</li> <li>- Act as an advocate for PHAs</li> <li>- Promote informed government and public action.</li> </ul>

## Appendix II: Socio-ecological Model Schematic



(91)

### **Appendix III: Interview guideline**

1. What services does your organization provide that are used by HIV-positive injection drug users?
  - a. Which are most commonly used?
  - b. Which of the services do you feel are most beneficial to the clients?
2. What are the main challenges you face when working with HIV-positive injection drug users? In your opinion, what are the biggest barriers for you to provide them with adequate care and support?
3. How do these barriers impact your ability to help clients with medication adherence?
4. Are there any policies in place that impact your ability to support clients with adherence?
  - a. Specifically, do these policies help or hinder your ability to provide support?
5. What you do feel needs to be done or changed for HIV-positive IDUs to be adequately supported for proper adherence?
  - a. Is there anything preventing these changes from happening?
  - b. Are there problems unique to your clinic or area?
6. Any additional comments or concerns to do?



## **Appendix IV: Consent Information**

### **Community Based Service Provider Perspectives on HAART Adherence among HIV-positive Injection Drug Users Enrolled in Methadone Maintenance**

#### Research Team:

- Jessica McCann (Primary Investigator/Master's student) – Student of Community Health and Epidemiology (Dalhousie)
- Susan Kirkland (Primary Supervisor) – Professor of Community Health and Epidemiology (Dalhousie)
- Jacqueline Gahagan (Committee Member)– Professor of Health Promotion (Dalhousie)

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  - (902) 494-1235
- Jacqueline Gahagan (Committee Member)
  - jacqueline.gahagan@dal.ca
  - (902) 494-1155

#### Contact for Dalhousie Research Ethics:

- 6299 South St, Suite 231, Halifax
- Phone: (902) 494-1462
- Email: ethics@dal.ca

You are invited to participate in this research study. Participation in the study is voluntary and you have the right to withdraw from the study at any time without it having an impact on your work or career.

#### Research purpose

The purpose of this study is to gain an in-depth understanding of the structural and contextual barriers and facilitators that service providers face when working with an HIV-positive, injection drug user population, and how that in turn can impact HAART adherence.

### Study details

This study is based on interviews conducted with 10-14 community-based service providers who work with current or former injection drug users who have had exposure to joint use of MMT and HAART. This exposure can be current or prior. Each participant will complete one interview. The topics being covered in the interviews will include service provision for HIV-positive injection drug users, experiences and perceptions of HIV and MMT treatment adherence, and barriers and facilitators of HIV and MMT treatment adherence. You will be asked to answer questions on these topics based on your opinions, experiences, and perceptions. Each interview should take approximately one hour. The commitment for each participant is a single one-hour session. The interviews will take place at Direction 180, Mainline, or another community-based agency at the request of the participant.

### Confidentiality

All data (recording, transcripts, consent forms, etc.) will be kept confidential by the research team. No names will be recorded with the data and each participant's data will be assigned a study ID. Workplace and job position will be removed from data if requested. Data will remain locked in an office at Direction 180 and Dalhousie University. Only the research team will have access to data and data will be destroyed after 7 years.

### Risks

Because the questions being asked may be sensitive in nature, there is a risk that some participants will feel emotions such as frustration or anger. We may pause or stop the interview if the participant feels uncomfortable. Participants should also be aware that the interviewer(s) have an obligation to disclose any indication of child or adult abuse and/or neglect to the appropriate authorities.

### Benefits

This project should ideally benefit the participants in the long-term. By gathering information regarding the structural and contextual facilitators and barriers experienced by service providers, we can learn what is needed to improve policy and programs from those directly involved and impacted. We then hope to use this knowledge to better inform and improve the policy and programs in place.

### Data/Results

Participants will be able to review their transcripts upon request but will not be able to retain a copy of the transcript. The final thesis and any publications will also be made available to participants upon request.

### Use of Quotes

With consent, direct quotes may be taken from the transcripts to illustrate findings of the research in publications and presentations. No identifiers will be used with quotes. All quotes will be anonymous.

Please feel free to contact us at any time regarding questions or concerns you may have.  
Thank you.

## Appendix V: Interviewer's Consent Record

ID #					
Interviewer name/ signature	<table style="width: 100%; border: none;"> <tr> <td style="border: none; width: 50%; text-align: center;">_____</td> <td style="border: none; width: 50%; text-align: center;">_____</td> </tr> <tr> <td style="border: none; text-align: center;">Name (Print)</td> <td style="border: none; text-align: center;">Signature</td> </tr> </table>	_____	_____	Name (Print)	Signature
_____	_____				
Name (Print)	Signature				
Date					
Consent for: Circle one	<table style="width: 100%; border: none;"> <tr> <td style="border: none; text-align: center;">Enrollment</td> <td style="border: none; text-align: center;">First Interview</td> <td style="border: none; text-align: center;">Second Interview</td> </tr> </table>	Enrollment	First Interview	Second Interview	
Enrollment	First Interview	Second Interview			
FOR INTERVIEWS					
Consent for use of quotes: Circle one	<table style="width: 100%; border: none;"> <tr> <td style="border: none; text-align: center;">Yes</td> <td style="border: none; text-align: center;">No</td> </tr> </table>	Yes	No		
Yes	No				
Consent to have audio recorded: Circle one	<table style="width: 100%; border: none;"> <tr> <td style="border: none; text-align: center;">Yes</td> <td style="border: none; text-align: center;">No</td> </tr> </table>	Yes	No		
Yes	No				
Consent for use of data in future studies on the experiences of injection drug users on treatment adherence: Circle one	<table style="width: 100%; border: none;"> <tr> <td style="border: none; text-align: center;">Yes</td> <td style="border: none; text-align: center;">No</td> </tr> </table>	Yes	No		
Yes	No				
Does you wish you have your position and workplace removed from interview transcripts? Circle one	<table style="width: 100%; border: none;"> <tr> <td style="border: none; text-align: center;">Yes</td> <td style="border: none; text-align: center;">No</td> </tr> </table>	Yes	No		
Yes	No				

## Appendix VI: Codes

Accessibility

Addiction

    Root Issues

Adherence

Autonomy

Basic Needs

Chaotic Lifestyle

Communication

Co-morbidities

Corrections

Detox

Drug Use

    Dealing

Expectations

Gender

Health Services

HIV Treatment

Income Assistance

Knowledge Translation

Legal Issues

Medication Regime

    Defaulting

    Transparency

MMT

Other Models

Policy

    Government

    Organizational

Provincial  
Population Density  
Programs  
    Between Program Support  
Provider History  
Reprieve  
Resources  
    Food or nutrition  
    Funding  
    Housing  
    Limited Space  
    Service Availability  
    Staff or Hours  
    Transportation  
Stability  
Stigma  
    Societal Perceptions  
Street Involvement  
    Sex Trade  
Support  
    Familial  
    Program  
Systematic Problems

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