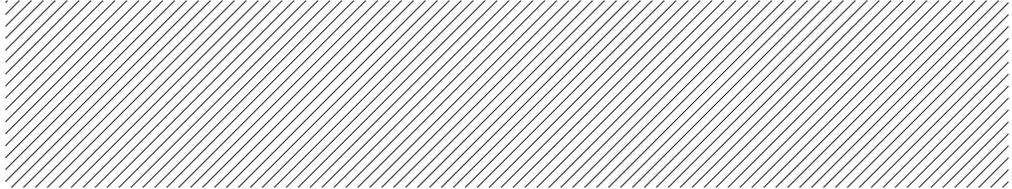
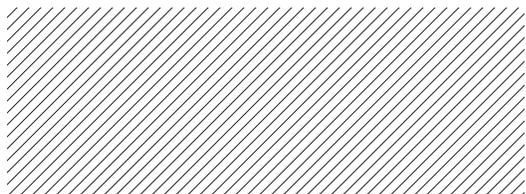


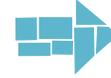
Client perspectives on improving health care in the Downtown Eastside





Vancouver 
CoastalHealth





VCH introduction



THROUGH 2012 AND 2013, WE'VE GATHERED FEEDBACK FROM HEALTH SERVICE PARTNERS, COMMUNITY LEADERS AND CITIZENS WORKING AND LIVING IN THE DOWNTOWN EASTSIDE (DTES). IT'S PART OF A MAJOR INITIATIVE TO IMPROVE HEALTH SERVICES CALLED THE SECOND GENERATION HEALTH SYSTEM STRATEGY.

The goal of the strategy is to identify opportunities for better collaboration, to define relevant health outcomes and measures, to support innovation in service delivery, to better employ evidence and best practices, to improve accountability, and to strengthen the relationship between the Vancouver Coastal Health Authority, our partners and the community of citizens we all serve.

The purpose of this *Client perspectives* paper is to gain a better understanding of the changing needs of DTES clients, needs that have evolved since the health crisis was declared in this community 15 years ago. To accomplish this we invited longtime community advocate Ann Livingston to lead consumer input sessions with a focus on the most vulnerable residents in the DTES. We also asked community engagement specialist Lizzy Karp to meet individuals for long-form storytelling sessions.

Their findings are included in this report, which continues a series of papers published in 2012 and 2013, including *Working with health agencies and partners in the DTES*, *Staff perspectives on improving care and working with health partners and agencies in the Downtown Eastside* and *A Second Generation Health System Strategy for Vancouver's Downtown Eastside*. The first two papers were quite critical of the health authority. DTES residents have also emphasized problems that arise when health services intersect with the work of housing and social welfare agencies, and the police.

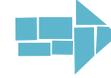
While we all see the issues from different perspectives, if we identify common goals and work as partners to achieve those goals, we can create a healthier community.

The challenge for all of us is to listen closely to criticism and use what we learn to build better partnerships. While we all see the issues from different perspectives, if we identify common goals and work as partners to achieve those goals, we can create a healthier community. The Vancouver Police Department, for example, has been at the forefront of calls for more health care resources for those suffering from mental illness. We agree that we need a new model of services that can more effectively meet the needs of DTES residents. We look forward to working with the police, the City of Vancouver, BC Housing and other provincial social service agencies, and will listen closely to their concerns.

Likewise, client voices are essential when rebuilding a health care system, and their personal stories bring to light complicated social interactions that affect their health. Gathering stories from the community creates new lines of dialogue and strengthens relationships. The stories included in this paper are powerful, and sometimes hard to read. I sincerely hope they continue to open up the conversation about clients' needs and experiences, so we can all work together to reimagine and transform the services in the Downtown Eastside for the benefit of its residents.

A handwritten signature in black ink, appearing to read "Mary".

Mary Ackenhusen
Chief Operating Officer
Vancouver Coastal Health



A note about this report

Lizzy Karp and Ann Livingston



TO GAIN HONEST INPUT FROM THE MOST VULNERABLE DOWNTOWN EASTSIDE RESIDENTS ABOUT THEIR HEALTH AND THE SERVICES THAT SHAPE THEIR HEALTH, WE ORGANIZED COMMUNITY-INPUT WORKSHOPS AND GATHERED THEIR STORIES.

We formally surveyed 219 individuals at 10 meetings with at-risk women with children, Aboriginal people who use drugs, people who consume non-potable alcohol, crack cocaine, or crystal methamphetamine, youth under 30, consumers of mental-health services, people on methadone maintenance, people living with HIV and people participating in the heroin studies.

We also informally canvassed them on issues of potential interest, such as whether they would like better mechanisms to complain about or to help improve services. These responses are incorporated in our analysis of survey results.

At the meetings, we also sought to educate residents about the components of the health system. We wanted them to understand how notions of “patient-centred care” play out in other communities, so they had context for their own experiences. How does the \$55 million that the Vancouver Coastal Health Authority spends annually in the DTES through non-profit agencies and its own clinics fit into provincial health spending that now exceeds \$18 billion a year? They wanted to know who ran what DTES service and what they were paid to do so. People got riled up. Their feedback also contributed to the creation of the Front Door

Project, part of a website — dtes.vch.ca — to help clients better navigate DTES services. Beyond that, 22 residents volunteered individually to share personal stories that reflect the challenges they face in achieving good health. We wanted to empower clients by letting them offer real stories that explore the barriers, as well as the potential for hope, recovery and understanding. These long-form stories begin each of the sections in this report. Some details and names were changed when requested by the storyteller, but the participants were proud to be heard, and many want to continue to contribute to change and help people in their community.

In considering the survey results, which are set out in more detail in a separate document, *Who Are the Downtown Eastside’s At-risk Health Care Consumers?*, readers should be mindful of the data’s

limitations. We held an open meeting at Dodson Hall, used the Interurban for a session with users of the Portland Hotel Society's services, and hosted an evening event at Sheway, where parents assembled with their children. Other sessions were hosted at Vancouver Native Health's Positive Outreach Program, Gallery Gachet and six regular education, advocacy and support meetings. While there were 219 surveys completed, some sample groups are small. We did not have the time or resources to reach people in treatment, in palliative care, or those with severe mental illness. We were not able to thoroughly interview people for whom English is a second language. We discussed but did not extensively gather feedback regarding secondary health issues experienced by residents, including dental issues, breathing problems, nutrition and weight, violence against women, seniors' issues, and the side effects of prescription drugs.

The report is structured mainly around 10 key areas of concern for residents. It concludes with Ann's personal reflections based on 20 years of helping the most marginalized create more effective tools to take care of themselves.

Fifteen years ago, drug fatalities and rampant hepatitis, HIV, tuberculosis, Methicillin-resistant Staphylococcus aureus and syphilis precipitated Vancouver's Four Pillars Drug Strategy and prompted innovative medical responses from VCH.

Today, while disease transmission and deaths caused by drugs remain serious issues, it's evident that there are even more complex challenges that need attention: quality of housing, the experience of the aging, social equity and social services, the role of the justice system in health, and the stigma people with mental illness and addiction face. Normal health requires normal lives, and VCH must work with others to create an environment where that's possible. If it does not, there will be no small cost to us all.

Meeting the challenge, though, is made easier through the keen and hopeful insights of people who are too often excluded from decisions regarding their care. Nothing About Us Without Us is a 500-year-old European democratic idea that is at the core of democratic tradition. We hope these stories and statistics will help to make marginalized Downtown Eastside citizens more active participants in the decisions that shape their health.

Lizzy Karp
Communications and Community
Engagement Coordinator
Vancouver Coastal Health

Ann Livingston
Community organizer and former executive
program director of the Vancouver Area
Network of Drug Users

Meeting the challenge is made easier
through the keen and hopeful insights
of people who are too often excluded
from decisions regarding their care.



Critical insights from the Downtown Eastside



THE DOWNTOWN EASTSIDE'S AT-RISK RESIDENTS HELPED US IDENTIFY 10 POLICY AREAS AS KEY CONCERNS. EACH OF THE 10 SECTIONS BELOW BEGINS WITH UNVARNISHED STORIES FROM DTES RESIDENTS.

These were garnered from private interviews, and the passages reflect their general experience of the issues. Key insights are then identified, based on a 37-question survey and other input from residents at the 10 community workshops.

We then place these insights in context, drawing on the surveys, the public meetings and some recent reports that analyze community needs. The last of these 10 sections looks at how the Vancouver Coastal Health Authority and other agencies might move forward to create a system that ensures marginalized Downtown Eastside residents play a more central role in decisions that affect their health.

1. Service design and implementation received much criticism, some praise

Services are not always well connected, and when they are, clients are often unaware of what's available. Yet while clients reported many bad experiences — and just one can end a relationship with a provider — there were also good ones, and people are hopeful for improvement.

