

Building Nutritional Health:

HIV, Injection Drug Use, Poverty and Nutrition in Vancouver's Downtown Community

Prepared by the HIV, IDU and Nutrition Working Committee

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Ce document est aussi disponible en français.

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EXECUTIVE SUMMARY

The Grocery program at AIDS Vancouver has provided HIV positive persons with limited incomes supplementary food assistance since 1992. By 1995, the number of people accessing the Grocery program who identified as injection drug users (IDUs) was increasing¹.

This research project came out of the desire to understand HIV positive injection drug users' (HIV/IDUs) experiences of attempting to access food and to identify how free food programs could respond to their needs. Though feedback was sought from food service providers in the community, this participatory project was guided by and focused on community members. It was designed to let people talk about their experiences of living with HIV, injection drug use, and their attempts to get enough food to eat. In addition to talking about their lived experiences, community members were encouraged to identify how they could eat better and to make recommendations to food providers.

Involvement from community members throughout the project was paramount. An advisory group of community members was established and they assisted with all aspects of the project: identifying which questions to ask and how to ask them; conducting focus groups; interpreting the results; and validating the information. Most importantly, community members helped ensure that everyone involved in the project was treated with dignity and respect and that a safe forum was created so that everyone could freely express their experiences.

Twenty-one service providers and community and hospital nutritionists were interviewed to discuss existing food services and to identify gaps in their knowledge about HIV/IDUs experiences. This information was compiled and used by the advisory group to form the basis of the community member focus group questions. Six focus groups were conducted with thirty-seven community members representing single men, people with mental health issues, youth, women, and First Nations. Time and budgetary constraints restricted the number of people involved. The transcripts of the focus group were analyzed using content and thematic analysis.

Three major themes emerged from the research: Life Issues and Eating Patterns, Access to Food Programs, and Food Quantity and Quality. These interconnected themes influence community members access to food in varying degrees.

Life issues and eating patterns have a major influence on HIV/IDUs nutritional health. IDUs depend on free food programs as money is often spent on drugs. IDUs seldom eat when using drugs and consume larger amounts when not using. Poverty is a major obstacle to HIV/IDUs obtaining a nutritious diet. HIV/IDUs who are sick are often isolated with limited access to amenities and social support.

¹AIDS Vancouver Support Programs statistics, 1995.

HIV/IDUs experience a number of issues that influence their access to food. HIV/IDUs value safe and supportive food service environments and fear the violence and harassment that occurs at some food line-ups. Accessing multiple food services in the community requires planning skills and motivation; those with fewer skills and challenged by illnesses have less access to food. There is also unequal access to food programs - men have less access to better quality food whereas women, youth and those with mental health issues have less access to food overall. There are also a number of other barriers limiting access to food: time and location of food services, poor communication between HIV/IDUs and staff and program volunteers, and HIV/IDUs feelings of shame when accessing programs.

The food available in the community varies to a great degree and is inconsistent between programs. HIV/IDUs are limited in their food choices and may have to eat foods that are potentially detrimental to their health. HIV/IDUs may be unaware of where free food providers get their food and the limitations within the food donation system. Illnesses such as HIV/AIDS, addictions and hepatitis result in nutritional difficulties including lack of appetite, fatigue and low weight which further compromise HIV/IDUs health.

Community members made specific recommendations which are attainable, and can resolve some of the barriers which reduce access to free food programs. By listening to the voices of the community, service providers can build food programs that are safe, accessible and meet the needs of the community they serve.

Creating programming that will meet the nutritional needs of the community can begin by redefining the mission of “Feeding the Hungry” to “Building Nutritional Health”. Only through involving community members in all aspects of planning, implementing and evaluating food service programs, can service providers begin to empower community members and create a healthier community.

INTRODUCTION

Background

British Columbia Centre for Disease Control statistics estimated that HIV transmission rates attributable to injection drug use have increased from 9% prior to 1995, to 38% of total transmissions in 1995. A 1997 study found that IDUs in Vancouver's Downtown Eastside, an inner city neighbourhood, had the highest reported HIV infection rate in North America(1). It is currently estimated that 25% of injection drug users (IDUs) in Vancouver are HIV positive(2). A 1998 Vancouver Richmond Health Board survey reported that an increasing number of people who identify as substance users are accessing organizations that provide free food as part of their services(3).

The Downtown Eastside is home to many vulnerable groups at risk for contracting HIV: injection drug users, women, youth, and persons with a mental health diagnosis. First Nation peoples are over-represented in these high risk groups(2). Women and youth, in particular, are experiencing increasing rates of HIV infection, especially among those who are IDUs. There are no current local or national HIV infection rate statistics for those living with a mental illness and a drug addiction.

The role of nutrition is vital in maintaining the health of people living with HIV. An adequate nutrient intake is important for preventing infections by building and maintaining a strong immune system, managing symptoms and providing protection from disease and drug side effects. Both injection drug use and HIV infection have deleterious effects on nutritional status. Mild to severe malnutrition has been identified in both persons living with HIV/AIDS and in persons living with a drug addiction(4,5). Malnutrition depresses the immune system(6,7) and the already malnourished person with HIV may develop AIDS more quickly(8).

There is a large body of research on the nutritional effects of HIV/AIDS. Malnutrition in persons with HIV/AIDS can result from: malabsorption or impaired use of nutrients(9,10), altered metabolism or increased nutrient requirements(11,12), inadequate oral intake from symptoms including nausea or fatigue, and loss of appetite(4,13).

There has been very little research on injection drug use and nutrition. Most studies have looked only at people in drug treatment programs(3,13,14). Malnutrition or poor nutritional status in drug users can result from: drug-induced loss of appetite, especially with cocaine use(16), or altered eating patterns, such as eating one meal per day(3,17,18), a high intake of refined carbohydrates and a low intake of fruits, vegetables, and cereal fibre(19).

Nutrition is just one of the many challenges facing injection drug users living with HIV/AIDS. Nutrition is inextricably linked to poverty and inadequate housing which are endemic to Vancouver's Downtown Eastside area. Many people in the

area live on a fixed income below the poverty line(3). Many live in single room occupancy hotels (SROs) which lack adequate cooking and food storage facilities and are infested with cockroaches and rodents(20).

The Downtown Eastside is home to many churches and community-based organizations (CBOs) that provide free food and meals as part of their services. Many of these organizations are dependent on donated food and operate on monthly food budgets of \$500 or less. In a recent survey, downtown food providers identified that many people who frequent their meal programs are substance users(21). AIDS Vancouver's Grocery program, a supplemental food pantry for HIV positive people with limited incomes, has also seen increasing use of their service by IDUs.

