Being Open: Exploring primary health care services for women who sell sex and do high risk drugs in Vancouver

By

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ABSTRACT

Women who sell sex and do high risk drugs in Vancouver’s Downtown Eastside have comprehensive primary health care needs. These women access health services much less often than would be expected. There is evidence that primary health care agencies can also be loci of social capital building in communities with a large multiply-marginalized population. This research aimed to identify how agency-level determinants act as barriers and facilitators to the uptake of care as well as to identify how these can enable or impede the development of social capital among women clients who sell sex and do high risk drugs. Fifteen interviews were conducted with primary health care providers and key informants. Data were analyzed using a modified warranted assertion method. Eleven agency-level determinants were identified. The study offers valuable insights into how sex workers who do high risk drugs can become agents in their own care and community experience, as well as how agencies can be reconfigured to facilitate uptake of primary health care by these women.

Keywords: sex workers, Vancouver, primary health care, qualitative, social capital
EXECUTIVE SUMMARY

Women who sell sex and do high risk drugs in Vancouver’s Downtown Eastside (DTES) have comprehensive primary health care (PHC) needs. Sex workers who do drugs in the DTES access health services much less often than would be expected of women with significant health needs. Women often wait to seek care until their situation demands acute care at which point they tend to seek care from other non-PHC providers in the community or take up emergency care. Primary health care providers and their agencies in the DTES are important actors in the PHC experience of sex workers who do high risk drugs. The perspective of providers in this context has never been explored formally. Individual providers, including doctors, nurses, support workers and other staff, can themselves be barriers to or facilitators of care through their actions, words, availability and conduct.

It is vital that PHC providers and agencies are set up to encourage and facilitate care-seeking by women who sell sex and do high risk drugs. First, the development of relationships in the clinical setting, a hallmark of good PHC, is an ideal way to link this group of women to consistent, mainstream social support. Second, PHC providers and agencies are perfectly positioned to help build networks, relationships and opportunities, all of which are forms of social capital. Also, the uptake of care by these women can lead to decreased health risk behaviours and lead to improved health outcomes. Lastly, improved access to PHC will decrease “perceived urgency” use of acute services, and encourage preventative use of PHC services, which is an effective way to both contain health system costs and inefficiencies.

Aims
This research aims to explore the Agency domain of determinants through qualitative interviews with PHC providers in the DTES and key informants. The specific goals are to:
1. Identify how Agency determinants act as facilitators or barriers to the uptake of PHC services by women who sell sex and do high risk drugs.
   1.1. Identify how Agency facilitators and barriers enable or impede the development of social capital among women clients who sell sex and do high risk drugs.

Methods
This study is based on 15 free-response interviews with PHC providers in the DTES and key informants. All interviews were audio-recorded and transcribed verbatim. Data analysis was based on Smith’s modified warranted assertion method and NVivo facilitated the coding process.

Results
The data identifies 11 themes, which are aspects of the clinical care experience, which explain how Agency determinants act as facilitators or barriers to the uptake of PHC services. These 11 themes also show how Agency facilitators and barriers enable or impede the development of social capital among women clients who sell sex and do high risk drugs. The 11 themes are:
Discussion

This research set out to understand how specific characteristics of DTES PHC providers act as barriers to and/or facilitators of care for sex workers who do drugs. The research also tried to identify avenues for social capital building within the context of PHC experiences. The eleven themes illustrate the heterogeneity of primary health care experiences for all clients in this community.

To the extent that they have been given freedom and funding, providers have been creative in identifying the ways in which this particular group of women can make increased contact with traditional primary health care agencies. However, providers from the four publicly-accessible PHC spaces, as well as every key informant, pointed to the limitations of providing creative, flexible, continuous and long-term care to women who sell sex and do high risk drugs.

Certain configurations of these themes serve as barriers to care while other serve as facilitators of care. In and of themselves, one theme configuration, such as limited hours of operation (Theme 1) or large black bars welcoming clients (Theme 5), may have a minimal impact on a woman’s willingness to seek care. However, a combination of barrier or facilitator configurations has the potential to make an agency particularly attractive to a women selling sex and doing high risk drugs in the DTES, and vice-versa.

Implications and Recommendations

The study also found that agency-level configurations are constrained by system-level limitations on resources and mandate creativity. There is an overarching lack of responsiveness by health system actors to the Downtown Eastside, despite the availability of evidence and community-level will to improve how services are delivered to women who sell sex and do high risk drugs. Leadership for the reconfiguration of services must come from both system and agency level, with legitimate involvement of community actors, including clients and providers. The study offers valuable insights into how sex workers who do high risk drugs can become agents in their own care and community experience, as well as how providers can themselves be retooled as assets in the risk environment.
"...I firmly believe in change coming in a moment - an inspired moment between two people, where there's space created for that person to come to their own realizations or have their own visions of themselves..."
– Support Worker in the Downtown Eastside
ACKNOWLEDGEMENTS

I am very grateful to each of the individuals who sat with me and shared their relevant experiences, as both clients and providers, with primary health care in the Downtown Eastside. I was privy to important critical reflection by social workers, support workers, physicians, nurses and other staff on their approach to care for women who sell sex and do high risk drugs.

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List of Acronyms

DTES – Downtown Eastside
HSDA – Health Services Delivery Area
IDU – Injection drug user
MAP – Mobile Access Project
MSP – Medical Services Plan
PHC – Primary health care
PHSA – Provincial Health Services Authority
SRO – Single Room Occupancy
STIs – Sexually Transmitted Infections
SIF – Supervised Injection Facility
VCH – Vancouver Coastal Health


Introduction

Women who sell sex and do high risk drugs in Vancouver’s Downtown Eastside (DTES) have comprehensive primary health care (PHC) needs. They are highly vulnerable to respiratory, dental, gastrointestinal and gynecological problems, nutritional deficiencies, sexually-transmitted infections (STIs) and mental health issues, such as post-traumatic stress disorder and depression. Further, over 70 percent of female injection drug users (IDUs) in Vancouver self-identified as sex workers and almost 40 percent of these women were HIV-positive. These health care problems are further complicated by disproportionately high rates of homelessness as well as histories of sexual and physical abuse.

Sex workers who do drugs in the DTES access health services much less often than would be expected of women with significant health needs. Recent studies have found that barriers to care for this group of women include lengthy wait times, irregular scheduling and availability, no access to female doctors, stigma or discrimination from staff and other clients, centralized care that limits access to particular physicians or previous clinical relationships as well as the location of clinics in high-

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1 Nguyen et al. 2008.
5 Nguyen et al. 2008.
8 Weber et al. 2003.
9 Spittal et al. 2006.
10 Stevenson and Petak 2007.
12 Gibson & Goldstein 2007.
14 Shannon et al. 2008 ‘Social and structural’.
15 VANDU Women CARE 2009.
traffic and violent areas\textsuperscript{16}. As a result, women often wait to seek care until their situation demands acute care at which point they tend to seek care from other non-PHC providers in the community\textsuperscript{17}. These access patterns are not only costly and inefficient but also ineffective as they often worsen individual health. Further, they exacerbate strained relations between clients, PHC and acute care providers in Vancouver.

Primary health care providers and their agencies in the DTES are important actors in the PHC experience of sex workers who do high risk drugs. The perspective of providers in this context has never been explored formally. Individual providers, including doctors, nurses, support workers and other staff, can themselves be barriers to or facilitators of care through their actions, words, availability and conduct. Agency-level policies, protocols and operating procedures can directly impact a woman’s willingness and ability to seek care. It is worthwhile to explore how certain features of DTES PHC agencies and providers can act as barriers or facilitators to care.

This research recognizes three interconnected domains of determinants of health service utilization for this client group in the DTES; Individual, Agency and Systemic (See Figure 1). The Individual determinants have been discussed and this research explores Agency determinants in particular. Systemic determinants refer to the larger institutional framework in which primary health care for multiply-marginalized populations is delivered in Canada. For example, up until the past decade Canadian medical school curricula spent little time addressing addiction issues\textsuperscript{18}. There is very little current emphasis on community-based, client-centred care for homeless and otherwise marginalized populations. Further, behavioural and social factors play a minimal role in mandatory medical education for physicians, nurses and allied health

\textsuperscript{16} Shannon et al. 2008.
\textsuperscript{17} Nguyen et al. 2008.
\textsuperscript{18} Cairney 1997.
professionals\textsuperscript{19}. This is despite the fact that community PHC physicians are perfectly positioned to provide identify substance use issues, and build addiction services support networks\textsuperscript{20}.

Agency determinants operate most obviously within the physical and social space in which health risk is created for women who sell sex and do high-risk drugs\textsuperscript{21}. That is, the PHC agencies in this study are necessarily nested within overt illicit markets for sex and drugs and related activities and are, therefore, community actors. As community actors, PHC agencies may be able to contribute to the social capital of the DTES through the care experiences with women who sell sex and do high risk drugs.