Resident voices

"I went to the DTES Clinic and was referred to the MAT (Maximally Assisted Therapy) program [to ensure HIV patients take complex medications effectively]. I went to my clinic for three years to pick up medication before I knew there was a dietician or a counsellor in that office. I was not told these services existed. Nobody told me about Positive Women's Network when I was there. I had to research a lot of this myself. Why did I fall through the cracks? I asked managers, and they said it was because I was not the typical drug addict, and they assumed I knew about those services. You can't let people fall through the cracks because you assume they know something. Tell them 40 times!"

"It's just so tough down there to get away from it. If you are addicted to drugs and you go to Onsite... I understand breaks

are good for addicts and keep them alive a little longer. But ... that environment has too many drugs there. I think the answer is getting people physically out. I always thought that you've got Insite and Onsite, but what about Outtasite? Have a place called Outtasite and have it so that you have a place run by the PHS that is in Burnaby or New West and you can go upstairs to Onsite to the detox ward, then go upstairs, then you move clients to Outtasite, and you have staff there and they learn tools on how to do laundry, make your bed, make toast, make food for themselves. There needs to be some sort of job skill program. Get them confident."

"A lot of people have been doing drugs for such a long time. Ashley told me she went to jail because of drugs, and she was in jail for 90 days. She was totally clean — she felt so great. She didn't want to do drugs. Then she was put out on the street, no place to go. So where does she go? Back down to the DTES — that is where her friends are. Doesn't take long for her to see her friends using. People need more guidance when they come out of jail or recovery so they can do something with their lives."

"Time is a tricky thing for someone in active addiction. To this day I don't wear a watch, but I know when I was in active addiction I had no sense of time. Either the sun was shining or it wasn't. Hours of operation were always difficult for me. I know there are lots of places you can go to eat in the DTES, and often I would go there and I would have just missed it, and often there is a huge gap until the next meal is offered."

"I was here [at Crabtree Corner] for a month and a half before I knew that there were infant development programmers. I still don't have a clue of all the programs here, and I've been living here since Valentine's Day. When you are going to a place that is offering you medical support, and is aware of what

addictions do to you, they should realize that when women are asking for the same thing over and over again, don't keep slamming the door. Give them some help with that. It becomes frustrating, and discouraging. I know 10 or 15 years ago I would have gone out to use when I've been frustrated. There wasn't this kind of stuff available then, this is such an awesome facility for people with my history, but you could be doing it in such a different way that would be so much more productive and have way more success stories. The proper support that we really need we aren't getting."

"At the Pender clinic, I had some great doctors, and got some real help. Got on a small amount of methadone, stabilized, got clean for the most part. I never really got more than three months clean at a time, but I passed all my drug tests. Got my son back and moved to Surrey. But I kept my doctor at Pender. They are my doctor for everything. I get regular STD checks, I have Hep C so I get blood work and I have a counsellor there, too. I live in Surrey but I keep my services in Vancouver because they are just better services."

Key insights

- Clients reported much confusion about what services are offered and how to access them, and felt there are persistent barriers to continuity of care
- Even when health services are integrated into housing and shelter programs, clients don't always know about, utilize or appreciate the intent of the services
- Operating hours are not appropriate for consumers with erratic lifestyles, and clients generally feel they are trying to fit within the services offered and not vice versa
- Clients reported feeling that frontline workers, staff and VCH are not working towards a common goal



- Consumers report feeling intimidated by clinic security guards, whose presence tells the clients they can't be trusted
- Many clients reported experiences of being shuffled from service to service, and being told "no" often
- Not all models of care support all patients, and active drug users in particular experience multiple barriers to follow-up
- If consumers don't know the goal of the service and don't get what they expect or need, they often have clashes or issues with those services
- One bad experience with a given service provider often means the person will not return

Community context

Despite VCH's efforts to provide one-stop clinics, DTES residents reported their health care consists of a combination of a wide range of services. These include ambulance pickups, hospital emergency rooms, street nurses, and often police officers, who sometimes arrest the mentally ill and addicted under the Mental Health Act and transport them to hospital emergency rooms. Survey respondents (individually and collectively) used many different medical, dental and methadone programs run by VCH, non-profits or private enterprise, as well as the 22 DTES pharmacies.

Most DTES health care consumers have been treated with derision and hatred all their lives, lack trust in government services that have often simply caused them grief, and feel they must creatively use the programs available to meet their needs.

Many services operate in isolation from one another. Health care consumers are frequently confused about what services are available and how they are connected. Even when we created an inventory

of services as a guide, there was still confusion.

Of the DTES residents we surveyed, 82 per cent use illegal drugs, and they feel it's not only the drug use that affects their health but also the resulting stigma they experience at health care services. Most are dealing with more than one chronic health problem, live on extremely low incomes, are homeless or under-housed, have frequent encounters with police, and do not have access to transportation. When they are turned away for "doctorshopping" or "drug seeking," it can prevent them from engaging with services.

Many physicians work part-time in the clinics, and so clients use a variety of health care providers because they can't find a doctor they trust, or even one who knows them. Some doctors prescribe methadone for a year or two and burn out, leaving their patients to find new providers. Many health care consumers feel they are "profit centres" for physicians who are paid for methadone follow-up visits that consumers frequently miss. Pharmacies that provide methadone to chronically ill patients are so lucrative that some participate in well-documented cash kickback schemes with patients. These are not circumstances that build trust.

Clients want a clear and responsive process for complaining about disrespectful treatment. When we asked if people had a particularly bad experience with health care, 68 per cent said yes, including 85 per cent of the Sheway mothers, 82 per cent of the heroin study participants, and 92 per cent of the youth (compared to 52 per cent of seniors). Only 50 per cent of our survey participants felt their health issues are taken care of, with only 33 per cent of people who smoke crack cocaine reporting yes.

On the positive side, asking if people had a good health care experience resulted in a higher overall yes (75 per cent), with 100 per cent of people who smoke crack cocaine and 92 per cent of the people from the Interurban meeting (who are clients of the PHS Community Services Society) reporting a good health care experience. The willingness to share stories and bring complaints forward also indicated an interest in, and even an enthusiasm for participating in a process to improve health care services.

2. Vancouver's criminal justice system often interferes with health care

Many DTES residents deeply distrust the police, and there are complex reasons for that distrust. Vancouver Coastal Health's partnerships with the Vancouver Police Department around treatment for addiction and mental illness are undermined by custodial experiences that damage residents' health.

Resident voices

"In Kelowna, I get arrested and have methadone within half an hour of being processed and sent to Kamloops. In Vancouver you are fucked. You will not get your methadone for three days. I was taken into custody and stayed the night in city cells, which are freezing cold and the cops say they are 'out of blankets.' The doctor at city cells gives me my sleeping pills and says I cannot have my methadone because I might get released and take my methadone twice. Then I spend the whole next day sick, waiting, and finally get into court. I cannot get bail so I get taken to remand in Surrey to await trial.

"I'm told I cannot see the doctor till the next day and it might be 10 am or it might be 3 pm the next day. Totally unnecessary

bullshit. At remand, even though I had to pee in a cup on my way in to see if I was on methadone, the doctor refused to give methadone to me but they gave me my sleeping pills. It totally fucked me up. I was continually shitting and puking from withdrawal and my cellmate got really pissed cause I kept her awake all night.

"By the time I got my methadone I was so sick I couldn't stand up. Methadone withdrawal is 10 times worse than heroin withdrawal. If I was a diabetic I would get my insulin right away, but because I'm dependent on opiates I'm treated like shit. Their pathetic excuse is that I might die if they give me my prescribed methadone 'cause I could double dose if I already drank my dose. But the doctors at city cells and at remand have access to PharmaNet, which says exactly what methadone I got, when I drank it and at what pharmacy."

"Police take people to the hospital and throw them in straitjackets and [they are injected by staff] against their will. It does way more harm than good. This happened to me at my place. A cop coaxed me out into the hallway, pretended that I stepped on his foot, put me into really tight handcuffs. I've never been to jail in all my life. He charged me with obstruction, and they tried to intimidate me for no reason at all.

"The same thing happened to my girlfriend Ashley. I said, 'Don't go out there! Don't listen to them!' She was a little upset and usually we talk things over, but she likes drama — they are used to drama on the streets. It's like a TV show, like a sitcom. So one night she went into the bathroom with a knife and said she wanted to hurt herself. And I've been taught to report this to the front desk. I said she doesn't want to talk to me, I don't think it's really serious, but this is what I'm supposed to do, and I want someone to come talk to her. They said they couldn't leave the desk because they had to stay there. I wish there was always someone



As VCH's second generation strategy for the Downtown Eastside works toward better "trauma-informed services," it needs to ensure the police are more informed and constructive contributors to its health mission.

on site with a background in mental health, someone with lived experience, not just some yuppie. Anyways, I'd never had that experience of her hurting herself.