In 1997, the BC Ministry of Health requested the Vancouver Richmond Health Board (VRHB) develop a plan of action to reduce the spread of HIV infection among IDUs in the Downtown East Side of Vancouver. A report, "Something to eat, a place to sleep, and someone who gives a damn", recognized that the basic food needs of many Downtown Eastside residents were not being met. The report also stressed the importance of giving a strong voice to IDUs and including them in the ongoing planning of all services that are developed for them(22). Health Canada's HIV, AIDS, and IDU National Action Plan also recognized that those using the services must be involved in the development of programs which affect them(23).

This research was motivated by the desire to meet the nutritional needs of the changing HIV affected groups and was designed to give IDUs a voice and enable them to participate in the planning of nutrition services in downtown Vancouver. In this report, Vancouver's downtown includes the Downtown Eastside, Downtown South and Grandview-Woodlands communities. It is hoped that this research will be the beginning of a partnership between food providers and community members to improve access to nutritious foods and adequate cooking facilities and, in turn, lead to improved nutritional health and self-sufficiency.

Project Objectives

- to provide a forum for HIV/IDUs to discuss their experiences of accessing food;
- to engage food providers and those who access free food programs in dialogue about barriers to nutrition for HIV/IDUs;
- to create viable recommendations to improve nutrition of HIV/IDUs; and,
- to establish partnerships between food providers and those who access free food programs to move forward with the recommendations.

Methods

Research coordinators from AIDS Vancouver and Vancouver Richmond Health Board initiated the research project based on their experiences in providing food

and nutrition services to the downtown community. The project was designed using participatory research methods and was guided by the principles outlined in the document “Guidelines on Ethical and Legal Considerations in Research on HIV/AIDS and Drug Use at the Community Level”(24).

The project was implemented in the following stages:

- Twenty-one service providers (organizations providing hot meal programs, food banks, and community and hospital nutritionists) were asked by the research coordinators to comment on existing free food services in the downtown Vancouver, and to share their gaps in knowledge about living with HIV and using injection drugs;
- An eight member community advisory group representing the diversity of the community members who access Vancouver’s free food services was identified by research coordinators and service providers to participate in implementing all aspects of the project;
- At bimonthly meetings, the research coordinators and advisory group finalized the methodology, and developed and field tested the focus group questions;
- Participants were invited to focus groups through ‘word of mouth’ by service providers and advisory group members;
- Thirty seven participants attended the focus group discussions (seventeen men, seventeen women and three who did not identify gender) representing single men, people with mental health issues, youth, women, First Nations and transgendered person. Participant ages ranged from eighteen to sixty-five;
- The focus groups were recorded and transcribed;
- The transcriptions were analyzed using a thematic and content analysis as described by Michael Patton (25) and Ernest Stringer(26); and,
- The advisory group interpreted and verified the results, made recommendations and monitored the ethical implications of the findings.

Limitations

Time and budget constraints made it impossible to include more people in this project. Due to the sensitive nature of both HIV and IDU issues, focus group participants were self selecting with the guidelines of living with HIV and currently or previously using injection drugs, but we did not ask for verification of their HIV status or drug use. Participants were identified through contact with either advisory group members or community workers in the downtown community. To create a safe environment, advisory group members facilitated the focus groups representing the communities they identified with the most.

Structure of the Report

The report is divided into three sections based on the major themes which emerged: Life Issues, Access to Food Programs, and Food Quantity and Quality. At the beginning of each section, a brief summary of the emerging themes is provided but the text is dominated by direct quotes from participants. This is intended to allow readers to hear the voices and experiences of the participants.

Interpretations (in grey boxes) follow the data and are intended to give the reader a sense of the themes in relation to each other. A final section contains recommendations identified by participants, advisory group members and the research coordinators.

THEMATIC ANALYSIS

Three major themes emerged from the focus group transcriptions. The themes presented in the diagram below show the interconnectedness and dynamic nature of people's experiences as they are related to one another.

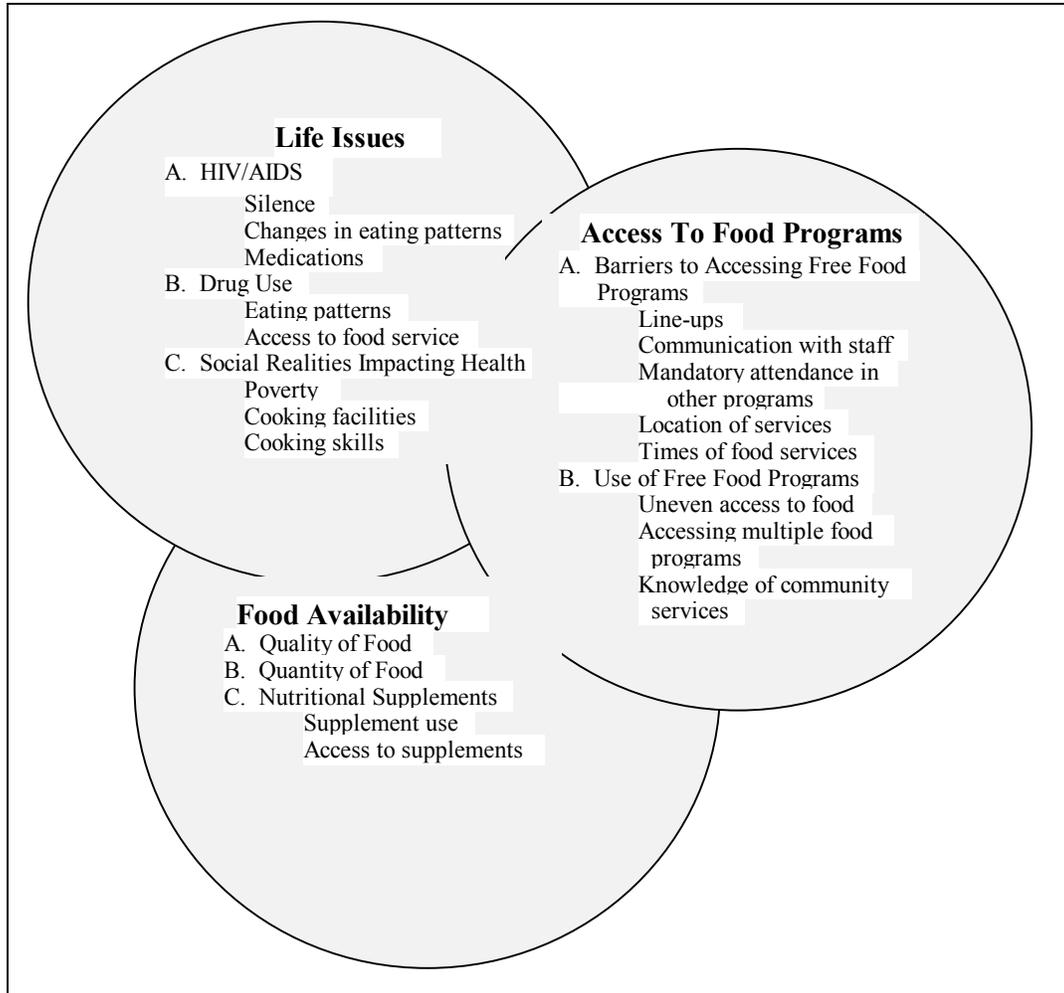


Diagram 1. Emerging Themes

Theme: Life Issues

The main themes to emerge under Life Issues were HIV/AIDS, drug use and the social realities impacting nutritional health.