\textsuperscript{19} Institute of Medicine 2004.  
\textsuperscript{20} Negrete 1990.  
\textsuperscript{21} Rhodes et al. 2005
Desired Outcomes:
Optimal PHC service use
Decreased use of acute care
PHC sites contribute to social capital building

Figure 1: Individual, Systemic and Agency Determinants contribute to PHC use outcomes.
Justification

It is vital that PHC providers and agencies are set up to encourage and facilitate care-seeking by women who sell sex and do high risk drugs. First, the development of relationships in the clinical setting, a hallmark of good PHC, is an ideal way to link this group of women to consistent, mainstream social support. Second, PHC providers and agencies are perfectly positioned to help build networks, relationships and opportunities, all of which are forms of social capital. Also, the uptake of care by these women can lead to decreased health risk behaviours and lead to improved health outcomes. Lastly, improved access to PHC will decrease “perceived urgency” use of acute services, and encourage preventative use of PHC services, which is an effective way to both contain health system costs and inefficiencies.

Aims

This research aims to explore the Agency domain of determinants through qualitative interviews with PHC providers in the DTES and key informants. The specific goal is to:

1. Identify how Agency determinants act as facilitators or barriers to the uptake of PHC services by women who sell sex and do high risk drugs.

   1.1. Identify agency facilitators and barriers that enable or impede the development of social capital among women clients who sell sex and do high risk drugs.
**Literature Review**

*Barriers to PHC Access for Sex Workers and Drug Users*

The interconnectivity of system, individual and agency-level barriers to care is apparent in the literature. Women who sell sex are often displaced from the DTES core and health service area in an effort to avoid violence and police\(^22\). The VANDU Women’s Clinic Action Research for Empowerment (CARE) study identified several themes in drug-using women’s negative experiences with PHC in the DTES: stigma from staff, lack of continuity and relationships, no opportunities for engagement, the structure of care provision does not reflect how women access care and significant wait times without guarantee of being seen by a provider\(^23\). Many studies of female drug users and/or sex workers emphasize the non-homogeneity of care needs and experiences for these women\(^24, 25, 26, 27, 28\). That is, what works for one woman may be detrimental to the care of another thereby underscoring the importance of agency-level flexibility and adaptability\(^29\). While there is research literature on the interconnectivity of system, individual and agency factors, it is mostly oriented from the client perspectives. Understanding the provider perspective on how to create a care experience for women who sell sex and do high risk drugs is an obvious next investigative step.

*Stigma*

Of the five studies that examined barriers to care for survival sex workers in industrialized settings, each highlighted stigma and fear of discrimination over other barriers\(^30, 31, 32, 33, 34\). Stigma,
from doctors and nurses in particular, and fear of discrimination or judgment manifested themselves through a woman’s willingness to accurately disclose her occupation or drug use, her willingness to wait for care, her ability to maintain a health care relationship with a particular provider and her willingness to access both tertiary (i.e. detox, rehab) and acute (i.e. hospital) services. There is a general paucity of research that focuses on how health care provider or agency stigma towards sex workers who use drugs plays out in either covert or overt ways, from the perspective of providers or agencies. The majority of provider-centric research is concentrated on HIV-related stigma which provides only part of the picture.35, 36, 37, 38, 39.

Social Capital & PHC

The DTES is exemplary of how an urban space can be “a proxy variable for behavioral, environmental, historical and/or structural factors” in that the community is known colloquially by its social capital deficits: low educational attainment or opportunities, low per capita income as well high rates of homelessness, crime and use of social service agencies. Investigators are just beginning to understand the depth and scope of the associations between social capital and individual health within countries, regions and neighbourhoods40, 42, 43. In a systematic review of empirical research on health and social capital, Islam et al. (2006) define social capital as:

A by-product of social relationships resulting from reciprocal exchanges between members involved in social associations or networks and can be recognized as a public good that generates externalities facilitating cooperation for the achievement of common goals.

36 Foster et al. 2003.
37 Li Li et al. 2007.
38 Li Li et al 2006.
39 Li Li et al 2009
40 Ciccarone and Bourgois 2003.
41 Islam et al. 2006.
42 Campbell and Mzaidume 2001
43 Kerrigan et al. 2006
It follows that in areas characterized by deprivation and factors of marginalization, there is evidence that the breakdown of social networks and social capital is associated with higher rates of drug use and HIV incidence\(^{44}\). Further, these relationships and networks include those between PHC staff and people who sell sex and do drugs and research on HIV risk environments shows that PHC services, including staff, are part of the physical and social space in which risk is created\(^{45}\). Thus, they can also be conceived of as potential loci of social capital building. Layers of marginalization within a community affect the health of the community through various drivers and mechanisms, but social capital theory first demands that community ‘insiders’ (i.e. sex workers who inject drugs) to be positioned as assets\(^{46}\). The theoretical base supporting the use of peers in health care settings has developed slowly over the past decade\(^{47}\). Campbell and Mzaidume (2001) that participatory peer programs can succeed when health knowledge is taken up by non-experts, there is space for rethinking the social and sexual labels of those ‘at risk’ and when health agencies promote the development of “community contexts that enable or support empowerment and social identity processes”. Thus, the role of DTES PHC agencies in building quality peer opportunities, as builders of social capital, is worth investigating.

\(^{44}\) Rhodes et al 2005.
\(^{45}\) Rhodes et al. 2005.
\(^{46}\) McKnight & Kretzman 1990.
\(^{47}\) Campbell and Mzaidume 2001.


**Methods**

*Literature Review*

A review of the literature was conducted concurrently with data collection to enable the iterative generation of potential themes and codes. Key search terms were searched in various combinations to improve search accuracy: health service delivery, stigma, social capital, health care services, sex workers, prostitutes, health care, risk environment, environmental prevention, structural interventions, structural barriers, physician stigma, provider stigma, discrimination, injection drug user, peer programs, peer interventions, peer support, drug use. Databases used were Psychlnfo, PubMed and Google Scholar. All abstracts of peer-reviewed, English language journal articles published between 1999 and 2009 were reviewed for relevancy. Articles selected (N = 291) were read in depth for content relevance.

*Data Collection*

This study drew from qualitative research methods to collect data from health care providers and key informants. Representatives of health provider agencies in the DTES were recruited through purposeful sampling. Participants were recruited via email, telephone and door-to-door. Seven agencies either actively declined participation or did not respond to repeated requests for participation. Providers from eight agencies completed a free response interview of approximately one hour in length. The individual participant representing each agency was someone directly involved in the day-to-day provision of clinical services. Respondents included three experiential support staff, two agency managers, two nurses and one personal support worker. Inclusion criteria for agency participation were:
1. The agency has a street-level presence within the geographic zone commonly understood as the DTES\textsuperscript{48}. In Shannon et al.'s DTES health services and violence avoidance mapping research (2008), the DTES was defined based on service concentration and population density as the "core encompassing 16 street sections, running approximately 6 blocks by 2-3 blocks, although not in a defined rectangle" (See Appendix A- DTES Map).

2. The agency's mandate is to provide some form of primary health care\textsuperscript{49} service to a population that includes women over the age of 18, not including those agencies ONLY engaged in harm reduction (i.e. condom and needle distribution).

The participating group of provider agencies one contact centre, one government PHC clinic, one non-profit PHC clinic, one evening drop-in shelter that offers a weekly nursing clinic, one multidisciplinary municipal outreach team, one nursing outreach program, one housing agency with some onsite PHC and one non-profit social service agency with particular health service mandates. Two of the participating agencies offer services only to sex workers. Among the non-participants were one private dental clinic, one medical services lab, one supervised injection facility, two social service agencies with particular health mandates, one pharmacy and one private family medical clinic.

Six key informants were recruited purposefully based on their expertise and experience with health service delivery and research in the DTES as well on the depth and scope of their experiences with or as sex workers who use high risk drugs. An initial set of two key informants snowballed rapidly to seven and could have easily outgrown the scope of the study. Interviews ranged in length from one to 1.5 hours. The professional designations of these individuals included two sex worker agency coordinators, one outreach psychiatrist, one social worker specializing in addictions, one

\textsuperscript{48} Shannon et al. 2008.

\textsuperscript{49} Shannon et al. 2008.
community support worker, one street nurse coordinator, one government PHC clinic manager and one physician specializing in harm reduction. Each key informant interview began with a free response question tailored to the informant’s experience and expertise and, once more, interviews evolved freely from the initial question. As is standard practice with qualitative research, emergent concepts and categories were tested on an ongoing basis with successive key informants for validity and enhancement, as well as to inform further data collection.

Free response interviews addressed career trajectory of respondent, agency strengths and weaknesses, anecdotes and other points of interest that emerged from the questionnaire responses. The initial question in each interview was, in effect, “Please explain your career trajectory, and how you came to work in this community”. Each interview unfolded organically after this point with interviewees rarely requiring prompting or clarification.