"The police have been taught if someone threatens to hurt themselves to take them to the hospital in a straitjacket, [where staff will] tie them down to the table and inject them against their will until they are docile. Wait until they are calm the next day. Don't offer counselling and let them go. This happened to my girlfriend. After she was coaxed out into the hallway, she was totally calm and said she was fine. They took her downstairs, her blouse was open, her breasts were visible. She asked if she could do up her shirt and they wouldn't let her.

"They took her down to the hospital She suffered severe trauma. After something like that do you think you are going to trust the police? No, not me. What kind of tenant training do they get? Those cops are not properly trained. I wasn't able to stop police to take her into the ambulance.

"She heavily protested, they shackled her hands behind her. She cried the whole way, publicly shamed. People that knew her saw her. Of course it totally upsets our relationship. Everyone we know thinks the worst of it. She got help from me. You think she trusted me after that? For the next few months she kept saying, 'you did that to me,' because I went to go to the front desk for help. I had to prove it to her I was on her side, not the cops' side. She is still going through emotional trauma."

Key insights

- Clients say they are often failed when police become the gateway to health services
- Many reported experiences with police that they considered traumatizing or harmful to their health
- Charges related to minor bylaw offences have exacerbated unprecedented levels of criminality in the DTES
- Conditional sentences keep people within the justice system in an unhealthy cycle
- People do not want police to view their medical records

Community context

Most marginalized Downtown Eastside residents believe their distrust of the police is well-earned. That distrust is fostered by arrests for public intoxication, selective enforcement of drug laws, ticketing campaigns for bylaw infractions such as street vending and jaywalking (which become more serious legal issues with nonpayment of fines or failures to appear), as well as stories about and the experience of abusive treatment. Methadone being withheld in jail is a common complaint. Historically, older addicts have reported experiencing severe, life-threatening opiate withdrawal in jail, and some have described police withholding medication to garner information about dealers.

Of the 219 people surveyed, 88 per cent had been arrested, 82 per cent had been to jail or remand, and 78 per cent had been on probation or had a conditional sentence.

Arrests and police lobbying increasingly relate to health issues. In September 2013, the Vancouver Police Department released *Vancouver's Mental Health Crisis: An Update Report*, which laments the enormous police resources used by the mentally ill and the lack of services for the mentally ill. Its first recommendation is for 300 additional long-term mental-health treatment beds.

The VPD report calls for more power to commit people under Section 28 of the Mental Health Act, as well as greater police access to medical records, and an active role in Assertive Community Treatment Teams that are increasingly charged with caring for DTES residents in the most difficulty. The report shows increases in Section 28 apprehensions — nine per cent in 2011, six per cent in 2012 and a projected 23 per cent in 2013. DTES health care consumers are now gaining "police records" from being apprehended under the Mental Health Act.

Overall, 28 per cent of people surveyed report being involuntarily committed or certified, including 50 per cent of the people in the mental health consumer group, 37 per cent of the people who drink non-potable alcohol, and 38 per cent of youth.

Many marginalized residents believe the police's increased role in health care has negative implications for their dealings with police and their potential ability to normalize their lives. Residents generally believe the most vulnerable among them are increasingly diagnosed and labelled as mentally ill, and they also believe they have no meaningful recourse to complain about police.

As VCH's Second Generation strategy for the Downtown Eastside works toward better "trauma-informed services," it needs to ensure the police are more informed and constructive contributors to its health mission, and to do that it must remain acutely aware of the role the police can play in creating trauma, weakening trust and perpetuating social isolation.

3. Clients report prevalent experiences of trauma

Trauma's complex implications are not adequately dealt with by many people in the health care system and others, according to DTES residents. This aggravates trauma and becomes a barrier to care. Responding appropriately can become a pathway to healing.

Resident voices

"The street nurses were my link to health services. The first person I slept with when I arrived to Vancouver gave me chlamydia, and I was informed by a street nurse. She did

Too often, the behaviours caused by trauma are labelled as problems, which aggravates the trauma and prevents clients from accessing services.



a pee test, gave me the treatment, told me to not sleep with anybody and made a list of people I'd been with. That was how I got my first pap smear done, or any feminine health. It was really traumatic for me to go through that because I had been through numerous amounts of sexual abuse in my childhood with my dad and stepdad, and whatever... and all the trauma, and the sex work. You get traumatized a lot. You think as a young girl you could make lots of money on the street, but you don't have the self-worth to fight for your money, or [have] somebody backing you up. People rob you, rape you, throw you out. All of that stuff happened to me."

"There is a great need for counselling. With the methadone program you just go to the pharmacy and swallow the drugs. You're put to shame. There isn't much clinical counselling support. It's not easily taken advantage by people who are getting their methadone in a clinical situation. It's taken Carrie months to listen to a dietician, and take the advice. [We should be] stabilizing a person and giving them the opportunity in a friendly setting to access these health care [services]. Counselling, people with lived experience — it's very, very helpful and really lacking."

"If I had a cut on my arm or something got infected, maybe I was getting flu symptoms, I'd go to street nurses. I couldn't go to a doctor. I didn't have one, and every doctor I went to didn't want to see me anyway. And I was like, 'Man, this sucks, where do I go?' Nobody likes to go to a hospital. They completely judge me for coming in on dope. I can understand that I might be aggressive or have a foul mouth when I'm high, but I'm not punching anybody or hurting people... I'm in pain, aggravated, I don't want to be there. I went once to St. Paul's and had an infection in my leg and I was thrown right onto the sidewalk by security guards, literally launched BOOM! And you know what?

I was so physically exhausted that I just passed out right there. It was snowing.

"When I OD'd at Onsite the ambulance was there to take me to St. Paul's and I said, 'There's no way. You're not taking me there.' I remember Sara saying, 'Well, you can stay here then.' I'd never go to that hospital. In emergency they treat you like shit but when you get admitted they take you upstairs to 10-C, which is an HIV ward. I don't have HIV, but I was in an acute bed up there. I'm on a floor watching these nurses that care so much about them, and I was like, 'Man, this is crazy.' But those nurses, I love them.

"I understand that people have long days, and when we are high on drugs we can be a little nasty, but you should never go to a hospital and feel like they are rushing to get you the hell out of there. I remember one time I couldn't even walk and they were like, 'You can go now.' I said I don't have anywhere to go, and they said it wasn't their problem. I should have been admitted, but instead I went to CTCT [the Community Transition Care Team]. I'd stay there and get my treatment, but at the same time use drugs like every day. But they didn't judge me for that. They just wanted me to get better."

Key insights

- Traumatic experiences prevent consumers from embracing services and becoming more stable
- Clients reported experiencing repeated trauma from involuntary hospital admission, repeated arrests, and frequent evictions from shelters and housing
- Personal trauma promotes heavy drug use and addiction
- Some health care consumers experience trauma in health services
- Clients feel like they should be "grateful" for the help they get, and yet some report feeling vulnerable, hurt, angry or invaded

The nature of trauma

Trauma is an unavoidable part of the human experience. According to *Trauma Transformed* (Columbia University Press, 2007), it is not the event that determines trauma, but the individual's experience of the event and the meaning they make of it. Regardless of the source, traumatic events are beyond a person's control.

- The event was unexpected
- The person was unprepared
- There was nothing the person could do to stop it from happening

Trauma is an injury. Something bad happened or was done. Each person experiences traumatic events differently. People affected by trauma may not yet realize how they have been affected. Shame and secrecy often shroud trauma, making it difficult to ask for help.

Trauma can continue to cause suffering and social problems, but traumatic events can bring people together, creating growth. Survivors show courage, strength and resourcefulness even while healing.

Trauma often causes people to feel emotionally overwhelmed. To help someone recover from trauma, those around them need to relieve their suffering, yet traumatized people are often treated in a way that makes it worse.

- People who have experienced trauma often get retraumatized, and will also at times create traumatic situations
- DTES residents have the capacity and desire to heal, and can do so given the right support in health care services and in other contexts

Community context

The stories residents tell about the DTES community are those of trauma: the racist treatment of Aboriginal people, violence against women, economic injustice, the damage caused by drug use, and the accelerating exclusion of DTES residents from their neighbourhood as it is redeveloped. Many of these issues arose in our workshops.

As such, trauma is an essential issue in designing Second Generation health care on the Downtown Eastside. While area residents are sometimes reluctant to give consumer input, or may be perceived by VCH as too poorly behaved to offer it, traumatized health care consumers' input is crucial to designing excellent services. Too often, the behaviours caused by trauma are labelled as problems, which aggravates the trauma and prevents clients from accessing services.

The finding that 72 per cent of the survey respondents want to tell their stories, and that those who reported bad health experiences often wanted to share them, illustrates their natural drive toward healing, which begins with telling and retelling the story of what happened to them. That requires open, collaborative relationships between providers and consumers.