HIV/AIDS

Participants spoke about how they were affected by living with HIV/AIDS. The issues that emerged included not feeling able to speak openly about serostatus, changes in eating patterns, effects of HIV/AIDS medications, and other illnesses.

Silence

Although statistics have shown HIV incidence to be high in the downtown community, it was difficult for many participants to speak openly about HIV/AIDS. In three of the six focus groups participants were reluctant to talk about HIV/AIDS at all.

[participant 1] “Nobody here has it. So we don’t care.”

[participant 2] “A few of my friends died of it, though.”

[participant 1] “Nobody here has AIDS.”

Changes in Eating Patterns

Some participants reported that since finding out that they are HIV positive, they had become more concerned about their diet.

“It made me more aware of what I’m eating. Now I want to eat more fruit. Before I wouldn’t. I couldn’t have been bothered ... I might have eaten ... maybe one banana in two months or something but now ... it’s like I want to have my fruit every day, whether it’s in juice or just eating it like that.”

Some participants stated that HIV positive people need more calories than other people but that poverty makes it almost impossible to eat what they need.

“In the case of being HIV positive, my understanding is my uptake should be not just three but five times your average to make sure I get the nutrients out of the foodstuff to help me maintain some sort of health ... I have maybe fifty to seventy-five dollars a month to spend on food ... I’m not living like the king that I should be living like to be able to get the right nutrition, so source funding is really the biggest shortcoming.”

Some participants reported that their eating styles have not changed since being diagnosed with HIV.

“It doesn’t make any difference at all for how it affects me. I mean, I can eat the way I’ve been eating for the past couple years.”

Many people noted that their appetite diminished after becoming HIV positive.

“I’m HIV positive and I find it’s restricting my appetite quite a bit. I don’t have the verve to eat a lot like I used to. I eat a lot less.”

The most frequently mentioned eating difficulties were lack of appetite and fatigue, resulting in low weight.

“Being an IV user, I don’t eat much ... I’m six foot one and I’m down to a hundred and forty pounds. I don’t know, like, so obviously whatever I’m eating, it’s not staying, so I don’t know.”

Medications

Participants on multiple HIV medications spoke about the drugs having adverse affects on their eating habits. Medications may taste bad, cause a loss of appetite and produce nausea.

“Like, I’ve just recently started it (the HIV cocktail of medication) myself ... and it’s taking my appetite away. I have to really concentrate on feeding myself.”

“They (the anti-retrovirals) seem to fill your stomach up like they’re foaming or something.”

“Those pills are really rotten on my stomach. I go through 4 ... 5 kinds ... they always chew up my stomach.”

Illnesses and Social Support

In all focus group discussions, participants identified other illnesses in addition to HIV/AIDS affecting their eating patterns. Conditions noted were Hepatitis A, B or C, bone density problems, blood sugar-level difficulties (e.g. Diabetes), stomach problems, flu, and being ‘junk sick’ which has been described as nausea, no energy and severe drug cravings. Participants primarily linked these difficulties to drug use, HIV and Hepatitis A, B, or C.

“So the fatigueness is always there. I don’t know if it’s from me myself detoxing or it’s a combination of not sleeping, not eating properly to begin with and with HIV and hepatitis C.”

Participants reported that they have little social support when sick. Although there is medical help through the ‘traveling clinic’ or community nurses, there is little assistance with accessing food services or buying food. The lack of amenities such as a telephone makes the situation worse.

“Unless you have a good friend ... but you have to have phones and that, right? We have no access to phones. To phone anybody and tell them, hey, I’ve got nothing to eat, I’m sick, you know, is there any way I can get some help, you know? So we tough it out. I tough it out.”

“Well, for me, I’ve got the hepatitis and I’ve actually got B and C right now. So I told people I was sick and nobody came by. So, basically, it’s a real difficult situation for any who is feeling not well.”

“Well, I’m so tired, I can’t stand in the line-up. I mean, really I am exhausted. I’ve got both (hepatitis) B and C. And I’m exhausted. And, you know, if ... I gotta go out and get groceries, I mean, that’s my biggest pet peeve, is I gotta carry them home now... It’s hard if you’re not well, to be shopping by yourself.”

The taboo around HIV/AIDS in the community creates a barrier to people coming to terms with their positive sero-status and accessing services specific to HIV/AIDS.

Some HIV/IDUs are aware of the relationship between their eating habits and their health and make changes to varying degrees. HIV/IDUs not getting enough to eat are at risk for malnutrition when other illnesses and side effects from medications interfere with food intake.

An illness combined with a lack of social support and limited amenities may result in HIV/IDUs becoming isolated and further impact nutrient intake.

Drug Use

There is a significant amount of diversity in the injection drug use community and the drugs of choice. Though participants were not always specific about the type of drugs they were using, they clearly spoke about how injection drug use affects their eating patterns and their access to food service programs.

Eating Patterns

Injection drug use may result in extreme eating patterns. Usually, during the active phase of using drugs, ‘being on a run’, IDUs eat very little or not at all. Participants identified that a run lasts from about one to four days and gave the following as some of the reasons for not eating:

“Cocaine is a suppressant. You don’t get hungry when you’re high.”

“I often will purposely not eat because it will kinda ruin the high ... suppresses the high.”

“You smoke for a couple of days, then it’s, oh yeah, I forgot to eat ...”

When IDUs come down from their high, ‘being off a run’, they often eat large amounts of food.

“Well, I go for two, three days without eating, then I just can’t get enough. You know, I eat like a horse, just shoving it into me ... Then I go two or three days without eating again and then I’m back to the same pattern again.”

The trigger for getting high again can be related to carrying cash which was intended for buying food.