All interviews were audio-recorded with extensive note-taking, transcribed using ExpressScribe and reviewed for accuracy with participants where available. Four of the audio files were corrupted in processing but all were recreated with the assistance of the interviewees. All transcripts were sent to interviewees for final review and amendment and most were returned to the investigator with minimal revisions. Follow-up reminders were sent to participants to encourage review of the transcript, but not all were returned early enough to be included in the analysis. In these cases, the original transcript was used as data. Definitions of key research terms are available in Appendix B: Key Research Terms.
Data Analysis

Interview transcripts were coded using NVivo. The analytic method for this study was initially chosen for its ability to integrate qualitative and quantitative data. With the exclusion of quantitative data, the qualitative data analysis was still informed by Smith's adaptation of a “warranted assertion” method which is based on “the researchers’ repeated reading of the data as a while and then arriving inductively and intuitively at a set of credible assertions....Next, the researcher goes through a process of establishing the warrant for each assertion, assembling the confirming evidence from the record of data50,51. In this study, the emergent, common themes of the clinical care experience are the warranted assertions. That is, the results assert that themes of the clinical care experience do act as barriers to or facilitators of care to sex workers who do high risk drugs based on qualitative evidence. The Discussion explores how the themes operate in a clinical setting as both barriers and facilitators to uptake of services, and how this is connected to social capital building. Themes were identified through at least three coding passes of the data. Themes were not determined a priori. The qualification of a particular category of data as a theme was predicated on its relatively frequent appearance in the data with both participants and key informants. All emergent themes were reviewed for relevance and fit vis-à-vis those characteristics of the care experience that were not included as themes.

50 Greene 2007
51 Smith 1997.
Results

Themes: Barriers and Facilitators

Eleven themes of the clinical care experience or clinical space emerged from the interviews. Each theme is presented in terms of how it acts as a barrier or facilitator to uptake of care by sex workers who do drugs. The order of the themes presented in this section represents the order of their appearance in the data. There is no evidence to indicate that one particular theme has more or less explanatory power than another. In fact, it is the intersection of themes that creates situations of marginality relevant to the primary care experience. The Implications section focuses on the order in which each aspect could be addressed according to effectiveness and to where the conditions for successful intervention exist. With each theme, participants’ description of how each operates as a barrier or facilitator is described. Textual examples are presented under each theme.

In general, the same strategy used by different agencies may manifest differently as a barrier or facilitator. Just as the needs of each woman cannot be homogenized, neither can the features of the care experience that may work best for this particular group of women. Further, it was found that some agencies implemented particular strategies, rules or work routines in order increase uptake of care opportunities by this client group, but it was later found that these very strategies, rules and work routines acted as barriers to care.

References to the failures and assets of the health systems in which DTES clinical services are delivered were made constantly by all interviewees despite the explicit focus of this study on agency-level factors and care experiences.
THEME 1: Hours of Operation

BARRIER: Not available at night or early morning when clients are working; Not open or at minimal capacity during peak periods; No women-only time considerations or hours.

*And again, it's a Monday to Friday, 9am to 5pm, appointment-based. So, really there are very few programs operating outside of those hours, on the DTES.*

FACILITATOR: Services delivered in the early morning and all night; Flexibility to respond to changing high-volume periods or seasons; Women-only hours.

*And people talk about that the patients in the DTES are not compliant with treatment, they're not compliant with treatment because things are not open when they are. We have no issues with compliance...*

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*What we deal with at 1am, we were the people that put pressure on that wound and got you to the hospital and you came back at 2pm the next day, and we were able to talk about it, and what exactly happened that you got so beat up. But, if we weren't there at 1am, you would never have come back at 2pm to have that conversation with us.*

THEME 2: Involvement & Asset Use

BARRIER: Clients skills and networking capabilities not acknowledged; Agency decision making does not include service users; Particular group of clients act as spokespersons for all clients; Input of clients or community-based providers not taken into consideration in service planning.

*Last summer... I did a consultation series of focus groups here to develop the Ranier, and one of the big things that I heard from our members is that nobody listens to them, and they get asked these questions and they tell them. And then they go ahead and do whatever the fuck they were going to do anyway.*

FACILITATOR: Opportunities for clients to be engaged in their own treatment plan or in service delivery that acknowledge individual barriers; Meets a critical clinical level of involvement; Staff value the experiences of clients in their own care; Clients demonstrate respect towards staff with which a rapport is developed.

*I would say 'have you thought about getting off the drugs? Into detox or recovery?'. Depending on what the answer is, 'well, what was it like for you? Where did you go?'*
What were the barriers?’. Depending on the answer. Because you’re following their lead all the time. Have you thought of? Well, you managed to get off for a few months last time, so you know you can do it. And build on that

THEME 3: Peer & Community Opportunities

BARRIER: No peer opportunities; Peer opportunities are poorly designed and inflexible; Past peer program failures deem future attempts impossible; Peers unsupported in their work and own personal care experience; Peer opportunities occur in activating environments with former or current clients; Peers not included, trained or held accountable in tailored, appropriate ways.

It’s hard to connect, for people with such low self-esteem you want to be able to provide opportunities that allow them to say, at the end of the day, ‘hey, look what I great job I did’. There are just not a lot of great peer opportunities, we can’t create them. It just doesn’t happen.

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... I don’t think it’s simple – just saying peers can handle it better than professionals, certainly some peers respond to aggression with aggression... It takes quite a bit of training to not respond to your fear. ... If you don’t have that training, and you don’t have some experience not responding out of fear, it becomes tricky.

FACILITATOR: Peers are treated with trust and respect by staff; Peer opportunities are tailored; Advisory boards or groups have community members; Using peers in innovative, creative ways in clinical settings; Peers are included, trained and held accountable; Peers are involved in the design of their own work plan; Peers are used appropriately as conduits to and between client groups who do not access traditional sources of care; Peer programs make use of Elders where appropriate.