Key desires of clients include consumer safety, consumer choice and consumer control. Welcoming, safe environments can minimize retraumatization and empower



people to improve their lives. If VCH and its agencies' staff are better trained to recognize and respond to expressions of trauma in an informal, constructive way, aggressive interventions won't be nearly as necessary.

4. Residents want medical treatment programs for crack smoking and other stimulants

Clients believe VCH has been slow to adjust to changes in drug use. They want the health authority to respond to crack smoking in a manner consistent with its response to the crisis in injection-drug use. They argue the lack of action has marginalized crack users and put them at greater risk.

Resident voices

"The stigma around crack use really affects my life. I cannot tell my doctor that I use crack or he will take away my T3s and my Clonazepam. I like my doctor and I feel like I'm getting excellent care, so I feel weird not telling her."

"Harm reduction for crack smokers is illegal but is super important. When I smoke rock outside I feel afraid, so I never do it. I smoke at my place and I'm lucky to have a place. For people who are homeless and smoke rock outside, an inhalation site would really impact the DTES and prevent psychosis. The fear of police is natural when smoking rock outside 'cause it is illegal. And then the actual high from crack cocaine makes you paranoid too. So you feel pretty intensely paranoid and when you have another toke, the paranoia escalates and intensifies till people lose it completely. There are tons of homeless, tons of people smoking crack outside, and tons of police. Now we have tons of psychosis. I swear if we can have rock smokers smoke rock in a place they feel safe, a lot of psychosis can be prevented."

"Not only is there no safe place to use rock and no treatment for rock addiction, but the funding for a support and education group is gone, too. Things change daily for crack smokers, and the meetings ensured people were warned about bunkers and crappy poisonous dope and how to be safe picking up and how to be safe while using and how to put screens in stems instead of Brillo and how to use a pipe safely. Since most people who smoke rock are poly drug users, we were also able to refer people to other resources."

"I totally believe in harm reduction. It's great they have methadone but they should have something for stimulant addiction. Addiction is a medical condition and should be treated as such. I want a pill for my damn cocaine, because I'm not a criminal and I don't want to be one. I don't consider myself one. I don't feel what I'm doing is wrong. I can't wait for the day that the SALOME [Study to Assess Long-term Opioid Maintenance Effectiveness] project happens for stimulant addiction, and make it so you can get a prescription, do your stimulants, take it in a controlled safe environment a few times a day. Then you can live a healthy productive life. Everybody wants to feel like they are contributing to the world. The opportunities just aren't there as much if you are labelled a drug addict or mentally ill or poor. Anybody can function if given a chance. That's what I want."

"Everybody does things for different reasons. You wanna get out of this world for a while. Nobody can force somebody to quit unless they want to. If that person wants to quit then they will. You shouldn't have to lie. You should have cocaine in a pill so it wouldn't be against the law. They give you heroin, they give you methadone. For me, I use cocaine as a painkiller before I use it to get high."

Key insights

- Many people who smoke crack cocaine feel abandoned, as effective harm reduction and addiction treatment are unavailable
- Residents want medical trials involving stimulants and safe consumption sites that include inhalation rooms
- Crack users understand the impact their use has on themselves and their community

Community context

The survey indicated that 78 per cent overall reported smoking crack cocaine now or in the past, with more women (81 per cent) and more Aboriginal women (84 per cent) reporting crack smoking. (Only 48 per cent of people labelled mentally ill report ever smoking crack.)

Yet harm reduction efforts such as safe crack kits were for too long done only as guerilla programs or as research. After a successful two-year trial, the safe crack kit program was implemented as a regular VCH program in 2013, but there is no sanctioned safe inhalation room for crack smokers, who are often vulnerable women. In Copenhagen, a safe, modern fully sanctioned inhalation room opened in 2012. Addiction treatment also lags, although funding is now being sought by Dr. Evan Wood, director of the St. Paul's Hospital Addiction Medicine Goldcorp Fellowship, for three small stimulant substitution trials to treat crack cocaine addiction.

People on methadone maintenance therapy in the DTES are most often also smokers of crack cocaine, and are frustrated that they are unable to get methadone “carries” because they must first produce three urine samples clear of cocaine for their doctor.

The ripple effect in their lives — they are unable to travel even to family funerals — increases their marginalization.

5. Experiences of children and families create lifelong health issues

Clients see the relationships between parents and their children as critical determinants in their health, with trauma and child-welfare apprehensions during their childhood, as well as the apprehension of their own children, cited by many as a deeply damaging influences that are not adequately addressed.

Resident voices

“I was in juvenile detention in Winnipeg when I was 12 years old for sniffing nail polish remover, but they can't charge you with sniffing so they charged me with being incorrigible. I stayed for one month. We were kept in jail cells in the basement with small opaque windows and there was no school or outdoor exercise yard. Some girls went to the Manitoba Home for Girls, which is a real juvie jail, but I was sent to Mary Mount Home for Girls. I lived there for two years. First you are allowed a day pass for Saturday and then if you are still doing well you get a overnight pass and eventually get weekends at home.”

“My children were apprehended from me and went to foster care and eventually to juvie, and now both of my sons are in jail. I fought to get my kids back but it was hell. The worst is when you are under a supervision order, so they live with you but you are being watched like a hawk. One had to be at school and another at a preschool program and another was just a baby. I took 13 buses a day to meet ministry requirements under the supervision order. It was exhausting. Every time I got them back



I ended up losing them to care again. Even my grandson went to care. My daughter died and I couldn't take my grandson in and raise him, because I lived in a hotel room. He did well at the same stable foster home, graduating from high school. But I saw him last week at Main and Hastings. He's living at a shelter and trying to find a better job. That's the problem with foster care — it ends when he has to leave at 19. And then all the investment of money that the ministry refused to give to our real family ends, and the foster parents are no longer involved."

"I started living in the DTES in about 1991. The Washington is where I stayed, in the heart of everything. There was a lot of youth programs when I was there, like the Youth Action Centre. If you were tired you could go sleep on the couch, and at 8 am you could go eat cereal and sleep, and at 4 pm they'd wake you up and back on the street I'd go. But the advocates down there would know me and I got to know them. Some were more like my mother figures than my own family. They always encouraged me to get off of drugs. You have a relationship with them."

"From ages of 12 to 15 it was like, drugs drugs drugs. From age 17 to now I have responsibilities, and I'm more aware of my body. As a kid it was a numbing process, now I like to go for a few drinks or smoke a joint once in a while, but it used to be anything I could get my hands on. When I was 13 I hung out with a lot of older people in the DTES, and I'd just ask around where I could get things, and could get access to anything I wanted. During that time I didn't see a doctor ever, but I'd go to a youth clinic on Commercial Drive. Thank God, because I went through a pregnancy and I needed to get an abortion and they were really great supporting me through that process.

"Mental health is important too. You just feel you're alone at that age. All your friends

feel alone. And what kind of got me through that cycle was finding something I was passionate about. Art made me really happy — I'd always go to art class.... The reason I was doing drugs is because I didn't have any interests. Once when I was 13 my mom had picked me up from being a runaway for four weeks and she didn't know where I was, and I was in the DTES, and we were sitting in her car. She said, 'What ... is wrong with you Lana, don't you want to do anything other than drugs? Don't you love to dance, don't you love to sing or anything? Isn't there anything you love doing? You have no passion, you have no drive.'

"It was tough love, but that's when it hit me. I thought, 'Whoa, what DO I love to do?' All I thought about was drugs and partying. Even then I still didn't get it, and kept partying. But that moment always sticks with me. I needed a spark, something to be connected to, ignite a passion inside of me. That shine that everyone has inside of them. And that later helped me become an artist, and later to work with kids. So it's all about the intentions, right? When people use drugs, what are they using it for? To get away from yourself? To replace a feeling that you're having? Or a ceremony that you go through?"

Key insights

- Trauma, abuse and apprehension by child welfare authorities were reported as a common experience during childhood and youth by a majority of DTES health care consumers
- Parents who have had their own children apprehended report a cycle of extreme grief, drug use and high-risk activities
- Children whose parents reside in the DTES neighborhood and actively use drugs are likely to do the same
- Many new mothers in the DTES reported a struggle in successfully

keeping their babies, and they are reluctant to access services because they do not want to have their babies taken away

- Clients at Sheway reported positive support to interrupt a cycle of hopelessness

Community context

Child apprehension has been experienced by a majority of parents among DTES health care consumers . Of those who reported having a child apprehended, 98 per cent had been arrested. This group is less likely to complain about their health care and more likely to feel intimidated by staff.

Women who feel grief over the loss of their children to the Ministry of Children and Family Development and feel powerless to change their lives often become wild — increasing their drug intake and high-risk activities.

6. Housing and services related to housing are a major complaint

Many people who are housed on the Downtown Eastside feel that their housing is not a home, and they believe better housing and more respectful housing-related services are a critical element in normalizing their lives and their health.