“When I used to use, I’d have 50 bucks, I’d be on my way to the store and get food. Someone would grab me, let’s go do a fix, back to my place to do a fix, let’s get some more dope ... then I’d eat whatever I could ... after 3 days.”

Many participants identified that eating is often their second choice when it comes to dealing with their drug addiction.

“... our first priority is getting stoned.”

“It’s my choice what I eat right now. Like, I prefer to buy drugs than eat. Unfortunately.”

“I’m a drug addict and I don’t get enough food in my body and that’s probably my own fault, too.”

Access to Food Services

IDUs’ schedules are often determined by their use of drugs. Often, food services are not open when IDUs come down from their high and are looking for food.

“You stay up for two or three days, then you sleep for two or three days, then when you wake up, it’s too late to go anywhere ...”

“It’s like, you’re out partying, you know, ’til like, whatever, seven in the morning, then you think, okay, I’ll sleep for an hour and come down here, and then you fall asleep and you wake up and it’s like five o’clock and you can’t eat for the day ’cause you missed this place, right?”

Participants reported that despite their drug use, they do access and depend on food services.

“I get meals delivered from (CBO), I hit the food banks and (CBO). I buy groceries here and there ... (I have a) problem with drugs, and a lot of cash that I get ends up going up my (arm).”

“I find that one of my first priorities when it comes to welfare day is getting high and food sort of takes a second seat because there are quite a few services in the Downtown Eastside that do give meals. I’m a member of (CBO) so I can come and have one good meal a day. So I can spend my money on drugs and still actually get enough to eat. I’m also HIV positive.”

Getting high is often the first priority for many injection drug users. Money is more likely spent on drugs than food and this creates a dependency on free food programs.

Injection drug use impacts eating patterns. Frequently, IDUs eat between runs, which is often late at night. Unfortunately, there are few food services available at these times which results in the cycle of starving and bingeing. This can lead to IDUs becoming malnourished which further impairs immune function.

When IDUs do eat, most need large quantities of food to make up for the calorie deficit incurred from not eating for a few days. However, some IDUs may be unable to eat large portions and feel full before consuming enough calories.

Social Realities Impacting Nutritional Health

Participants spoke about how poverty, the lack of cooking facilities and cooking skills affects their ability to eat an adequate diet.

Poverty

Many participants recognized that many others in Downtown Vancouver are ‘in the same boat’ in relation to poverty. Participants spoke about how living in poverty affects their ability to buy food.

“Like, everybody is experiencing the same thing ... you’re just like a marginal person that lives here. It’s really reflective of the housing situation and the financial picture ...”

“If I had more money I could buy more food.”

Cooking Facilities

Most participants said they have limited or no cooking facilities such as a fridge, stove, sink, or hotplate. Participants also mentioned lack of utensils and limited space as barriers to cooking.

“... if you live in one room, and you’re tripping around your suitcase and the cockroaches and whatnot to get to your toaster oven or your little hotplate or whatever and running into the hallway and putting your breaker back on the fuse box ... actually you become quite an artist to be able to cook at all, eh, if you want to cook. It really taxes your imagination and you gotta have a sense of humour, otherwise you’d go nuts, you would just give up. But I learned to overcome a lot of these things ...”

“I don’t even have a sink so that’s what screws me up, the facilities to cook. I lived uptown on Granville, I used to eat stuff cold out of cans because I had nothing. You couldn’t even use your hotplate.”

“Where I live I’m not even allowed to cook in the building.”

Few cooking utensils was also reported by many participants and many of those who did cook reported making ‘one-pot’ meals.

“I cook everything in ’cause I own one pot. I own one knife, fork, spoon, one glass. I lead a very simple existence and that.”

Maintaining hygienic standards while cooking and storing food is difficult due to inadequate facilities.

“I’ve been in my apartment for three years now and there is a stove but I’ve never opened the oven door because it’s where the cockroaches go, and so I cook everything in one pot and try and maintain my simplest paraphernalia so that I don’t have a hygienic problem.”

“I’m in a room with a little tiny bar fridge and the freezer’s about this big, the food goes really fast, it spoils right away. It’s frozen when you get it and within two, three days it’s thawed out and no good. It’s gone sour or something.”

The lack of cooking facilities and inadequate food storage are the main reasons why participants may not access food banks and prefer free meal programs.

“I used to use them (food banks), when I had a place to put my food, but now I don’t have a place to store my food, so I don’t use them.”

Participants’ ability to store and prepare food may be complicated in shared housing situations where other people have may have access to their food.

“It’s been unfortunate, ’cause I’m in one of these rooming houses, not too many women are in them. They’re very male chauvinistic ... I have to keep my food in my room ... I can’t keep it in the kitchen because they’d eat it.”

Cooking skills

Most women stated or implied that they had cooking skills. Many men did not mention cooking skills but some men mentioned they ‘tried anyway’.

“In fifty-four years here I still can’t cook my way out of a wet paper bag although I can make French toast and something that looks like scrambled eggs ... but basically ... it just goes in the same pot.”

Some participants recognized that they have to be motivated to cook but that other factors such as depression may interfere with their motivation.

“You see that my health seems to be improving and my head space is clearing up thanks to some anti-depressant pills, but for a while it was difficult to motivate myself to get up and cook, especially when I don’t know how in the first place.”

The monthly income for someone on income assistance is inadequate to purchase enough food to meet their nutritional requirements. Drug addiction further depletes limited financial resources that could be spent on food.

Those who want to purchase food and use food banks may not bother if they live in housing which lacks adequate cooking facilities, if it is infested with cockroaches and mice or if they lack the skills or motivation to cook.

Many single room occupancy hotels (SROs) require a complete overhaul to rid them of pests and provide adequate cooking facilities. Other opportunities must be created so people can cook in clean, properly equipped kitchens.

It takes huge effort and creativity to cook in SROs. People living in SROs who are to cook for themselves have skills that could be shared with others in the community.

Theme: Access to Food Programs

The main issues to emerge under the theme Access to Food Programs were barriers to accessing free food programs and patterns of free food program use.

Participants spoke of three types of free food services, Community Based Organizations (CBOs), Charities, and Food Banks. CBOs and Charities offer prepared meals (though some also offer groceries) and Food Banks give free groceries to be prepared at home. CBOs were characterized as organizations accessible to persons with a common identity (for example, women only organizations), which offer free meals in addition to other services such as advocacy and counseling. Participants described Charities as organizations open to everyone. Participants in the focus groups accessed Charities primarily for free meals.