Like the woman cleaning outside right now, so it’s a little bit of this and sooner or later, she’s going to say ‘I want to do this’ and it takes years. We do not pay you on the day, we’ll feed you, you hang your coat with us, you go for lunch with us, you get called by your first name, it’s everything but a key.

~~~

I’d be walking down the street with a peer, and somebody would come up to me that I had not quite been able to connect with, and they would come up to the peer first, and then that peer would help that person get connected to me. And some things that another person would ask, would be ‘well, how’s so and so hotel and what would you recommend for a place to stay?’ And I would say – you can’t ask me, well, you can but I don’t know and here’s the person [peer] that can help you.
THEME 4: Location

BARRIER: Located in very ‘activating’ or violent corner; Service built in high-traffic and high-chaos area; Agencies demand ‘extensive’ travelling on clients; Services not available in known ‘stroll’ areas.

There’s areas on Cordova, Powell and Hastings, that the women don’t want to go to... it’s either police presence or drug dealers. But they’ve, they’ve got their ways of getting to places. But sometimes what happens that prevents women from accessing services is, you know, they have a no-go thing from the police. And so they’re too afraid to go in case a police officer sees them.

FACILITATOR: Clients are met and engaged with in their routine spaces; Services are spread apart across community; Agencies understand how community dynamics affect services use; Agencies have non-invasive presence in ‘stroll’ areas.

For anyone in the DTES, walking 3 blocks is like going 300 miles. So, the women who access WISH are not the women who are in this area, so they’re not being serviced. So, we see a different population than what WISH would see, just because of our location. As I said before, women are in and out quite a bit and not sitting down..

That means, given our location in this laneway, you could be using in this laneway and come in.

THEME 5: Physical Structure

BARRIER: Black bars on entrance; Spit shields between reception and clients; Buzzers required to enter agency while open; Security service people are intimidating waiting room presences; Clinic rooms designed to reinforce power hierarchy

And up goes the Plexiglas shield and people who won't look you in the eye and all that kind of stuff.

And if you’re going to build a facility that is supposed to attract the most marginalized people in the world, you don't put up gates, and fences and spit shields to keep them out. You're sending a message 'It's us, and it's you'.

FACILITATOR: Space enables movement and privacy of clients; Space enables staff to create safe distances in case of particularly aggressive clients; Space is not intimidating and does trigger client; Security measures are muted (i.e. white bars) or well integrated into agency space.
I am always a more open person. I just think the look of having it more open is better. And I have also had some really uncomfortable experiences with clients. If I was running the show, I would have a much more open look. I think you need to have some distance – you can only spit so far. And the bank look, big counter, no place to put your feet...

THEME 6: Attitudes, Work Routines and Clinical Protocols

BARRIER: Personal biases not addressed and assumed; Judgmental looks or comments; Personal issues playing out on clients/members; No staff debriefing, sensitivity training or other meetings; Clients are removed from agency for unusual or chaotic behavior; There is no formal way for client to submit complaint.

... So, you can have training on how to diffuse the situation, but do you get training on ‘ok, here’s a person that’s looking like hell, she’s obviously working on the street, she’s injecting, she’s swearing...’ the thoughts and feelings that come up for you in that moment...need to be talked about, need to be discussed. Need to be thrown out there... But, there’s another part – on you know – society tells us, that it’s not good what these people are doing – so, well it’s not good what they’re doing – why are we delivering care to them?

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The implication that I am a vector of disease, that I’m an environmental risk to anyone was profoundly hurtful.

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... and so the doctor is automatically on guard the minute you go in there and you’re an IV drug user or a sex worker...”

FACILITATOR: Personal biases addressed and critically examined in a supportive staff environment; Staff can “get naked”; Staff engage with harm reduction and social determinants of health discourse/head space; Routine staff meetings; Flexible protocol; Autonomy; Judgments are unacceptable; Specific accommodations made for clients demonstrating unusual or chaotic behavior; Established and appropriate complaint mechanisms available to clients.

I have a saying that, you know, you gotta get naked. Our barriers are in our head. Ok. So I was raised middle-class. I am white. I am a whole bunch of things. I understand. I have empathy. I haven’t been a sex worker. I haven’t been an IDU. So, how can I make that leap?

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You wouldn’t be excluded because your behaviours were different or unusual, and the staff are expected to manage those behaviours.

THEME 7: Gender Awareness

BARRIER: Limited acknowledgement or understanding of how gender impacts health decision-making and access to care; No time or space options for women only; Ongoing violence towards women clients not consistent part of treatment plan or care experience; Sexual and reproductive health care is very secondary to drug use-related care.

And to the extent that gender plays a role in terms of how you engage is minor in the context of everything else that is going on.

A: What about women only? Would that be important? Do women care about accessing services that are only for women?

Some do, some don’t.

I think if there’s a section for women, but just strictly mental health population down here, there has to be something for them.

A: The Burnaby Centre is not good enough? Big enough?

6 month wait list now.

There is the Tuesday Women’s Night, but it’s not enough.

FACILITATOR: Aware of and sensitive to gender dynamics of violence, migration, drug use and sex economies in DTES; Women-only services, time blocks or spaces available; Women providers available upon request for clients at all times; Sexual and reproductive health is a cornerstone of care experience.

I found it extremely difficult to connect with women, who are very complex, compared to men ... I think it’s the emotional side... due to where they find themselves, how they find themselves where they are. Why. They’re more prone, I think, to the rapes, the second-on-the-needle, a lot of things.

We have 3.5 hours on Wednesday night, that women can come in for clinical service. The reason we did this because it was clear that there were many women who simply were not going to access services during the day when the clinic is usually very busy and there are usually many male clients waiting to be seen. The idea about holding it in the
evening was really to attract sex trade workers and homeless women who were able to come during these hours.

THEME 8: Services in Community

BARRIER: Cannot address “crisis access” profile of clients; Services are not integrated into DTES service network; Working with clients’ desire to remain in community; No links with sex worker agencies in community; Agency does not recognize the multiple simultaneous needs of client group; Agency does not act on or is unaware of under-accessing groups of women.

...And so here, it's a clinic. You come in with a medical complaint, and we don't have a facility for people to spend time, just in rest, sleep somewhere. Talk to other women with like circumstances, networking, that sort of thing."

FACILITATOR: Understanding the migration potential and direction of specific clients; The hazards associated with movement and work in DTES; Agencies make use of DTES service network/ high concentration through referrals and partnerships; Agencies directly seek out under-accessing populations and advocating with them; Agencies are flexible and responsive to emerging demands.

A: what about having a physician in here?

Yeah, we’ve thought about that, that would be fabulous.

A: Can you get anyone to do it?

Nobody’s offered, but we haven’t asked either. I think that would decrease the barriers a lot, because they know that anybody we bring in here, we trust. And if they trust us, they will trust these people.

THEME 9: Staff

BARRIER: Staff do not want to work in DTES or with these populations of clients; Staff work in isolation; Staff are without wide berth of relevant experiences with vulnerable populations or chaotic clinics; Staff are unsupported by management teams; Hiring processes do not reflect challenges associated with working in DTES; There is insufficient staff to handle case loads; Insufficiently staffed clinics are rounded out with inexperienced, under-qualified support staff; Hierarchy of staff is clear (physician, nurse, experiential support workers) and interferes with team cohesion.

Because as much as experiential knowledge can help us to understand, it also allows for much larger blind spots in our thinking.
A lot of people here, when I first came and started to talk to a client, they’d be like ‘oh don’t bother, they won’t go’ or ‘no!’’. One of the women wanted a bed at a recovery house, she went the next day, we got her a bed, she was clean for three weeks, but everyone was like ‘don’t bother’. A lot of people in this field, not only do you give up on yourself as a client, but the staff give up.

...with regards to barriers and judging, people don’t choose where they work sometimes...I really think that if you’re not wanting to work with this community, I think that would be a barrier. But, you know there’s an urgency to fill a job...

I mean, [stigma] can’t not influence the work environment. ...you become to some extent desensitized to the experience of crisis because it’s going on all the time, that desensitization is good at times, and not so good at other times....if there’s been a traumatic event, like an assaultive client, we tend to not see the impact on staff, and it comes out in ways that are not constructive...so it’s very hard to tell the impact on a staff member, and we’re not particularly good at helping staff when those things happen. And staff aren’t really good at being up front and honest about how difficult it was...we have all the right training, but there still is that human piece that doesn’t quite fit theory quite as nicely as we’d like it to.

FACILITATOR: Staff want to work in DTES and with people with addictions and mental health issues; Staff are experiential or have extensive experience with vulnerable populations; Staff are expert ‘de-escalators’; Staff are community members; Staff act/feel like a team; Staff are hired based on their specific expertise with similar communities and/or populations; Sufficient number of staff used effectively; All staff input is considered in planning services.

I think the beauty of both [] and [] is, um, nobody who works for either organization is going to sit down with you and say ‘when are you gonna get out of sex work? Don’t you think you shouldn’t be doing this anymore? When are you gonna stop using drugs?’ We never have those conversations...

We all feel very passionate about the job that we do. For me personally, you need to work as a team. Because you will not sustain down here if the dynamics of your team do not work well.

THEME 10: Availability & Demands on Client
BARRIER: Agencies closed to new clients on a regular basis; Difficult to get appointments; Consistently long wait times; Cannot leave agency space and remain in line to see provider;

*If they are coming in, then they are proactive and if I don’t see them, then they aren’t proactive. There are a lot of women that I am not seeing.*

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*Sometimes, it’s difficult to get the women into those places just because they’re short of doctors...essentially, that’s it. Essentially, they’re not taking new patients.*

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*There are not enough sheer numbers, and they bar people! What is this barring business? The people getting barred are the ones you need to help, the tough ones.*

FACILITATOR: Flexible appointment structures; New clients taken; Outreach is part of primary service delivery; Clients can return to agency during long waits; Waiting is productive; Agency understands and values client’s time; Reasonable expectations on client; Clients can meet other needs while waiting; Agency uses non-traditional means to contact clients without traditional contact information.