Resident voices

“Of course even when my grandchildren came from Alberta, they couldn’t come up [to my apartment]. But what makes me madder is that they [the housing managers] have their ‘pets’ that can do anything. You know, the ones who really look good in public or rather in the stats [as success stories]. And these girls don’t even realize they are being used.”

“So when you let yourself in the front door with your fob, the [mental health and addiction] workers on the 10th floor see you on the monitor. They have a picture of you so they know if you live there. If you have someone with you they disable your fob in the elevator so you cannot go to the floor you live on and make the elevator go to the 10th floor. You have to sign your guest in before you can go to your apartment, and if it is after 11 pm your guest is not allowed to go to your room with you.

“It’s really insulting. No matter how long you live there and how stable and trustworthy you are, you get the same paternalistic treatment from staff. I asked why they keep doing this to me when they know I’m not a problem and they said they need to know who is in the building in case of a fire. But they don’t register guests at the condos next door. I point this out. ‘Don’t lie to us. Just say you don’t trust us.’ I hate it, but I have to put up with the politics. There is no where else to live so I put up with it.”

“My place has a rule that you cannot have overnight guests except once per month and you have to give 24-hour notice. Of course, they have to have picture ID or they cannot visit, even in the daytime. We are allowed to have visitors before 11 pm, but they are super strict about ID. They made an exception when my daughter and her baby came from Chilliwack, because they had nowhere else to sleep. I was so grateful, as she could not pay for a hotel.”

“I lived at Kye7e [Housing for Women] before Bridge, and people say, ‘How do you like Bridge?’ I actually liked Kye7e. I only had a room instead of a nice apartment, but I could talk to my neighbors. At Bridge you go to your apartment and you can’t have your neighbours visit. No one is allowed to have anyone else in the building [such as another tenant] enter her room. I’m lonesome in my own apartment. I was scared of being



People living with mental health and addiction issues want more input into and control over the housing policies that affect them.

alone. Even when my husband abused me, I went back to him, and they took my kids away because I did. But I don't like living in isolation. My whole life I've lived in a big family, or been in juvie with other girls where we weren't alone."

"This whole system of housing for addicts and mentally ill people in the DTES is really fucked up. You can get a nice brand new apartment or even a fixed-up SRO room but people live in a fishbowl. It's like jail in that way. You are monitored and watched all the time. Some places let you have visitors overnight only four nights a month, even if you are in a stable relationship. I think it is wrong to have people that are really in bad shape all together in the same place with all these staff up in their business all the time."

"When they tore the Marie Gomez down I ended up homeless. Then I got into another building. But then there was some bizarre technical issue regarding rent and disability, and I was evicted and on the streets again. I lived on the streets, out of dumpsters, ended up living in a camp with 11 other people near Strathcona Park in an empty lot down there. After it hit the media, BC Housing got involved and I ended up in [an SRO hotel]. It was hard to believe it existed. Bugs and mice crawled over you all night. There were no fridges in these rooms and I started to get really angry."

"I'm healthier because I have a decent place to live, but it's too small. According to studies they've done, for a person to live a normal, healthy existence where they are physically and mentally happy, they need

about 600 square feet to live. I have half of that now. Because I'm on a very limited budget I grow my own food and preserve my own food. I have planters in my place and grow vegetables that I know are good for me, like Belgian endive. We are growing a garden upstairs at Woodward's now. About three weeks ago we got seedlings going. This week we took out a whole bunch of rosebushes and put in new soil. We are replacing them with a veggie garden."

Key insights

- The negative health effects of welfare policies and homelessness were discussed by many participants
- Sixty-two per cent of survey participants reported being homeless or living in a homeless shelter now or in the past, and 66 per cent currently live or have lived in an SRO
- Housing generated a large number of complaints from a majority of clients, including stories about forced administration of medication, harassment, theft and surveillance
- Living in housing where no visitors are allowed is a constant reminder that you are seen as dysfunctional and a barrier to moving forward in life
- Residents felt demeaned by being screened and having guests screened by staff
- Among those who had access to VCH services within their housing, many wanted health care to exist outside of the housing program
- People are frustrated by services where access is limited by criteria for care

- Many want to build a culture of citizenship, trust and accountability within their building by self-monitoring and working collectively with frontline staff to manage problem tenants

Community context

Of the DTES expenditures that we discussed with health care consumers, the least understood and the most criticized were “shelter and housing services.” People did not understand that BC Housing owns NGO-run housing with funding from VCH to create “support.”

We asked if people lived in buildings that contain primary health care services. A surprising number of people were confused about or unaware of health services periodically available in shelters, and nursing stations that operate part-time in SROs run by the larger DTES not-for-profit societies. Among survey participants, 36 per cent reported having access to health services in their building.

Some housing providers are viewed as intrusive. When asked, *Have you ever felt intimidated by staff at a building, clinic or shelter?* just over half answered yes. Among youth, 78 per cent felt intimidated. People report being threatened with eviction if they do not take their meds and that staff enter their apartments without permission. People living in NGO-run housing and shelters were not that grateful for the “support” and felt closely monitored and even harassed by VCH-funded staff.

The rule that there should not be children in adult housing set up for people labelled severely addicted or mentally ill prevents underage people from being sexually exploited, but it also prevents normal relationships from developing. Likewise, picture ID requirements may allow police to

track dangerous criminals and discourage predatory dealers from taking over a vulnerable person’s apartment to deal drugs, but the rule is really a Band-Aid that speaks to more fundamental failures of the system. Residents believe restrictions on tenants’ ability to socialize with friends and family is another paternalistic interference in the lives of people who see normal homes as their key to creating normal lives. People living with mental health and addiction issues want more input into and control over the housing policies that affect them.

Housing and health services for the 8,000 people in the DTES who are in very poor health is not adequate to stabilize this target population, and people feel they must choose between evils, if they have a choice at all. Although homelessness is now falling in Vancouver, it tripled in the preceding 15 years. While some new housing for those most at risk is being created in Vancouver, the Carnegie Community Action Project research suggests that privately run housing affordable to those on welfare in the DTES is being lost at an alarming pace. Many buildings that offer affordable social housing reject people labelled as mentally ill or addicted or those with a criminal record. Yet decent social housing remains a much cheaper option than shelters or jails. Rethinking how we spend money on housing is critical to stabilizing the lives and the health of the people VCH wants to help.

7. Residents feel pain medication is widely needed and mishandled

At-risk DTES residents say chronic pain is a central feature in their lives, and that treatment is badly managed because of stigma, the monetary value of the medications to very poor people, and medical guidelines that are often arbitrarily applied.



Resident voices

"For me, I had a broken back as a baby, and my mom didn't even know. I didn't find out until I was 20 because I was wondering why my back was always hurting. So I was really in a lot of pain with my back. Finally, when I did start smoking [crack] I could feel the pain relief. As soon as I had a toke I could feel it go down the spine of my back, and I wasn't even in pain anymore. In the morning, I have to rock to get up. I was also on antidepressants after Deanna died. I first went to the Downtown Clinic after having a nervous breakdown. I was unhappy I had come back down here, and was using, and lost my daughter. But the people there wouldn't put me on anything to help. I didn't like them there. They didn't listen to me. So I went to Native Health, and I have a doctor there, and they really help me and support me. They give me the things I need for pain, for depression, for insomnia. I have pills that really work for me."

"I had some issues such as sexual and physical abuse in my younger years. And when I got introduced to cocaine I was like, 'This is an outlet, a relief.' I had just always cut and was suicidal before then. The therapies and prescriptions that I was given as a youth really didn't work for me, or I didn't like them, or I didn't take them, so I started self-medicating."

"I went to the clinic on Powell Street and they said I couldn't see a doctor. The receptionist was rude. I never went back. I found a doctor on Commercial and he recently reduced my [pain medication] prescription to half. Just announced it one day with no warning! I was on the same dose for 11 years without any trouble. So I'm trying to find another doctor. Says he had to cut me back, that the College of Physicians and Surgeons ordered him to. But aren't they just 'guidelines,' not laws? I am stable and

have a medical condition that causes pain. So I bought an Oxy for \$10 from the corner and I couldn't even feel it. I'm in pain all the time from my spine. I wake up in pain and I can't sleep. I go buy Valiums for \$2 at the corner. The Valiums help knock me out."

"There is a huge misconception in society in general. I do realize addicts have earned a reputation, but I think people fear what they don't understand. Unfortunately, that carries through."