Barriers to Accessing Free Food Programs

Participants identified line-ups, communications with staff, times and location of food service programs, and mandatory attendance in other programs prior to obtaining a meal as barriers to accessing food in the downtown area.

Line-ups

Line-ups were identified as a barrier to accessing free food programs. There were a number of issues in relation to line-ups that were discussed, including safety, health issues, vulnerability, and the amount of time required to access food.

Participants talked about the difficulties experienced when lining up for free food from charities, CBOs and foodbanks.

“Line-ups. That’s how Vancouver is. If you’re on the street in Vancouver, you gotta put up with line-ups and that’s no two ways about it.”

“You have to stand in line for half an hour or so by the time you get to the table it’s cold.”

Participants reported that they may not always be safe in food line ups as physical violence can erupt at any time.

“A lot of people do get beat up. Well, here’s a good example, like. The other day, this guy came in here, eh, and pulled a stick on me ’cause he got beat up in the alley ’cause he was holding dope for this friend of mine.”

“There’s always a chance of fightin’ when you go.”

Women reported that they often experience sexual harassment in line-ups and many women will not access ‘line-up’ meal services by themselves. A women accompanied by a man may still be harassed. Men too, are susceptible to verbal harassment by others.

“I don’t hit any line-ups unless I do have a male partner with me. There’s no way I could stand in any of these line-ups because you would be, I would be harassed.”

“It doesn’t matter what sex you are. It’s just, they’re there to bug you.”

Participants related that line-ups are often not conducive to their health.

“It’s just the wait. I mean, I’m not healthy to start with and I cannot wait out in the pouring rain while this line goes around the block, and the (CBO) is the only place I use.”

“... the trouble with food banks is you get long line-ups and I have neuropathy so an hour and a half in the line-up is really cruel when you’ve got full-blown AIDS.”

Often participants had to wait long periods in line to access food. Participants reported the disappointment of having to wait a long time for a meal and then receiving a meal which did not meet their expectations.

“... if you wait out there for two hours to get in and then you have another hour for, for worship, right? And then you go in. By the time you eat it’s, like, three and a half hours of waiting in the cold ...”

“Yeah, ’cause, I hate waiting hours, like, you go inside, you wait another hour, it’s like, after two hours, you finished a little plate like that ...”

Participants reported feelings of shame for having to use free food services. Some participants also mentioned that line-ups left them visibly exposed on high traffic streets, which heightened feelings of humiliation and shame.

“I could see a lot of improvements made, particularly in the areas of line-ups and in the areas of, the shame issue and the, feeling shitty while you, well, the reasons that you have to access these places.”

“Cars were going by and people were going by and so instead of me facing this way ... I’m facing that way, lookin’ up at the tree there. ’Cause I just don’t want anybody to see me. Oh, I know her! I wonder what’s she doing standing there, right?”

Communication with staff

Participants expressed concern about their treatment by food service staff and volunteers. They had encountered mistrust, rudeness, racism, and little understanding of ‘the life’ on the street which produced feelings of anger, intimidation and degradation.

“I just thought, you better keep your mouth quiet because you’re not going to end up getting nothing if you act annoyed so I just had to take what she wanted to say.”

“They shouldn’t make you feel bad when you go to these places offering you this food. They’re offering these services to you but meanwhile when you take advantage of them, they make you feel like you’re lazy, you don’t want to do anything to help yourself. Well, you *are* trying to help yourself. You’re trying to feed yourself so you can live, right? ... They should have people working at these places that know what it’s about ... so they can understand where you’re coming from and what’s really going on, eh?”

Mandatory attendance in other programs

Participants were ‘put off’ accessing some food services when taking part in a ceremony or organized group activity was a prerequisite for getting a meal.

“But the thing is, you have to go to the group. If you don’t go to the group, you don’t get the meal at nighttime.”

Location of services

HIV positive participants, in particular, noted that some food services they use or would want to use are geographically too far away. Some felt that transportation between services is needed.

“But transportation’s a big problem ... shuttle buses between the service agencies that are beyond the downtown core for people that are down here that haven’t got anywhere to go.”

Some participants reported that there are not enough accessible food banks in the Downtown Eastside.

“The food bank for single people is too far away.”

“(We need) a closer food bank down here for women over the age of 24. You know, there is not one around here.”

Times of food service

People noted that few food services are open later at night and over weekends.

“Nothing’s open past eleven, is it? Nothing.”

Barriers existing at food programs are formidable challenges to service users attempting to get enough to eat. Many of the barriers centre around service delivery. Participants value food service environments that are safe and supportive where they do not have to fear violence and harassment. Also, participants want respectful, compassionate and understanding interactions with the staff and volunteers of food programs. Food services should be open at a variety of times making programs more accessible for people in the community.

Patterns of Free Food Program Use

The main issues to arise under Patterns of Free Food Program Use were uneven access to food, accessing multiple food programs, and knowledge of community services.

Uneven Access to Food

Participants discussed the unequal access to free food in the community. Better quality food is obtained by belonging to a specific ‘category’ such as being a youth, or having an HIV diagnosis. Some participants felt that if you belonged to a certain group, you can access more food or food of better quality whereas, if you belonged to another group, your access to food or quality food decreases.

Overall, many participants felt that women and youth have access to better quality meals at CBOs that have free meal programs. However, although women and youth have access to a number of CBO meal programs during the day, their access to food is limited during the evening and on weekends when CBOs are closed and Charities are too dangerous to access.

“A few people get a bit of extra support ’cause maybe they fall into a special category, like the youths have YAC.”

“If you’re young and pregnant, which is really good, you fit those categories, or like youth, if you’re under twenty-four, yeah, that’s another one. Good food.”

“There’s not many women that go to the (charity meals).”

In contrast, participants felt that men have easier access to more food services open all week and weekend, but have limited access to better quality free food.

“Men have very many places down here where they can go.”

“The twenty-five to fifty-year-old guy that’s down here ... his experience, an anonymous person still eating the same food, going to the same line-ups, still scrambling for the same stuff.”

Participants also noted that the more categories a person fits into the more services they are eligible to access. This was discussed mainly in relation to women’s services and youth under twenty-four.

“I just want to see something down here for single women ...”

“And not age restricted.”

Most free charity meals are limited to individuals and are not suitable for families. Mothers reported that when they brought their children to attend free food programs, they were discouraged by staff from accessing services.

“I had myself and another adult with me ... another mother ... but they told me, next time, don’t bring the kids here.”

Accessing Multiple Food Programs

No individual’s needs can be completely met through accessing one free food service. Despite barriers, most people access food from more than one service.