*So, people will access care, and they do in their own time, just like us, when they have 5 minutes. Their work consists of how to be safe in the day, how to get food in their mouths...*  

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*Wherever you are, is going out. To where people are at. That, for us, can be an alley. An agency. Their home. Wherever. So, when you start to do that, you leave the comfort zone of the 4 walls. Whether it be the clinic or hospital or this office here.*

THEME 11: Orientation Towards Relationships & Trust

BARRIER: Care experiences offer little opportunity for relationships with clients; Staff do not want relationships with clients; Staff are unable to spend time with each client to deal with interwoven health and non-health needs; Clinical skills are not modified to meet the unique needs of this client group; Professional relationships with clients not seen as a way to enhance their treatment.

*Yeah, but even with a counselor on demand, to deal with that level of trauma, you got to get the trust going. And then you got to start breaking that stuff down, you got to get them reconnected with their bodies, which you don’t want to do if they’re still actively involved in the sex trade because that’s damaging.*
Connection and communication is fundamentally the crux – you’ve gotta focus on those two elements to really crack the nut, and I don’t think health is really good at listening. I think we are getting worse and worse at it. I think there’s absolutely elements that work in this system, for sure, but it’s a hard thing to do. It’s a hard thing to do when you’re rushed. Every day, there’s more tasks to do, from a nursing perspective, the emerg nurse – they do a fantastic job, nurses on medical floors, they do a fantastic job, but there’s no time for them to have a conversation with an individual who really needs you to listen.

FACILITATOR: Client-provider relationships are central to care experience; Providers attempt to tailor care to relationship; Actively engaged philosophy of care; Disclosure of occupation is voluntary; Provider is available to listen to all concerns; Staff understand the importance of support for this client group.

A: What is your work?

Building trust....capitalizing on trust...and making sure that the barriers come down.

And, so, yeah, for me it’s 90% listening. You actually don’t have to say much. But you have to be comfortable in that listening mode. They’re not looking for advice mostly, and if they are, they’ll ask for it. They are just looking for you to be someone that they could trust, that they could have a relationship with that is possibly around to maybe help them out.
Discussion

This research set out to identify understand how Agency determinants act as facilitators or barriers to the uptake of PHC services by women who sell sex and do high risk drugs. A sub-aim was to link these agency facilitators and barriers with their capacity to enable or impede the development of social capital among women clients who sell sex and do high risk drugs. In doing so, the research tried to identify avenues for social capital building within the context of PHC experiences. Eleven themes of the clinical care experience at DTES primary health care agencies were identified as important in understanding the relationships of interest. The eleven themes illustrate the heterogeneity of primary health care experiences for all clients in this community. Before discussing these eleven themes, a few comments on the systemic and institutional networks in which agencies are situated are important.

 Outsiders: Systems and institutions

To the extent that they have been given freedom and funding, providers have been creative in identifying the ways in which this particular group of women can make increased contact with traditional primary health care agencies. However, providers from the four publicly-accessible PHC spaces, as well as every key informant, pointed to the limitations of providing creative, flexible, continuous and long-term care to women who sell sex and do high risk drugs. These limitations exist as individual and systemic determinants of PHC utilization (See Figure 1). Individual determinants for these women include, but are not limited to, the multiple ways in which problematic drug use affects one’s ability to make and keep doctor’s appointments, wait in line at clinics, keep track of personal health information and implement preventative and harm reduction practices. Systemic determinants identified include insufficient staff and resources to operate all, or
even a fraction of, agencies at necessary capacity or to mainstream outreach activities into primary health care practice, were even more prevalent in the responses of participants.

When clinicians ventured to explain those clinic-level processes relevant to this study, they quickly situated their descriptions in the context of health systems, funding constraints and often made broad philosophical forays into the usefulness of individual, biomedical health models for this group of women in this particular community. That is, they reiterated how the systemic domain of determinants is a fundamental part of the risk environment. Moreover, the extent to which primary health care settings in the DTES are free to respond to community- or agency-identified need may depend little on insider-driven forces, and very much on high-level systemic and institutional leadership. Providers routinely commented that services designed for this community are not equipped to deal with the most urgent and most severe cases, nor are they implemented in a way that would ensure the uptake of services by the hardest-to-reach clients. The systems and institutions which dictate how primary health care services are delivered are unresponsive.

*Our regional health authority has yet to really say in a way that indicates they mean it, how can we best respond to you? Find a way to ask that question, and then act on that information. It’s not rocket science, and I don’t think it’s all that complicated. Find a way to ask that question...*

*~ I have seen them design services down here. What is that responding to? ~*

*Community resources for these women, there is the [] and this is a clinic? Really? It’s more of a group of independent solo artists. Vancouver Coastal Health is dysfunctional, and they run that outfit?*

It is no longer up for debate that access to PHC for non-acute complaints, which is a proxy variable for access to a large number of social services for marginalized populations, is low for women who sell sex and do high risk drugs in the DTES. This
paper discusses agency-level options for addressing the barriers to care, but these must be implemented by a system that is listening to community voices, which includes providers in the DTES. Many providers expressed deep frustration over showing up at work each morning with a ‘hands tied’ sense. That is, they are not supported in doing the listening, care-giving and comprehensive treatment planning in the creative, original and sometimes unprecedented ways demanded by the clients in this community. When asked about whether all-night access to a primary care provider would be particularly important for women who sell sex and do high risk drugs, one provider commented,

*Is it needed? Who answers that question? You do a needs assessment, and we don’t do that stuff, we don’t ask those questions in ways that are meant to illicit a response that – whether we’re comfortable with it or not – we’re going to respond to it. So, we don’t go out and really, really ask those questions. So, we as a system, if we really cared about providing a service that was going to respond to whatever the community threw at us, we would have answered that question a long, long time ago. But, whose responsibility is it? It’s VCHA’s responsibility. They have the authority for and the responsibility for providing effective, appropriate health care services within their HSDA, which includes the DTES.*

Neither the ‘top’ nor the ‘bottom’ is seen as particularly mobile, active or assets-oriented despite widespread acknowledgement of major problems. It seems that clinicians are kept at arm’s-length from the systems by which they are employed which means the clinicians do not have the support required to address observable service gaps. One excellent way for a system to hear service user voices is through its clinicians. However, when agencies are structured such that large contingents of service users are not making ‘through the door’ and clinicians have no mechanisms through which to channel community voices, it makes for a situation in which no one is listening. Thus, the observations made by this investigator of profound provider frustration with the unresponsive systems in which their work is enmeshed.
Even agencies that do not report to VCHA, such as the non-profit centres with nursing care available, are dependent on the health authority for partial or full operational funding. These agencies were also the ones with the creative license to consistently make use of the ‘facilitators’ in each of the eleven themes identified by this research. Still however, comprehensive primary health care is delivered almost solely by VCHA services in the DTES, with the exception of two non-profit clinics, one of which was included in this study. That is, constraints within and implemented by VCHA affect the entire network of services providers by limiting how user input is collected, heard and rendered important. Though this study intended to explore agency-level characteristics and will avoid examining in further detail the system level limitations of this work, this is an important area for future investigation that must be taken up by health system authorities themselves.

**Agency themes: Bringing people into their own care experience**

Eleven themes of clinical-level care experiences which can be used to increase uptake of services by, as well as enhance the social capital of, women who sell sex and do high risk drugs were identified. Certain configurations of these themes serve as barriers to care while other serve as facilitators of care. In and of themselves, one theme configuration, such as limited hours of operation (Theme 1) or large black bars welcoming clients (Theme 5), may have a minimal impact on a woman’s willingness to seek care. However, a combination of barrier or facilitator configurations has the potential to make an agency particularly attractive to a women selling sex and doing high risk drugs in the DTES, and vice-versa. Each theme will be discussed individually in terms of its relevance for the social capital building in the DTES as well as in context of the other themes.
Figure 2: Eleven agency factors are important to the care experience of women who sell sex and do drugs.
In the DTES, after 9:30pm, primary health care is unavailable without accessing emergency services. While the same is true of most other communities in Canada, women who sell sex and use high risk drugs are dramatically over represented in this community and it is at night when street-level sex workers are awake, working and actively engaged in meeting their needs. One centre is open, without nursing support, until 6:30am but individuals who come to this centre in need of primary health care support during the night are linked with emergency services. They will be asked to leave the community to seek care, usually via ambulance, at a Vancouver hospital. According to staff of this centre, when individuals face this situation they consistently demonstrate reluctance to use emergency services but will sometimes return during ‘nursing’ hours to the community agency to seek primary health care. Provider perspectives are contradictory on whether all-night services are really required. In explaining a recent scale-back of clinic evening hours during one of the three women-only evenings in the community, one provider stated that there was insufficient demand after 8:30pm to justify operation. Another outreach-based provider insisted that the cost of staffing all night hours with physicians and/or nurses could not be justified by observed demand. Yet another outreach nurse explained that the sole reason her agency adjusted its hours to begin at 6am, as opposed to 8am, was to access sex workers as they ended their work periods.

If it were consistently available, sex workers may make use of primary health care services at night. Explanations offered by providers in this study for why night care is not currently available rely on economies-of-scale rationale. That is, not enough sex workers, as opposed to no sex workers, would access care during these hours. Providing physician, nurse and support staff is, admittedly, very expensive. However, there is no
evidence of a long-term, comprehensive cost-benefit analysis or cost-effectiveness analysis ever having been taken up by VCHA on this issue. One senior VCHA addictions specialist verified that type of costing has never been done. An investigation of this nature would be required in order to determine exactly how many and how often sex workers would have to seek care before any provider could say with reasonable evidential support that night-time demand is insufficient to justify night-time PHC services.