Key insights

- Many DTES health care consumers experience chronic pain, with 65 per cent in our survey reporting that they take prescription pain medications, while 58 per cent reported buying pain medications on the street
- The underground pill market is fuelled by people unable to get prescriptions for medicine and by people who are prescribed medicines they do not want or need, and then sell those medications to buy the medicines they need but cannot get prescribed
- Youths, Aboriginal men, people who have been homeless, those committed under the Mental Health Act, and those who have had their children apprehended buy pain medications on the street at a greater rate than the average in our survey
- Some people feel stigmatized by doctors, pharmacists, welfare workers and family because of pain medication needs
- Because the welfare rates are extremely low, families sometimes strategize to get valuable medications prescribed so they can supplement their income with pill sales
- Clients would welcome a constructive public dialogue on the use of opiates and the control of pain

Community context

The management of pain is a dominant issue for most at-risk members of the DTES community. Physicians who follow the College of Physicians and Surgeons of BC Opiate Prescribing Guidelines are discouraged from prescribing opiates and sedatives to “people with addictions; patients with psychiatric illness and personality disorders; young people; and people with chronic pain syndrome.” Doctors who don’t follow the guidelines face sanctions.

The use of opioid painkillers is growing and fraught. However, in the DTES when a doctor cuts a patient off they often buy their prescriptions on the street or buy heroin. The more the police try to shut down the black market for pain pills, the higher the prices get. The more tightly regulated prescribed opiates become, the more people in pain will be denied pain medications and will buy pills or heroin from the streets. Desperately poor people also exploit their access to valuable medications to supplement their incomes.

Seniors and women may have the easiest access to prescriptions for their pain. Some 74 per cent of seniors in our survey reported taking prescription pain medications with only 60 per cent reporting they buy them on the street. Seventy-one per cent of women report taking prescription pain medications with only 55 per cent reporting buying them on the street. Sixty-one per cent of men report taking pain medications with 60 per cent buying meds on the street. It is likely that young people have difficulty accessing prescriptions for pain, as 84 per cent report buying pain medications on the street. People labelled mentally ill, and those who drink non-potable alcohol, have the lowest use of pain medications, at around 50 per cent.

All patients in BC have a legal right to have their pain treated. If they are patients who are labelled “drug seeking” they may find themselves doubted and desperate. People who are being treated with methadone report being denied pain medication on the grounds that methadone should cover pain. Many people report becoming street-involved addicts after they are injured at work or in a car accident. They may be healing well, but with chronic pain, when their physician cuts off their pain medication. It’s only then that they enter the expensive new world of the marginalized addict.

8. Alcohol-dependant people want a safe drinking space

People who drink non-potable alcohol have extremely limited options and their obvious needs have not been met. The consequence has been a number of unnecessary deaths.

Resident voices

“At Pigeon Park yesterday, the cops came along and dumped out the drinkers’ Listerine. Why are they doing this? They were so sick and one fellow especially was shaking real bad. People can die from alcohol withdrawal. It’s really serious. Taking away their alcohol in the morning like that can kill them. If the police take away someone’s only supply of alcohol, they should give them something legal to drink. You could tell they were upset; that they had pulled all their pennies together to get that one bottle to share. They just hung their heads. I gave them \$5 I felt so bad for them.

“It is ironic that people addicted to a legal drug — alcohol — but who are homeless and poor, have no place to drink without breaking the liquor laws and risking being ticketed or arrest by police. People who inject drugs have successfully lobbied for



Insite, so they do not have to inject their drugs in public."

Key insights

- The Eastside Illicit Drinkers Group for Education reported serious health issues and complications from drinking non-potable alcohol
- Some report that these drinkers go to emergency by ambulance as much as once a week, with police involvement and the potential for a criminal record for being drunk in a public place
- Community members actively requested a safe drinking site for safer cheap alcohol
- Drinkers do not want the experience to feel "medical," but they do not want to drink in bars

Community context

People who drink non-potable alcohol are a cohesive group who, with a little supervision, are capable of running a clubhouse where they can drink potable alcohol that they buy or brew communally or receive as donations. Many alcohol programs operate around the world. Seaton House in Toronto has operated an alcohol program effectively since 1997.

The police, Vancouver Fire and Rescue Services, the BC Ambulance Service and St. Paul's emergency department are over-involved in the short lives of people who drink non-potable alcohol. Most are unhoused and are repeatedly kicked out of shelters. Detox centres have determined that many are too violent to serve. Years of lobbying to create a sobering centre to meet their needs funded instead "sobering beds" at the detoxes that have refused them entry.

Drinkers face daunting days

Illicit Alcohol in British Columbia: Results from a Qualitative Research Study, published by the British Columbia Centre for Disease Control in 2013, examined illicit or non-potable alcohol, including what people were drinking, what harms drinkers faced and what drinkers thought they could do to reduce these harms.

Police were a major presence in their day-to-day lives. People spoke of being arrested often and spending a lot of time trying to stay away from the police to avoid having their alcohol poured out, being fined or put in the police drunk tank.

"We prefer to get it [buy alcohol] little by little because it's not worth losing it all to the cops," said one. Some people seemed to accept police involvement in their daily life. Others were upset: "A lot of us get bullied by the cops really hard. When we do get the money together it's to cure the shakes," adding that people have died from withdrawal.

They said police frequently ask them to move and that they were running out of places to drink. Said one: "I spend most of the time running away from the cops."

Last year, in the three months after the First United Church shelter was forced to change its open policies and lost most of its capacity, six drinkers died.

An alcohol maintenance program is run at PHS's 80-unit Station Street Hotel, where eight people are prescribed alcohol and dispensed one drink an hour. However, access to safe potable alcohol should not be restricted to those living in supported housing.

9. Aboriginal community has distinct health needs and often unsatisfactory experiences with VCH services

Racism is a central element in the experience of urbanized, marginalized Aboriginals trying to navigate the health care, justice and housing systems without sufficiently robust community infrastructure. Significant changes in care need to take place to meet their needs.

Resident voices

"My mom had me when she was 18 and addicted to heroin in Whitehorse. The doctors said I would be dead in 72 hours. I was a preemie, an incubator baby. I lived with my grandma and mom, who was a severe addict and alcoholic. My mom was high and drunk and was cutting up moose meat and stabbed my aunt to death arguing over a boyfriend. She got 12 years in jail for manslaughter.

"I lived with my aunt and uncle and he was in the navy so we moved a lot. Ended up in Nova Scotia and my aunt was strict and cruel, probably from growing up in residential school. She scrubbed my back raw and my teacher at school noticed and called the police and I ended up in foster care. At the first foster home I was in, I was sexually abused. The next one I stayed from

when I was nine till when I was 18. But when I was 13, I was rebellious, got kicked out of a series of schools and at 15 was put in the Nova Scotia Youth Residential School. The place was closed down when I was there. They weighed us every week and if I gained weight they took food away from me — no second helpings. I told my social worker and they punished me.

"When I went into that juvie, I was cocky and disobedient — when I came out, I was angry and violent. Mi'kmaw Family Services refused to extend my care to 21. So I couldn't go back to the foster home. They sit you down and say, 'You can go anywhere you want. We'll put you on a plane.' I was unable to do anything for myself as I had lived in an institution and felt useless. I ended up in Prince Rupert with an aunt and uncle. There was crazy domestic assaults, drug use and lots of drinking. I got a job looking after kids for two women who were selling sex and crack and they were nice to me. I had nice clothes and they told me that men would take advantage of me to have sex so I should make them pay me. They took me to places to have sex with men and they waited in the car outside. I got \$400 a night.

"I moved to Calgary and got back into selling sex. There was a fight with another sex worker and when the cops came I ended up getting arrested for assaulting a police officer and got a six month suspended sentence. Getting a criminal record wrecked my life. I couldn't get a job 'cause of my record showing I assaulted a police officer. I had to do community hours and I couldn't work at anything else so I sold sex again and got into crack. I kept screwing up my probation appointments and rearrested 11 times in one year. Arrested, rearrested and held in remand, and I was selling sex. I called the police once because these guys in a hotel room raped me and the police wouldn't even charge them and they drove me way away from the stroll and I had to walk back.



"I finally left Calgary without completing my probation order, which was six months but had lasted for three years because I failed to adhere to my conditions. I came to Vancouver, was still selling sex and using crack and went to PACE [a counselling and education group led by sex workers] and then to PEERS [Vancouver] to exit the sex trade. When I went to the Downtown Clinic to see a doctor, they asked my history, and as soon as I said I was a prostitute they asked, 'Have you been raped?' I'm sitting in a paper gown with these two med students asking me about rape. Seems every time I tell a doctor I was in prostitution, they ask me lots of questions about rape.

"I was assaulted, broke my nose, did the police report and went to victim services, who said they would pay for surgery. I finally get to a surgeon's office and he sees my file with sex work in it and drug use and he says, 'What did you put up your nose?' I told him I smoke crack, which has nothing to do with my nose, which was broken from being punched in the face, and he was so rude and stupid. He refused to operate. The other time at the DT clinic I needed my disability welfare forms filled out and the doctor says: 'If you are going to use this extra money for drugs, I'm not going to help you.' "

Key insights

- More than half the DTES VCH health care consumers we surveyed self-identified as Aboriginal
- Aboriginal health care consumers reported being treated with discrimination wherever they go to access care
- Aboriginal residents are more likely to be homeless, with high rates of illiteracy
- Many Aboriginal people reported difficulties in methadone care, as some providers would not serve them due to bureaucratic complexities

- Members of this group use VCH services more selectively and often buy or sell pain medication on the street

Community context

Aboriginal people in BC have been marginalized like no other group, and the consequent addiction and trauma issues play out every day in the Downtown Eastside. Despite efforts to address this, racism, paternalism and poverty persist, with dire consequences.