“... Around nine o’clock in the morning I go to the church and I have my tea and my muffin. I go to the (CBO) and I ask them to help me out with some food and then they give you a voucher and you go to the (food bank) and they give you a little bag of groceries and then at noon you can have lunch there. Then I leave there and at two o’clock I go up to the (Charity) and get some bread. Then I go home. And, let’s see, well, around, I guess dinnertime or seven o’clock I’ll go back to the (Charity), see if I can get any juice or anything or I’ll go to (Charity) and see if I can get anything from there. But usually Tuesday I’m gone from nine in the morning ’til about three o’clock. Sometimes later if I stop at the (Charity) and get some sandwiches, ’cause it doesn’t start ’til three-thirty ...”

“Sometimes it’s almost like having a job when you have to feed yourself like that, the hours that you have to put into it. If you’re hungry, you gotta do it, right? ... If you don’t do it, right, you’re not gonna get anything.”

Knowledge of Community Services

Many participants expressed uncertainty about times of meal programs. There was a lot of spontaneous peer sharing about the times and quality of food services as well as the attendance criteria. In the focus groups, some participants expressed concerns about sharing information about food resources. A woman concerned about finding enough food for her children had the following to say:

“I have to be very careful who I tell because it goes from one person to the next to the next to the ... next thing you know all of a sudden they’re totally abusing it and then they’re gonna shut it down. And that’s what I worry about.”

There is uneven access to food in the downtown community. Many women and families experience greater difficulty in accessing free meals that are open to anyone, although they may have access to quality food at CBOs at specific times. Single men have less access to better quality food.

Accessing multiple food services is time and energy consuming, but is necessary to get enough food to eat. A person requires a thorough knowledge of all food services. Accessing food also takes a lot of motivation, planning and fortitude. Those dealing with issues such as mental health challenges, active addictions and illnesses may have access to less food. HIV positive people may find it difficult to stick to time sensitive medication doses due to the time it takes to access multiple services for food.

Theme: Food Quantity and Quality

IDUs do not always get enough to eat and often the food they do eat is not nutritious. Many IDUs use nutritional supplements.

Quantity of Food

Many participants reported that they do not get enough food to eat.

“And, um, eating once a day is, I don’t know, that doesn’t do it.”

“I don’t believe I get enough to eat. Like, I work part-time doing casual labor ... a lot of the time I have to go to work without eating ...”

Some participants reported that they are getting enough to eat. However, a distinction was made between ‘getting enough to eat’ and ‘getting enough nutritious food’.

“It’s enough to fill up. Is it enough to stay healthy? That’s the question.”

“Soup, sandwich, coffee and, uh, usually at home I have my other dinners, so it’s basically, it’s not probably the best diet in the world, but it’s sufficient to sustain me if I use it properly.”

“I had to laugh at what they give me to live on for a month. I got about six bottles of pop. Looks like mouthwash and a little tiny can of ... tuna that’s already mixed with little crackers, eh? And, uh, what else they gave me? Oh, a little box of Froot Loops ... how’s that supposed to be healthy for me?”

Less healthy foods are often more available than healthier more desired foods. Participants reported that there is a lack of fruit, vegetables and meat irrespective of food program.

“If I’m lacking in fruits and vegetables, I’ll try to get those, but it’s harder to get vegetables than anything else. They serve a lot of, it’s easy to get starch and sugar and stuff like that.”

“... there’s crap all over the place ... day old doughnuts and watery coffee.”

“Well, due to my medical condition, I gotta have a high protein diet and I don’t get a high protein diet where I eat at.”

“I don’t eat as much fruit and vegetables as I should and meat is a luxury and that’s kind of important. I love fruit, and I’m getting half of what I need, I guess. I love to eat fruit.”

Participants expressed their confusion about why some foods are less available than others.

“A lot of places sure serve you a lot of these cookies and doughnuts and stuff like that. ... and you just fill your thing as much as you want ... But I was thinkin’, like, instead of them ... spending money on big boxes of cookies, they could get some oranges and apples.”

While some HIV/IDUs may be able to consume adequate calories to function day to day, most may not be meeting their nutritional requirements due to a lack of nutrients found in fruits, vegetables, meat, and dairy products. A limited intake of nutrients may result in clinical nutrient deficiencies. Nutrient deficiencies may further lead to an inability to stave off HIV related infections.

Some HIV/IDUs may be unable to obtain the nutritious, tasty food they should be eating if they are dependent on getting their meals from free food programs. At times, IDUs may not be able to make healthier food choices due to cravings for simple sugars.

The confusion about the availability of certain foods at free food programs may stem from people’s lack of awareness of where providers get their food and the limitations food providers face within the food donation system.

Quality of Food

Satisfaction with the quality of food depends on the food program. Participants were asked to identify food they like to eat and foods they didn’t like to eat. These foods were identified by participants as ‘good’ foods or ‘bad’ foods.

‘Good’ food was characterized as being fresh, identifiable, hot, tasty, firm and nutritious. An additional feature of ‘good’ food was that it is a complete meal. Participants highly value a ‘complete’ or ‘full’ meal.

“They have hot meals ... they make good bannock there and good soup.”

“... Stew ... shepherd’s pie ... pasta something, linguine, big salad. Some nights they’ll have hamburgers. So, it’s quality food.”

‘Good’ food is also described as having nutritional quality.

“They do give you edible, really good, edible food and believe you me it does definitely help in your diet.”

“I think I eat pretty good, quality’s what I eat ’cause I eat at the (CBO).”

Participants identified the characteristics of ‘bad’ food as unidentifiable, cold, visually unappealing, decaying, past-dated, overcooked, overheated, bad tasting, and having little nutritive value.

“I don’t know what it was, it was supposed to be ... ’cause it was green, like, they put curry in it or something, that spice that’ll turn food that heavy colour.”

“They carve up hot dogs and anything at all that’s left over, that’s the thing, every day ...”

“I will not eat their sandwiches. I’m afraid to eat them. I see a lot of people getting sick. They have black lettuce.”

“The sandwiches are already expired three days, right, they hold them for three days and then give them to you.”

“Their pastries ... they’re mangled and crushed.”

“I’ve had mouldy meat in my sandwiches ... Mouldy bread. Mouldy cheese.”

“It’s cooked to the shits, the way they boil up the vegetables.”

“They could make a much better meal that’s at least more appealing to the eye.”

“They just throw slop on your plate.”

“Some of it’s really good, not bad, and some of it I wouldn’t touch it with a ten foot pole. It tastes bad.”

“What they serve at free food places, is, I don’t believe myself, is very nutritious.”

People reported that ‘bad’ quality food can make people sick.