Further, the establishment of the only all-night government-run centre in the DTES in the early 2000s was predicated on the then pervasive notion that people in the DTES required a place to receive support at night. The original intention for this centre was to become an all-night clinic, located at the intersection of Main and Hastings Streets, with full physician services. Thus, system actors have been aware for at least a decade of the community’s demands for such a centre. The current iteration of this centre has no physician support, is not open 24 hours per day and has nursing support between 1:30 and 9:30pm on four days per week. There is a clear disjunction between what level of service provision can be economically justified and what level is actually required by the community, sex workers included. Until a traditional comprehensive economic analysis is done, with community consultation, arguments about whether the cost is justified are moot.

The justification of all-night services could, however, be made without reference to economic feasibility. In Canada, access to primary health care is a clear federal directive, regardless of cost and the “disposability” of the population, and is linked directly to the right to health. Women who sell sex and do high risk drugs are among the least likely to access care and it follows that measures, even if not economically
justifiable in a short-term sense, must be taken to engage this group of women. The most obvious place to begin such a process is to be “open when they are”.

Theme 2: Involvement & Asset Use

Those providers for which outreach is a significant portion of their work were emphatic in their acknowledgement of the intangible assets of this client group, “Absolutely, the women that I come across that use drugs and work in the sex trade have fantastic amazing skills. Communication wise. Non verbal and verbal. And a whole bunch of assets that we as a health care system could draw on, use, work with and work alongside!” They were equally insistent that bringing these women and their assets into the fold of traditional primary health care services was ripe with challenges and depended on the ability of service providers to build relationships and develop trust (Theme 11) as well as the availability of programming for these women (Theme 3). Agencies must be equipped to welcome and support women who, initially, will likely refuse to wait for service, potentially cause waiting room disturbances and may be unable to adhere with recommended treatment plans. Agencies must also be able to recognize that each of these women is a powerful actor in their own care. While many agencies respond to clients exhibiting these behaviours with sanctions or suspensions, the participating providers from agencies that respond by providing space, ‘ears’ and support suggested that they have success in maintaining relationships with these women. Unfortunately, these are not the same agencies that provide comprehensive PHC services, staffed by physicians and mental health workers. In fact, one PHC clinic manager stated their preference for the division of medical and support services between the government and non-profit sectors in the community, “You have to look at it like that the medical can't do everything. There are a lot of community organizations that offer housing, and various
types of support that are not medical, and we work with those organizations, and they
don't do medical. And they refer here, there are many places in the community that
provide these services.”. This divisive orientation is examined in more detail in Services
in Community (Theme 8).

Involving women who sell sex and do high risk drugs in their own care happens in
very subtle but oft-overlooked ways. Participants were able to describe these ways in
context, but rarely as overarching principles. Primarily, it requires providers to relinquish
the assumption that, in seeking care, a woman is implying her intentions to stop selling
sex or doing drugs. Second, it requires providers spend the majority of their time
listening. Thirdly, for outreach workers, it requires that they pay attention to the
community dynamics easily witnessed from any agency’s door: Who knows who? Who
influences others in potentially positive ways? What do women say they need? Where do
they spend their time during the day? Where do they avoid going? Most providers do
not have a deep knowledge of the community dynamics of the DTES, because the two of
the three markets upon which this community depends - drugs, sex and social services –
operate at a careful distance from mainstream services. Women who sell sex and do high
risk drugs in this community are, inherently, community experts. If an agency truly
wants to exist as a constructive force in this very unique community, women who sell sex
and do drugs must be seen and treated as experts, not environmental hazards.

Theme 3: Peer & Community Opportunities

Three creative examples of peer programs operated by participating agencies
emerged in this investigation as being potentially adaptable to a clinical setting. These
programs exist within a non-profit community outreach agency, a drop-in shelter and a
mobile outreach van respectively. Consistent peer programs, that draw participation from


women in the DTES, are non-existent within PHC-only sites. The features of facilitator peer programs are described in detail in the Results section. Drawing from these features during interviews with providers from PHC-only sites, I asked about the feasibility of various suggestions floated over the course of this study by sex workers and providers alike such as peer ‘booths’ in waiting rooms and peer navigators to assist clients while in clinic rooms with physicians. These suggestions were met with hesitancy and reluctance, usually with good reason. Past attempts to integrate peers into health care settings have been unsuccessful because, according to representatives from PHC-only sites, requiring peers, many of whom are active drug users, to complete four hour shifts on a regular basis while surrounded by individuals who could be former clients, dealers, intimate partners or abusers is unreasonable. Successful peer programs in the DTES, however, possess none of these features. Prevailing ideas about peer programs appear to be based on rather rigid principles for involvement. Peer programs are opportunities to help individuals build self-esteem, keep busy, meet new people and be an example to their community. Peer programs are not simply ways to complete menial agency tasks, and the most successful peer programs in the DTES involve individualized training, accountability mechanisms, opportunities for growth and future employment. Each peer is included in the development of their peer role. No one can take a particular individuals’ peer shift, in the event that they are absent, because the role is tailored and facilitates a sense of ownership, as well as camaraderie amongst peers and agency staff.

The link between quality peer programs and individual health is intuitive and demonstrated clearly in the case of one participant agency. When an individual, including women who sell sex, becomes a peer with this agency, they become a community ally. In exchange for their regular work detail, they receive scheduled monetary compensation and assistance navigating various social service agencies in the
community. The peer also provides staff with a wealth of knowledge about the community and its social networks. This, in turn, helps agency staff locate and maintain relationships with other clients (Theme 11), allows them to implement preventative care and to establish a cooperative community presence (Theme 8). Because of their peer reputation, this particular agency was asked to facilitate a weekly women-only PHC clinic evening. Their ability to capitalize on the assets of community members meant that their presence would be a welcoming and supportive one for women reluctant to access this same clinic during regular hours. Even if a woman herself was not involved in this agency’s peer program, they very likely know someone who is and, through these informal mechanisms, trust networks are built in the DTES. This is one particular loci for future efforts of traditional PHC agencies.

*Theme 4: Location*

The recent Vancouver Area Network of Drug Users (VANDU) Women’s Clinic Action Research for Empowerment Study (CARE)\(^52\) group critically examined the benefits and disadvantages of the two government-run comprehensive, multidisciplinary clinics or ‘one-stop shops’ in the DTES. Most significantly, no other PHC sites in the community, either for-profit or non-profit, offer the same scope of services in one centralized location as these government clinics. While some PHC sites in the community are located in chaotic, dense intersections, most are displaced slightly from the highest traffic areas, as is the case with the two government ‘one-stop shops’. One of these is also located in close proximity to the most well-known ‘stroll’ in the DTES at the intersection of Powel and Princess Streets. Centralization of care in this community may be an effective strategy for some clients, but for women who sell sex and do high risk

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\(^{52}\) VANDU Women’s CARE Team 2009.
drugs, their daily routes, social hubs and venues rarely shift. Most have well-established mechanisms for meeting their most pressing needs within a few blocks, or even less. They are expert at avoiding violence, building networks and ensuring the safety of their belongings, whether homeless or not. Every participant in this study acknowledged the existence of these micro-neighbourhoods. Therefore, centralized care is ill-suited for maximizing contact with this group of women. Asking a woman to traverse the neighbourhood to use the supervised-injection facility, Insite, located on a very high-traffic strip of Hastings Street or to take up an OST program at a pharmacy on Abbott and Pender Streets when she lives on Princess Street is unreasonable. Establishing comprehensive clinics in every corner is, clearly, not a viable solution. Thus, the integration of comprehensive outreach nurse networks (Theme 10) into the care mandate of these centralized clinics will facilitate access to new groups of women from across the community.

Theme 5: Physical Structure

Maintaining a physical structure that successfully prevents vandalism and theft as well as protects staff from extremely aggressive clients without also deterring reluctant potential clients is an ongoing challenge for all social service agencies in the DTES. Black bars, ubiquitous throughout the DTES, that surround entrances to nearly every building in the community, from convenience stores to food banks, became a focal point of most interviews completed for this study. In two different instances, the appearance of clinics with these black bars was likened to Holocaust-affiliated cities, Auschwitz and Warsaw. One agency, who had recently installed the bars on their front entrance, has noticed a marked decrease in walk-in attendance which the staff attributes directly to the bars. The agency co-coordinator shared her experience with one client who indicated that the black
bars conjured memories of her time spent in prison. The black bars are an obvious deterrent to would-be clients, but many agencies have experienced theft, vandalism and other such frustrations by leaving their entrance un-barred. A reasonable compromise would be to install white bars, as one non-profit clinic has done with much positive feedback from clients.

The internal physical structure of an agency can also impact a woman’s willingness to use the service. Large waiting rooms guarded with security personnel are the norm for the government clinics, as are buzzer-equipped entrances and tall, banked reception counters. As one participant who regularly accompanies clients to PHC clinics, commented, this reinforces the inherent ‘us-them’ divide that permeates the life of a woman who sells sex and does high risks drugs in the DTES; She is ever the ‘Other’. PHC sites cannot be complicit in this gulf between insiders and outsiders, if they are truly intent in bringing in this particular client group and providing them with a legitimate client-centred care experience. Suggestions regarding potential structural changes to DTES agencies were easy to come by in discussions with providers and include having quiet personal wait rooms for agitated clients, taking down the plexi-glass “spit shields” that separate clients from receptionists, playing movies in waiting rooms and offering acupuncture to clients. The clinical care experience includes everything that happens before and after a client makes contact with a clinician. For this client group, very particular arrangements must be made in order to create a positive care experience.