Aboriginal people in BC have poorer health overall than other BC residents, as do those incarcerated by the justice system. So it is not surprising that Aboriginal people who have been incarcerated experience the poorest health of pretty much any group in the country.

The provincial health officer, Perry Kendall, is so concerned that BC's Aboriginal people will likely be disproportionately affected by the new federal Safe Streets and Communities Act, which calls for mandatory minimum sentences, that he released a special report in March 2013: *Health, Crime and Doing Time: Potential Impacts of the Safe Streets and Communities Act on the Health and Well-being of Aboriginal People in BC*. The mandatory minimums have the effect of overturning the requirement that judges "consider all possible appropriate penalties prior to choosing incarceration" for Aboriginal people and youth.

Conversely, the formal creation in October 2013 by the British Columbia Aboriginal community and the federal government of the country's only First Nations Health Authority in October 2013 creates an opportunity for new partnerships and new models of care. Those partnerships could help to reinvigorate VCH's own efforts to ensure it more effectively serves the

Residents would welcome an ombudsperson, with real independence, to create a safe forum for people labelled mentally ill and/or addicted to raise grievances.

Aboriginal population. VCH needs to bring Aboriginal experiences and circumstances to the forefront in its efforts to build a health care system that offers hope where too often there is humiliation. Effectively engaging the Aboriginal community must be the cornerstone of that effort.

10. Residents want a culture of consumer input

Too often, in the boardroom and the examining room, health care clients are not included in decisions regarding their care. Residents want a change in culture so they have a say in and can contribute to their care.

Resident voices

"There is a need for people in my situation to be heard, and understood.... When we ask for help and doors get closed, it's frustrating and discouraging, and there is no inspiration in that. For a lot of people who are not as strong as I am, I think it's something that could honestly make somebody want to go use. It's frustrating, discouraging and hurtful. You start to feel, 'Why would you bother to change?' It's not about just quitting drugs. It's about living a normal life and get back into what living life is about — being a mother, doing your shopping, tending to your kids needs, having family time. When you get treated the same way you did when you were using, it doesn't give you a lot of hope."

Key insights

- DTES health care consumers are proud of their accomplishments fighting for and getting expanded needle exchange, a supervised injection site and volunteer opportunities that contribute to their community's well-being
- DTES health care consumers want a say in how services are delivered to them, and they are capable of providing constructive input

Community context

Downtown Eastside residents want better health care and they believe they can help to shape it. They have the intelligence, experience and desire to do so — that is one of the most evident truths to emerge from this process. Experience suggests that quite often the cheapest and most effective tools are those that give roles and influence to residents: peer counselling, peer disease testing, sharing knowledge or clean needles, meeting to develop advocacy plans, working together to teach each other about better nutrition, strengthening the local economy through business enterprises such as street markets and urban farms, helping a neighbour who has fallen on the street.

What have we got now?

Most low-barrier projects that provide social support, free food and services,



and no-barrier employment training involve consumers in running their programs. There are some agency advisory committees made up of service users. Other NGOs allow clients to approach the board in person or in writing to complain. A few have some limited requirements for lived experience on their boards. The Vancouver Mental Patients Association (a VCH-funded agency now known as MPA), was originally set up in 1973 as consumer group to call for an end to electroconvulsive shock therapy, but it has evolved into a service agency not controlled by a mental-health-patient board.

While the work of all these groups is laudable, the point here is that they are not user-controlled and cannot be mistaken for consumer advocacy groups. Member-driven DTES not-for-profits such as the Western Aboriginal Harm Reduction Society and VANDU (whose board is elected by drug users and former users) are rare.

Expectations of compliance can become built into the culture of social support organizations. The senate report *Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada* put the issue this way: "Pejorative labels such as noncompliant, manipulative, difficult to direct, hard to serve, attention seeking or interfering have discredited assertive behaviors and have further silenced people." However, when those people are given tools that they control — to provide input regarding their services and to take charge of improving their own lives — quite a few good things can happen.

How can we build a better system?

Funding evaluations can include rigorous requirements for consumer feedback.

Evaluations such as CHASE (Community Health and Safety Evaluation) can be an excellent but costly way to gauge quality of care and effectiveness at improving desired health outcomes. However, evaluations and consumer feedback don't necessarily ensure a meaningful consumer voice or provide a mechanism where an ill person facing barriers to health care can have their immediate needs dealt with.

Ensuring input from DTES residents with multiple barriers who experience the poorest health outcomes and mortality can be accomplished by taking a multipronged consumer-input approach.

Residents would welcome an ombudsperson, with real independence, to create a safe forum for people labelled mentally ill and/or addicted to raise grievances. Right now, people are often afraid to complain about mistreatment because they fear losing their privileges or not being believed. Complaints from people labelled mentally ill are too often seen as "part of their illness," and addicts expressing a need for pain relief can be written off as "drug seeking." Many ombudsperson programs have high thresholds with strict criteria for complaints. Care would have to be taken to ensure complainants are not turned away.

It is also important to ensure there is a small network of low- or no-barrier self-run consumer groups that focus on a social-justice approach to improving their lives, and the health and well-being of their neighbourhood. Groups that seek to represent residents must be open to new members, even the most marginalized people. They must operate transparently, so people know how to join and gain leadership positions, and have democratically elected, accountable leaders.

VCH's Second Generation Health Strategy for the Downtown Eastside is an opportunity to create the structural shift needed to make sure that even people with disruptive behavior are treated with respect. They need a complaint process that is safe and transparent, and resources that enable them with expertise in citizenship and social justice advocacy procedures. They need organizations that they control, to help them shape the policies that affect them.



A view from the front lines

Twenty years of advocating for the Downtown Eastside's most marginalized people

Ann Livingston



THE SERVICES FUNDED BY VANCOUVER COASTAL HEALTH ON THE DOWNTOWN EASTSIDE ARE NOT MEETING THE NEEDS OF DTES CITIZENS MOST AT RISK.

Programs have expanded and some critical health issues have been well-managed, but despite many innovative and earnest attempts to create both “integrated” and “wrap around” health services, far too many people don’t access those services.

They may come to a clinic, but too often it's just once. Even regular clients often don't know what services are available. Or, like the growing number of severely addicted and mentally ill — a group that some have pegged at 2,000 — they rarely leave their squalid rooms and are unable to access services at all.

And for many who do begin to stabilize their health, progress is impaired by justice and social-welfare systems that do not adequately consider the impact they have on health. Police circulate vulnerable people, often for minor offences, repeatedly through the justice system. Shelters, unable to place people in housing, sometimes find fault with their behavior and discharge them to the street. This creates an eternal “shelter shuffle” for the “hard to house.” DTES residents feel too many agencies play whack-a-mole, as they wait to see

where the people we have failed will emerge — at an emergency ward, or a shelter, or a jail. And ultimately, all too often, the morgue.

The provincial Ministry of Social Development's welfare program has become increasingly unresponsive to the financial realities of those at the economic bottom in Canada's most expensive city. People who have fallen on hard times are now treated with suspicion and contempt, and inadequate welfare and affordable housing have contributed to increased health costs. Since people are not turned away from health care services, residents in the DTES are picked up by ambulance in shockingly high numbers. A 2001 study of injection drug users by researchers at St. Paul's Hospital showed hospital acute-care and emergency services at the hospital were used at 50 times the rate of average

Vancouverites their age. While the drugs have changed, the costly problem remains.

People are damaged by their repeated rotation through shelters, ERs, SROs, jails and recovery houses. And these expensive, disruptive interventions seem extravagant and pointless to people whose most basic needs are not being met.

DTES residents believe those who provide health and welfare services have overlooked, silenced or ignored their voices, and VCH is among them. Perhaps VCH has rested on its considerable successes, from controlling epidemics of disease to hiring physicians to take patients that no one else will. It could also be that competition between VCH bureaucrats and the agencies they work with, and between the agencies themselves, has impaired progress. Individual agencies remain uncoordinated on the ground, perpetuating misery, confusion and chaos for the most vulnerable DTES health care users.

Stable health requires stable, normal lives, and provincial government agencies in particular do not work adequately in concert to help DTES residents achieve stability. The message from health care consumers on this count is overwhelming, and the chorus of frustration travels along the following lines.

BC Housing labels people "hard to house," insists on health-funded support workers in order to house them, and robs people of their tenancy rights by arguing they live under special-needs housing rules.