“It makes people sick. I see a lot of people getting sick.”

“But on the whole around here, I think the quality of food is substandard. I see a lot of people getting sick.”

However many participants reported that they eat the food that is available to them despite their ongoing dissatisfaction with the quality of food.

“It smells gross, tastes like shit. You know, when you’re hungry, you fuckin’ eat it, right?”

“I eat it to survive.”

The free food offered in the downtown community varies from program to program and the quantity and quality of the food often depends on what is donated.

Community members living with compromised immune systems put themselves at risk for food borne illnesses by eating food that is going bad. People who are

experiencing poor appetites due to illness may be more inclined to eat if they are presented with nutritious food that is visually appealing and good tasting.

There is a conflict between what people are told they should eat via healthy eating messages (e.g., eat a variety of foods, eat more fresh fruits and vegetables) and what food is available in food bags and at free meals. In addition to making more nutritious food available, health messages in the downtown community would be more appropriate if created in consultation with people using free food services.

The food available from service providers is often determined by what they have donated to them and what amount of food they can buy with a limited budget. When community members are served donated food products that are past-dated, decaying and damaged, they may feel this reflects how the service providers feel about them and that community members are not worthy of fresh, appealing foods.

Nutritional Supplements

Liquid supplements are available at no cost for a limited period of time, through the BC provincial government for income assistance recipients. To be eligible to receive these supplements, one must have a medical reason (e.g., weight loss), have seen a physician and/or a dietitian and have the recommendation approved by Ministry of Human Resources staff. Free vitamin and mineral supplements are available in the downtown community at certain clinics, community-based organizations, and needle exchanges.

Within the focus groups, nutrition supplements were defined as liquid supplements², vitamin and mineral supplements. Participants had many different opinions about nutrition supplements.

“Neither (liquid supplements) are good for you ... It’s full of sugar, it’s very hard on your stomach ’cause it’s very concentrated and sugar causes diarrhea and all kinds of stomach problems.”

“I think that nutrition as a whole has to be personally tailored to the individual, given his standing and his background ... In the case of people with AIDS, definitely (liquid supplement) is not necessarily the best thing. But, an IDU person who hasn’t eaten for years, sometimes they have value minerally and other things.”

Supplement Use

Participants mentioned different reasons for taking nutrition supplements. The most common reason was that supplementation is a sure way to get calories, vitamins and minerals. Participant reported that liquid supplements often assists in keeping weight on and stimulating the appetite.

² For example, products such as Ensure™ by Ross Pharmaceuticals and Boost™ by Mead Johnson.

“People could be a little more educated ... instead of buying two pieces of pizza, I’ll buy two pieces and a can of (liquid supplement) because I know I’m getting those vitamins and stuff like that and 350 calories right there.”

“Vitamins, (liquid supplements), you name it, I’ll do anything to keep my health up. Plus I’m forty pounds underweight.”

“I find when I take the vitamins, I eat more. It gives me an appetite, so I just take vitamins.”

Many participants recognize that vitamins cannot replace food.

“Yeah, you need real food to simulate the vitamins. Can’t just take a little red thing.”

“Right now, what’s needed is, I think what’s really needed is vegetables and fruits ... We have very little fruit. Very little vegetables, you know.”

Access to Supplements

Many participants reported that it is extremely time consuming and difficult to access liquid supplements through the BC Ministry of Human Resources, Health Services program.

“I finally got it. It took me about a year to get it from welfare.”

“They make it a hassle to get it.”

“So if you do happen to get your application in and you’re rejected, I would like to reiterate in my case that it happened to me and I appealed and I was rejected again and I appealed again to the tribunal and I was finally accepted, only because it went to, get an advocate and an agency to make the final phone call, through my worker ... but once a year we have to fight with them again to get it.”

Some participants expressed confusion about why other people’s efforts to access liquid supplements were different than their own.

“I’ve seen other people like here, they give 6 months a crack and Loomis comes up and delivers, like forty boxes. And I got to fight to get like four boxes.”

“It’s crazy, so it’s simpler to buy it.”

Participants did not report as many difficulties in accessing vitamins. Participants reported that they access individual vitamin doses from needle exchanges and that some CBOs give vitamin packs out with their meals. Some HIV positive participants access vitamins through AIDS service organizations but some found it difficult to access these programs. Others said they had vitamins prescribed from their doctors. Some participants reported that they bought vitamins and liquid supplements when they could afford it.

Some people understand the role of vitamin supplementation in the diet and want the nutrients they know they are not getting in their food.

There is a lot of misinformation about the need and value of liquid supplements, how these supplements are used, and who is eligible for them. Some of the misinformation may result from people receiving prescriptions for liquid supplements at time of HIV diagnosis when there may be no medical need for supplementation and the strong advertising messages produced by pharmaceutical companies. Further, there is a perception that inequities exist when trying to obtain liquid supplements from the Ministry of Human Resources.

Liquid supplements have been promoted to the point that their value has reached mythical proportions and created a street value for these products. These products are valued because HIV/IDUs believe they improve health, and are convenient to use as they are easily stored and do not require cooking.

RECOMMENDATIONS

The recommendations below are based on information provided by participants. Participants were asked to identify changes that would make it easier for them to eat better in the downtown community. These were primary issues, raised independently in almost all groups, with much agreement and consensus within each group.

Improve IDU access to food services by creating 24 hour food service programs and mobile food units.

“Well, I guess, more accessible food, not just at certain times, you know, like. It should be made, like, twenty-four hours.”

“In Montreal, we have Pop’s ... that’s a van like the Blue Bus and it, like every street, and stops, it gives some every night hot dog, coffee, you know, chocolate, and bags of food.”

Explore and establish self-empowerment food service models, for example, pre-payment systems where consumers could access food on credit.

“I wonder, if, through welfare, maybe on top of your support cash that you get if they couldn’t somehow initiate a program that you got some kind of a food stamp or you got something that you had to use to purchase food. So you couldn’t actually be spending all your money on dope and alcohol. I know there’s a lot of people that feel that it’s like the American food stamps.”

Create safer and more supportive food service environments by developing consistent standards of behavior guidelines across food programs, reducing the amount of time people need to stand in line and providing communication, sensitivity and conflict management skills for food provider staff and volunteers.

“But for me, a wish list would be, uh, indoors. ’Cause I’ve stood outside in those line-ups. And then you have to eat it outside as you’re walking along or something.”

“Give you some warmth, especially when it’s raining. I’ve noticed a lot of them standing there and it’s freezing.”

“And the people who are giving out the food, their attitudes towards why they’re there and if they’re there to be volunteers, some of their attitudes need to change and be a little more compassionate.”