Theme 6: Attitudes, Work Routines and Clinical Protocols
There are very few ways to mandate staff attitudes towards client groups, but several participants commented that PHC training, for nurses, physicians and allied health professionals, rarely includes preparation for daily contact with clients who are homeless, have poor hygiene and who behave erratically or emotionally. Providers spoke of their personal approaches to their work and, especially for outreach workers, an emphasis on reflexivity in practice emerged clearly as important in creating a welcoming, open agency environment. All providers mentioned the importance of understanding the dominant health issues of this client group (addiction, skin and STI issues) in their social, economic and environmental contexts. The social determinants of health model is largely embraced, at least in a superficial sense, by DTES agencies. However, providers also emphasized the difficulty of maintaining a constructive attitude towards clients on a regular basis. One provider commented on how personal issues can cause a staff member’s attitude to change from day to day. While this may not be a concern in an average PHC setting, providers’ regularly emphasized the ‘one shot’ notion. That is, in their experience with women who sell sex and do high risk drugs, one odd look or one poorly-timed comment from a staff, regardless of how innocent, can be enough to prevent an individual from ever returning to the agency. There is little room for error with this group of clients, which has as much to do with individual limitations as it does structural. They are always busy, always rushed and very sensitive. Agencies able and willing to make concessions to these individual limitations, while slowly developing rapport with individual women (Theme 11), commented that clients become increasingly comfortable in the agency environment as a result of a series of prior positive experiences.

For the four interviewees with life histories in which drug use and sex work are or were significant features, fear of stigmatization was the most often cited reason for not seeking care at a DTES agency. These interviewees, however, all concurred that
experience in sex work or high risk drug use was not required in order to build appropriate attitudes, routines or protocols. It should be noted, however, that none of these participants are employed by traditional PHC-only sites. Regardless of current efforts to build positive staff attitudes, design sensitive clinic protocols and deal openly with discrimination and issues of judgment amongst staff, there is more work to be done on this theme. The facilitator features of this theme emerged as suggestions from participants.

Theme 7: Gender Awareness

Women in the DTES face a unique set of challenges and the majority of these relate to remaining safe and clean. Women are more restricted in their movement around the community and this directly impacts their willingness and ability to access services. Some agencies offer women-only spaces or women-only hours, while some are dedicated solely to female sex workers. While some women have no preference for a woman-only space, all providers did acknowledge the importance of providing a safe and supportive environment for women in the sex trade. This generally implies a women-only space in order to avoid conflicts between women and their clients, partners, pimps, dealers or other aggressors. Further, while not all women do prefer a female clinician, access at all times to a female clinician for the purposes of physical exams was generally noted by providers as a basic requirement for appropriate care for this client group.

One nurse commented that women’s health exams, including PAP smear and pelvic exam, were mainstreamed into the care experience at her clinic. The regularity and routine of these contact experiences allowed this particular clinician to build rapport and to learn about the community. She acknowledged that women who are proactive
about seeking care can generally do so at this particular clinic without reminder or outreach efforts. However, she noted, there are a large number of women for whom accessing this, or any other, clinic in the community, is difficult and the gender-specific health needs of these women are likely more significant. Gender-specific concerns need to be mainstreamed across community clinics. According to participants, deepened partnerships with the three well-known and highly reputable women-only spaces in the community are important loci for future work.

Theme 8: Services in Community

This theme of the clinical care experience reflects an agency’s self-conceptualization as a community asset and can be measured by their level of cooperation with other community agencies, their willingness to go out into the community in order to locate and support clients and the creative ways in which they try to bring new clients into the service. Most PHC clinics do not have established partnerships with local sex work agencies. This seems a likely place for a PHC site to begin understanding the barriers to access to care for women who sell sex and do high risk drugs. Integrating into pre-existing networks of trust is but one way to challenge any perceptions of ‘us-them’ held by potential clients. One key informant mentioned that a particular challenge to working with different community groups is that each agency has a different conceptualization of what constitutes a barrier to care. For some agencies, being visibly intoxicated is a reason to refuse service. For others, staff are expected to manage the behaviours of people who are intoxicated and this is not a service barrier. To provide appropriate services within a community context, service thresholds should reflect the needs of the community. Having established non-punitive mechanisms to address potentially chaotic, urgent or ‘crisis’ behavior of DTES community members was most
often mentioned by participants as the first step to providing ‘Services in Community.

Some agencies are highly-skilled in this theme, and some have yet to establish appropriate service thresholds.

While agency representatives have enjoyed prior networking opportunities, working with agencies with different resource sets, philosophies, regulatory structures and community accountability mechanisms is challenging. Some agencies have community advisory boards and regularly engage in consulting their clients on how services are delivered. Some have no such boards and limited capacity for community input. In order for each agency to optimize their relevance to community demand, leadership in this regard must emerge. Throughout this research, only one potential candidate was mentioned as having both the resources and capacity to lead the community towards facilitating ‘Services in Community’: Vancouver Coastal Health Authority. VCHA has demonstrated limited interest in community consultation in their work in the DTES and is facing significant resource and operational constraints. It is here, that system limitations most definitely constrain agency-level opportunities for positive change. Without outsider resources, the mobilization of the health service community within the DTES, in the interest of developing more and enhanced routes to care for marginalized women, is highly constrained.

**Theme 9: Staff**

In a given DTES agency, the staff are the most visible and expensive component of the provision of care. Their attitudes and work routines (Theme 6), self-conceptualization as community members (Theme 8) and their education as clinicians (systemic themes) are elements of the care experience that can facilitate or impede care, but this theme refers
particularly to the agency-level processes for recruiting, selecting and managing staff within a particular setting. Lengthy wait times are the most oft-cited barriers to care among most populations in Canada and the same is true for women in the DTES, according to the VANDU Women’s CARE Study. Participants in this study most often linked wait time issues to insufficient staff. In this community, per client needs are significant and, in order to create an agency environment based upon facilitator features, sufficient staff are required. Maintaining sufficient staff, based on availability and ability to pay, was a noted challenge by participants in all sectors: government, non-profit and for-profit. Expanding hours of operation (Theme 1) would further complicate matters.

In addition, participants regularly commented that staff in PHC-only sites, including auxiliary staff, do not necessarily want to work in the DTES but the reverse was true of the other sites in the study. One PHC site manager commented that their hiring processes do reflect the specific demands of working with this population (i.e. tolerance, flexibility, energy, enthusiasm) for nurses and physicians, but not for receptionists and security staff. However, reception and security staff are most visibly in waiting rooms, where most of the clients’ time is spent, and are the first points of contact for clients. These positions demand unique skill sets and community experience and it is important that hiring and training processes reflect these challenges. They are constantly being asked to de-escalate waiting room tension or conflict. Conversely, non-PHC-only site staff emphasized the importance of working as a team, engaging with clients informally, in alley ways and waiting rooms, as well as formally and of using each staff members’ particular assets to connect with different clients. When sites include highly-specialized staff, such as addictions doctors or pharmacists, this becomes more difficult, but also more important. Further, when staff are visibly divided from clients (Theme 5)
with walls, shields and bars, the agency staff must automatically work harder to engage with clients.

With clinicians, in particular, one key informant noted that in his experience hiring nurses in the DTES he found that most successful applicants had experience with highly vulnerable populations, either globally or within Canada. Another participant commented that hiring is particularly difficult in their agency because applicants exhibit major reluctance to even enter the agency’s building due to the rather chaotic scene that plays on continuously outside. Many participants noted the difficulty in drafting Terms of Reference or job postings for positions in the DTES that accurately reflect the reality of the job and rely as much as possible on internal hirings and word-of-mouth. One non-profit representative noted an observed defection from government PHC clinics to non-profits over recent years and attributed this to subtle, but profound, differences in service delivery philosophy. Observations from this non-profit clinic indicate that physicians are regularly communicating with patients in the waiting room, as acquaintances rather than chaperones, and make regular concessions to clients who need to leave and return later in the day to the clinic. Observations from government clinic waiting rooms indicate an entirely different set of rules and atmosphere.

The recruitment and management of staff is one measure of how extensively a team-based, egalitarian and co-operative philosophy are service delivery is embraced by an agency. One manager, when asked about how a recently-completed, intensive two-year staff shuffling might have affected clients, insisted that it had a substantial impact on staff, but could not exactly describe how this impact would have played out in daily client-staff relations. Similarly, it is difficult to measure accurately the ways in which staff issues affect clients but it seems certain that they do, in fact, have an effect on the access profile of clients, including women who sell sex and do drugs.
Theme 10: Availability & Demands on Client

The availability and demand theme is related to issues of sufficient and properly managed staff (Theme 9) and hours of operation (Theme 1) especially. It is best described by a basic tenant of social work theory that decries the importance of “meeting clients where they’re at” in both literal and figurative senses. It means that if an agency’s mandate is to reach the hardest-to-reach, it does not place unreasonable demands on a client, it is available when and where the clients are and requires little client navigation in order to be brought into the fold of service provision.