St. Paul's Hospital and Vancouver General Hospital staff label some residents "drug seekers," others "frequent fliers," increase hospital security for staff safety, and release people to the street who have no transportation and are too ill to walk. Drug detox facilities call many people "too violent for sobering" and turn them away permanently to be held at either the police drunk tank or hospital emergency.

Police pick up people in psychosis, often drug-induced, and take them to hospital emergency, where psychiatrists label them SAMIs (severely addicted mentally ill), MIAs (mentally ill and addicted) and "people with concurrent disorders." Yet both police and psychiatrists block efforts that would reduce the need for crisis response, such as offering safe smoking rooms for crack smokers and stimulant replacement therapy.

When people are repeatedly arrested for drugs or "being drunk in a public place" or ignoring a subpoena to court for unpaid bylaw tickets, judges issue warrants for their arrest. When they continue to miss court dates and probation appointments,

Stable health requires stable, normal lives, and provincial government agencies in particular do not work adequately in concert to help DTES residents achieve stability.



judges label them “high risk” and give them ever-increasing conditional sentences, with strictures that are impossible for them to meet. They may require that addicts not use drugs or alcohol or carry drug paraphernalia, or restrict them from the DTES. This leads to more warrants and more arrests and more jail time and even longer impossible conditional sentences.

For women in particular, warrants for minor offenses put them at risk, because the possibility of arrest prevents them from seeking help when they need it and allows them to be exploited.

Residents believe the most vulnerable among them are increasingly diagnosed and labelled, and swept into initiatives that are enthusiastically planned and generously funded without meaningful input from those most affected.

When powerful groups weigh in with solutions, key information is often absent. In September 2013, the Vancouver Police Department released *Vancouver’s Mental Health Crisis: An Update Report*, which laments the enormous police resources used by the mentally ill and the lack of services for the mentally ill. While there is a call for more health care support for those with mental illness in both supported and market housing, there is no discussion of the desperate underlying circumstances of these people.

While the report describes in graphic detail 10 recent incidents of mentally ill people randomly and viciously attacking members of the public, events that contribute to the deep distrust that many mentally ill people feel toward the police are not mentioned. Not the least of these is a video released in 2012 of Paul Boyd being killed in 2007 by a VPD officer. Boyd, a mentally-ill animator, had been disarmed of his bicycle chain and

lock, shot seven times, and was crawling on his hands and knees across the street in South Granville when he was fatally shot in the head.

While the VPD report calls for more power to commit people under Section 28 of the Mental Health Act, as well as greater police access to medical records, and an active role in Assertive Community Treatment Teams that are increasingly charged with caring for DTES residents in the most difficulty, it does not talk about how it intends to build trust with a community of DTES residents whose confidence in the police could not be much lower.

DTES health care consumers are now gaining “police records” from being apprehended under the Mental Health Act. These records are accessed when routine criminal record checks are done for employment or for community volunteer positions, and marginalized people do not have the tools to have a mental health incident removed from their police record.

Police both tolerate and undermine VCH’s attempts to reduce drug overdoses and disease epidemics in the DTES. This becomes most obvious around the much-studied and admired Insite. Last summer, as the federal government introduced legislation to limit such safe injection sites, Tom Stamatakis, president of both the Canadian Police Association and the Vancouver Police Union, supported the legislation. In a story in *The Lancet*, Stamatakis claimed Insite “increases criminal behavior and disorder in the surrounding community.”

Welfare workers bar people from their offices, calling them violent and high needs, but they also force them fill out complex application forms for disability, or they are cut off welfare for not looking for work.

Financial indignities arrive in the silliest ways. One of the people who assisted in this project told me that because the Medical Services Plan does not cover the partial ambulance fee of \$80 per pickup, the fee was garnished from her GST/HST payment.

Canada's drug laws are increasingly unenforceable, yet drug users now make up more than 70 per cent of BC's incarcerated population. Harm reduction and treatment in prisons are not adequate. Too often, pee testing is viewed as a substitute for treatment.

The Drug Treatment Court of Vancouver, set up in 2001, and the Downtown Community Court, established in 2008, have little impact on those who are unable to stop using drugs. VCH is a partner in both these initiatives. A long-delayed evaluation of the community court was promised by the provincial government this fall, but it has yet to be released. The cost of an average offender's 14 appearances before the drug court is \$22,248, as opposed to \$26,736 for a comparable person in the regular justice system, according to a 2008 federal government assessment. The problem is not so much the court process itself, but the poverty into which people are discharged. The economic irony is not lost on those in the system.

Fifteen years ago, VCH planned to work with "partners outside the health care system" to improve essential social factors that contribute to poor health and early death. As the health authority acts to achieve the goals of the Second Generation Health System Strategy, including "social inclusion, housing, health improvements, improved intergenerational outcomes and employment," we need to measure key outcomes, and review and adjust the strategies accordingly.

Public health agencies engage in public education campaigns, but not about the obvious damage to people's health from extremely inadequate welfare income and from living outside, shuffling from one homeless shelter to another, or residing in horrid rooms with shared toilets and no kitchen. Sure, with the best intentions, charities have created urban farms, healthy food programs and community kitchens and gardens, but most people would still prefer an adequate income and an apartment where they can cook their own meals.

Fifteen years ago, indicators, benchmarks and performance targets were supposed to measure and guide the creation health services for high-risk health consumers. How have we done on those goals? We have improved access to health services and enhanced community response to disease epidemics. However, on strengthening community collaboration and accountability, advocating for inter-sectoral action on health, and addressing the basic determinants of health, not nearly enough has been accomplished. The Ministry of Health should not be the refuge of last resort, where expenses that result from the failures of others are met without regard for the cause.

Drug use is now viewed as both a crime and an illness. In fact, it is neither. It's a complex social problem that requires comprehensive solutions. For the health authority, this may be daunting, but it is not deniable.

Many Downtown Eastside residents do have a sense that VCH is on the side of marginalized health care users, but they also believe that VCH is fearful of conflicting with other powerful organizations. Yet that is what's required to improve health outcomes. Much can be accomplished if health care consumers



Residents know that everyone is making money off of them, they are given nothing to live on, and they have no voice.

themselves are empowered to stand up to harmful policies and practices, which too often enter the realm of routine abuse.

VCH has a history of implementing and supporting others in developing evidence-based, innovative health care, even when it's been controversial. VCH's Second Generation strategy for the Downtown Eastside is an opportunity to listen to the people the health authority serves, to educate the public about determinants of health, and to empower DTES health care users in a system that works all the angles to create a healthier community.

There is much that VCH can do change this culture: work to normalize heroin-assisted therapy, inhalation sites for drug smokers, stimulant replacement therapy, and innovative treatments that draw on shamanic and other Aboriginal traditions. VCH can bring both science and compassion to better addiction treatment. It can be more transparent about what its policies and programs are trying to achieve by tracking key indicators, setting targets and measuring outcomes.

There are huge vested interests — the pharmaceutical industry, lucrative private clinics and pharmacies that dispense methadone, doctors' associations, housing agencies, ambulance and police services, real estate developers and drug dealers. The costs associated with care on the Downtown Eastside are enormous. Do AIDS medications in the DTES cost \$24 million, or is it less? Is the crack market

worth \$6 million, or is it more? Are DTES policing costs in the same order as health costs? How much do we spend in the courts to prosecute people for relatively minor crimes? How many of the 30,000-odd ambulance calls from the two stations that primarily serve the DTES — at between \$800 and more than \$2,000 a pop, depending on what's counted — are for the high-needs patients in the neighbourhood? In this context, the \$55 million that Vancouver Coastal Health spends to deliver health care services such as clinics and mental-health care on the Downtown Eastside begins to seem small. An accounting of all these costs — and a look at ways to spend that money more effectively — would be an illuminating and helpful basis to establish a broad new set of priorities.

For those who live at the bottom of this pile on a little more than \$200 a month once their rent is paid, the exact amounts don't matter. They know their health is a function of constant arrests, surveillance, disrespect, addiction and poverty, as they move from shelter to squalid SRO, with no hope of getting a real home. Residents know that everyone is making money off of them, they are given nothing to live on, and they have no voice.

Although VCH has faced criticism and opposition, most know that it remains a leader on initiatives that other Canadian cities and health authorities refuse to implement. VCH can continue to lead, but its success will depend on how it deals

with obstacles — some will need to be circumvented, some require compromise and some will need to be confronted head on.

VCH can use the development of its Second Generation Health Services Strategy for the DTES to give hope to those they are serving by including them in the process. By using its cornerstone position in the Downtown Eastside to leverage improvements in other determinants of health, by allowing consumers to help it shape more responsive and effective care, by continuing to push innovation that others resist, is it possible that VCH could affect not just the health of the neighbourhood's most vulnerable but also the health of their children? Weirder things have happened.



Vancouver 
CoastalHealth