Create safer environments for women to access food in the community by creating more women only or women and families only times.

“It seems, women get along together ... men, women would be just a catastrophe, I think, you know.”

“Yeah, like a women’s only (section) and then like a couple-only section, right, so that you can have companionships and safety without being the only woman in a group of three hundred.”

Improve and monitor hygiene standards for all food services, including free and licensed food establishments. Establish training programs on safe food handling for all food services and specialty training to address food issues relating to HIV/AIDS and Hepatitis ABC.

“Anybody who sells anything, like chicken, where you can get salmonella, especially, should be looked into a lot more frequently ... All the places around here, all the restaurants, all the free food facilities should be looked at, every single last one.”

Standardize quality of food across food programs and increase access to fresh fruits and vegetables, meat and dairy products at all food programs

“It’d be nice if Safeway or some place like that would, you know, donate some stuff, like for salads and stuff like that, ’cause you don’t really get that much fresh vegetables, you know, which is really what you need.”

Advocate for the creation of appropriate cooking facilities.

“I know darn well that my, my eating habits would definitely improve hundred percent if I had proper facilities.”

Establish more peer sharing and education opportunities for HIV/IDUs

“I quite frankly am not one to access a trailer that pulls up or a mobile unit and there’s a kind of a mob rule to get in the line-up and get a plate and get the food. A sit-down situation is certainly where you can begin to get a social exchange of ideas as your consciousness is raised thanks to the food. So that’s what I would like to see is something of a generalized open area meal.”

“Also most doctors don’t tell people they gotta change their eating habits. They just put them on the drugs and people go away thinking that, hey, just fix their lives by going away and taking these pills like a magic bullet.”

Explore alternative food service programs including communal food programs which are respectful to people and available on their terms.

(participant 1) ”Community kitchens, that’d be excellent. So you could go in and make your own meals on wheels.”

(participant 2) “Can I just pipe in about storage, though? Where are you going to put your four meals? Can you fit them in your fridge? So what we need to work on is, how about a communal freezer somewhere where people can access it or at least if one person had a freezer, maybe some people could put all their food in there ...”

Food providers should actively support other community initiatives that directly impact on IDUs’ nutrition. For example, housing and better and more drug treatment opportunities.

“I’d like to find doctors ... to seriously look at helping people get off drugs, not through methadone, being addicted to something else, I’m sure there is a way to help somebody through the whole thing. It’d probably take a couple of years, maybe even seeing a counsellor, but, you need like, anti-depressants, all those kinds of things, after you actually kick the habit ... and probably something to help you sleep for, like nine months or so.”

“A proper bachelor suite. That would be the answer. Like, to have a proper sink, you know, stove and proper fridge and whatnot and a countertop where you could actually make some food, you know, instead of having your stuff on your bedroom floor and god know where else.”

Additional recommendations were put forward by the advisory group and research coordinators.

Hold a forum of food providers and community members to develop an action plan to address recommendations put forward by this research.

Create a consumer driven advisory group for food service providers to increase communication between service providers and community members.

Encourage more outreach service providers to be actively involved in client's efforts to feed themselves.

Healthcare providers such as Doctors and Dietitians/Nutritionists should collaborate with the Ministry of Human Resources on efforts to educate the HIV positive community about liquid supplementation.

CONCLUSION

As the HIV epidemic continues to impact the health those living in the downtown community of Vancouver, a new role for free food programs is emerging. Food providers must re-focus their programs to start building the nutritional health of the community accessing their services. Creating meal programs in social environments where community members can access nutritious meals in a safe supportive space needs to become a priority. Access to nutritious food means access to better health overall.

Unfortunately, free food programs experience limitations within the food donation system. Community members are often unaware of where food providers obtain their food and the limitations faced in providing a variety of nutritious foods. To improve the quantity and quality of the food available for service providers, there needs to be more education for donors, private and corporate, as to the types of foods required. Funding agencies should be invited to recognize the important role nutrition plays in staving off illness and building the health of the community.

Free food programs should explore programs that would assist service users to take back some of the responsibility for feeding themselves and focus on self-sufficiency instead of dependency. In the long-term, this would lessen the load carried by food providers. Stronger relationships between food providers and the HIV/IDU community should be developed through the establishment of advisory groups to guide community initiatives aimed at improving access to nutritious food. HIV/IDU community members have useful and positive contributions to make to increase the effectiveness of free food programs to better serve their needs.

Improve IDU access to food services by creating 24 hour food service programs and mobile food units.

Explore and establish self-empowerment food service models, for example, pre-payment systems where consumers could access food on credit.

Create safer and more supportive food service environments by developing consistent standards of behavior guidelines across food programs, reducing the amount of time people need to stand in line and providing communication, sensitivity and conflict management skills for food provider staff and volunteers.

Create safer environments for women to access food in the community by creating more women only or women and families only times.

Improve and monitor hygiene standards for all food services, including free and licensed food establishments. Establish training programs on safe food handling for all food services and specialty training to address food issues relating to HIV/AIDS and Hepatitis ABC.

Standardize quality of food across food programs and increase access to fresh fruits and vegetables, meat and dairy products at all food programs

Advocate for the creation of appropriate cooking facilities.

Establish more peer sharing and education opportunities for HIV/IDUs

Explore alternative food service programs including communal food programs which are respectful to people and available on their terms.

Food providers should actively support other community initiatives that directly impact on IDUs nutrition. For example, housing and better and more drug treatment opportunities.

Hold a forum of food providers and community members to develop an action plan to address recommendations put forward by this research.

Create a consumer driven advisory group for food service providers to increase communication between service providers and community members.

Encourage more outreach service providers to be actively involved in client's efforts to feed themselves.

These questions were used by the focus group facilitators to guide the discussions.

1. Food. “First we want to talk to you about the foods you eat. We will talk more about the places you get food a bit later.”

What kinds of foods are you eating?

How would you describe the quality of the food?

Is it enough?

If you have HIV, how does living with HIV affect the way you eat? Why?

What kind of nutritional supplements do you use? Why? Where and how do you get nutritional supplements?

2. Food Places. “You may have already mentioned some of the places where you get food. Now we would like to talk more about those places and what situation in your life makes you go there.”

Where do you get your food?

What situation makes you go to those places?

How often do you go to those places?

How often do you eat with others?

3. Recommendations. “We would like to take some time now to find out what you think would make the food you eat and getting the food you eat better.”

What would it take for you to be eating better?

What food would you like to eat and why?

What kind of services would you like to see?

Anything else you would like to comment on that you feel is important or that hasn't been mentioned yet?

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