Outreach programs in the DTES, several of which participated in this study, are designed to be available to women who sell sex and do high risk drugs. However, these programs noted, without exception, the difficulties they face when, once they have made contact with a woman and she is ready to devote time to seeking care, trying to get this client an interaction with a PHC clinician. It is here where community partnerships (Theme 8) and mainstreamed outreach mandates throughout community agencies would be particularly beneficial. One key informant indicated that her usefulness to the clients would increase exponentially if she was able to attend meetings and appointments with clients. Outreach is not part of her agency’s mandate, but fellow staff are regularly found out in alleyways or standing on proximal street corners encouraging clients in their quest to fill prescriptions, locate clothing, attend clinic, etc. When asked if this was counterproductive to helping clients build self-sufficiency, the informant insisted that, for the most part, these types of skills are not in the current repertoire for many clients and women in particular need to be supported in these endeavours. For clients that do possess
these types of skills, addiction and other severe mental health issues regularly interfere with important daily tasks

The second component to this theme requires that once a client becomes established within a given agency, the demands on this client are not beyond their capabilities. For women who sell sex and do high risk drugs, it is very difficult to time when they will need to fix and to wait for several hours in a clinic space. Agencies that allow women to leave and return without losing their right to use the space, their spot in line or their permission to use the agency’s service demonstrate their flexibility and willingness to respond to the demands of the client, as opposed to vice-versa. These agencies are continuously trying new appointment and drop-in structures and piloting new ideas in client care that may work for these women. Individual limitations are an important part of the ‘availability and demand’ narrative and, as Draus\textsuperscript{53} comments in \textit{Consumed in the city: Observing tuberculosis at century’s end}, noncompliance “is not merely irrational, malicious or self-destructive behavior. Its motivations are often rooted in factors that lie outside the scope of the medical institutions or public health agency”. That is, the agency may not be responsible for the majority of factors that detract a woman from seeking care, but they have an important role to play in helping women overcome these factors. The primary care centre represents a very biomedical orientation towards health and health care and, in this, there is a risk for these ‘auxillary’ services – such as support, provision of quiet space, group sessions – to become over-medicalized. That is, the activities of women who sell sex and inject drugs that are pathological by nature – using high risk drugs and engaging in high risk sex – risk being bound up with those that are far from pathological, such as relationship-seeking, self-soothing and community building. Still, agencies in the DTES are best situated, both proximally and

\textsuperscript{53} Draus 2004.
metaphorically, to help women seek care, ensure positive care experiences and, accordingly, improve individual and collective health outcomes. It may necessitate some reflexivity on the nature of services provided, to whom and when but this could, in itself, be a productive exercise.

**Theme 11: Orientation Towards Relationships & Trust**

While making contact with primary health care providers in the DTES is an initial step, maintaining relationships, building rapport and enhancing the care experience to the extent that it could be considered social capital building remains an enormous challenge for participants. As one support worker observed, “It's the trickiest group of clients that we work with as far as building a relationship and having the service be consistently accessible to them”. Providing care is easiest in the context of a client-clinician relationship. Outreach workers claim that this is the implicit majority of their work and it enables them to reach other people within social support networks of current clients. The care experience must offer opportunities for relationship building, by allowing informal interactions between staff and clients, creative partnerships between different community agencies with different catchment neighborhoods and offering each client significant time, without high demand, to get their needs met in a comprehensive way.

**Social capital**

The eleven Agency aspects, taken together, describe the particular context(s) in which interactions between women who sell sex and do high-risk drugs and their primary health care providers are situated. If it is to be understood that these interactions form the basis of relationships, the by-product of which is known as the public good social capital, then the primary health care setting is one of the places where social capital is produced.
and, accordingly, destroyed. The eleven facilitators and barrier categories are, in
essence, parameters for relationships. For survival sex workers who use drugs,
individual and systemic limitations are such that the cultivation of any relationship is a
major challenge. This paper illustrates how the third set of determinants, at the agency
level, can serve as a platform for social capital building. While it is neither the primary
mandate nor the professional obligation of primary health care providers and agencies to
engage in community development or social capital building, this research illustrates that,
for women who sell sex and do high risk drugs, better care is delivered more often where
facilitating factors are conscientiously implemented within the agency space and in the
community in general. Social capital and delivery of good primary health care operates
in a mutually-reinforcing positive feedback loop.

While the results of this research are clearly applicable to other hard-to-reach
populations, the particular relevance for sex workers who use high risk drugs is clear.
For a woman who sells sex and does high risk drugs, daily activities intersect with
various layers of marginalization resulting from gender, poverty, ethnicity and class.
Thus, the willingness and opportunity to engage in or initiate trust-based relationships
with health providers, who are seen as authorities, is very limited for this group of
women. The eleven groups of facilitators acknowledge this inter-sectionality as it relates
to the daily activities and priorities, and the specific threats to social capital for women
who sell sex and do high risk drugs.

Limitations

The main limitation of the study reflects the difficulty I had in balancing the
desire to produce meaningful, relevant work with the need to develop an a priori research
strategy and aim. The research aims shifted throughout the entire research process
because the initial aims, determined prior to deepened familiarity with the subject matter, were irrelevant by the time data collection had completed. This type of iterative feedback between the results and the objectives is not ideal science. However, the paper has been rendered relevant by my persistent reflection on direction, meaning and coherence.

Another key limitation of this work is a selection bias towards providers with a specific bent of service delivery philosophy. That is, there were more non-profit and community-oriented providers interviewed than government or private providers. However, each type of provider was pursued with equal vigour by the researcher. The sample of interviewees represents those who were willing or able to engage in brainstorming and reflexive exercises on these sensitive and controversial topics. This research does not aim to anger, neglect or alienate any specific type of primary health care provider in the Downtown Eastside but explicitly calls to action those providers for which their inherent role in social capital building has not been actualized.

More time and resources would have enabled more interviews with more providers, some from within the same agency. As is, the research points to future directions for more rigorous research but can make no unequivocal statements about the successes and failures of DTES PHC sites in providing care to women who sell sex and do high risk drugs. The study would have also benefited from a more structured interview schedule, as well as built-in follow up interviews after first pass coding to facilitate more rigorous comparative analysis. Again, the scope of the research limited opportunities and time for follow-up.
Implications and Recommendations

This study points to eleven themes of the clinical care experience that can assist providers in better delivering services to women who sell sex and use high risk drugs, as well as in building social capital opportunities within PHC settings. The study uses the perspectives of providers and key informants to understand which configurations of these eleven themes could be used to increase uptake of care, thereby improving community and individual health outcomes. The study also found that agency-level configurations are constrained by system-level limitations on resources and mandate creativity. There is an overarching lack of responsiveness by health system actors to the Downtown Eastside, despite the availability of evidence and community-level will to improve how services are delivered to women who sell sex and do high risk drugs. Leadership for the reconfiguration of services must come from both system and agency level, with legitimate involvement of community actors, including clients and providers. The study offers valuable insights into how sex workers who do high risk drugs can become agents in their own care and community experience, as well as how providers can themselves be retooled as assets in the risk environment.

The specific recommendations for primary health care providers in the DTES are divided into two levels.

Level 1 Recommendations: These are inexpensive, relatively simple adjustments that can be made at the agency level with little interaction with systemic constraints.

- Reduce or remove ‘thresholds’: These include black bars, spit shields, barbed wire, buzzers, highly visible security in waiting rooms. These also strict reactive policies to difficult behaviour. Behaviour management should be a core competency of all staff.
- Make connections with local sex worker advocacy groups.
- Provide optional woman-only spaces and woman-only blocks of time, open to all individuals who identify as women. Co-ordinate with other community agencies to ensure daily availability.
- Build flexible appointment structures.
- Use innovative de-escalation techniques for waiting rooms (i.e. play movies, offer quiet spaces, acupuncture).

**Level 2 Recommendations:** These require more time, resources, specialized training, specific capacity building and, most challenging, conceptual shifts. These directly involve system-level actors and require their support, cooperation and backing.

- Adopt a culture of listening throughout service delivery and systems.
- Comprehensive CEA and CBA of 24-availability of PHC services in DTES.
- Adopt care philosophy in which sex workers and high risk drug users are ‘experts’.
- Mainstream peer opportunities wherein peers are trained, accountable, compensated and legitimized.
- Staff training/hiring processes include experiential community ‘listening’.
- Agency governance includes local voices.
- Mainstream PHC outreach to micro-neighborhoods within DTES.
- Create staff culture of openness, reflexivity and honesty.
- VCHA leadership should complete and act upon comprehensive asset/needs mapping for DTES.
- Hire people who want to work in the DTES.
References


Institute of Medicine, Committee on Behavioural and Social Sciences in Medical School Curricula. 2004. *Improving Medical Education: Enhancing the Behavioural and Social Science Content of Medical School Curricula.* P.A.Cuff & N. Vanselow (Eds.). Washington, D.C: National Academy Press.


Appendix A: Map of the Downtown Eastside

Source:

City of Vancouver. 2009. Downtown Eastside Revitalization. Available at:

http://vancouver.ca/commsvcs/planning/dtes/.
Appendix B: Key Research Terms.

1. *Agency*: the physical space in which contact experiences between the staff and patients occur.

2. *Female sex worker who injects drugs*: a biologically female individual who, over the past two years, regularly or semi-regularly has *both* traded sex for drugs and/or money *and* injected drugs of any type.

3. *Peer educator or peer support worker*: community member of the downtown eastside with a history of sex work and/or addiction who is either employed by or volunteers with your agency to work with other community members with similar histories.

4. *Primary health care*: The medical care a patient receives upon first contact with the health care system, before referral elsewhere within the system.

5. *Service*: all health-related treatment, examination, referral, support, counseling and other experiences provided by the agency to its clients.

6. *Staff*: all individuals affiliated with your service that might encounter a patient through routine administration, care or follow-up practices during any given contact experience. These include professional and non-professional staff.