Needs Assessment For A Centralized Service Coordination Pilot Project for Homeless PHAs Facing Health and Mental Health Crises: Final Report
August 7, 2009

Submitted By: Deborah Leach + Associates
Team: Deborah Leach and Dino Paoletti

Table of Contents

1. Introduction

This document presents the results of a needs assessment conducted as one of the first steps in the Centralized Service Coordination Pilot Project for Homeless PHAs Facing Health and Mental Health Crisis, conducted under the auspices of the Housing Working Group of the Toronto HIV/AIDS Network (THN).

The pilot project is funded to March 2010 by the AIDS Community Action Program (ACAP) of the Public Health Agency of Canada (PHAC). The pilot involves developing and delivering a service coordination and case management model that will serve homeless men, women, transgender and transsexual persons with HIV/AIDS and focus on short-term crisis.

The formal project objectives, as outlined in the funding proposal, are as follows:

- o To increase access to and (enhance) continuity of health and community services for People Living with HIV/AIDS who are homeless and have mental health and/or substance use issues;

- o To increase service coordination and integration between HIV/AIDS community agencies and services in the health, shelter, housing and mental health sectors.

In advancing these objectives, pilot project staff will work with each client to help them identify needs and barriers and develop an action plan tailored to their needs and choices.

The project involves members of the THN Housing Working Group and a project partnership that has been established between twelve organizations (note that finalizing a formal partnership agreement is an initial project task).

2. The Needs Assessment: Focus and Process

Before beginning service delivery, a number of key tasks were to be completed. Among these was the completion of a needs assessment that would help confirm the service model.[1]

The funding proposal noted that the needs assessment would focus on "… identifying the barriers to access and coordination of services for PHAs in Toronto who are homeless and have mental health and/or substance use issues."[2]

At the beginning of the needs assessment, project staff stressed the importance of focusing even more narrowly, on people who are experiencing a health or mental health crisis.

The project was conducted over a 3 month period and, in keeping with GIPA (greater involvement of people living with HIV/AIDS) principles, pilot project staff recruited and hired a PHA peer facilitator/researcher to assist with interviews and focus groups with homeless PHAs.

The needs assessment involved the following activities:

- o A review of project-related documents (e.g., the funding proposal, letters of support, working group notes, draft commitment statements);

---

[1] Finalizing a formal partnership agreement was another initial task.
[2] Application for Funding, Public Health Agency of Canada, Ontario Region, AIDS Community Action Program Time-Limited Project, July, 2008. p.23

- Six key informant "framing" interviews with targeted partner organizations, conducted in the needs assessment's planning and design phase, to help formulate more detailed research, interview and focus group topics. Drawing on these interviews, the documentation review and the terms of reference, the consultants then developed draft interview and focus group protocols which they submitted to pilot program staff and the peer facilitator/researcher for review. Final protocols were approved by project staff.

- In-person interviews with 9 people living with HIV/AIDS who are or have recently been homeless. Five of the interviewees were women (two of whom identified as Aboriginal) and four men. Eight of these people had previously experienced an informal case management service over the past year to help stabilize their lives. This informal service included collaboration between housing, shelter, hospital, hospice and clinic service providers. Several individuals who participated in this service found housing as a result of their participation;

- A focus group with 13 PHA's who are homeless. This group consisted of ten men and three trans women whose inclusive membership consisted of Asian, European, Aboriginal, Black and South Asian participants. A second focus group for women was scheduled but due to the low turnout, individual interviews were conducted instead.

- A focus group involving 16 staff of 12 service provider organizations including AIDS Service Organizations, hospital and community health care providers and social service agencies. Organizations included:
    i. Sherbourne Health Centre
    ii. 2-Spirited People of the First Nations
    iii. Toronto People with AIDS Foundation (PWA)
    iv. Street Haven
    v. Fife House
    vi. St Michael's Hospital (Positive Care Clinic)
    vii. PASAN
    viii. Seaton House
    ix. McEwan House
    x. Centre for Spanish Speaking People
    xi. The Black Coalition for AIDS Prevention ((Black-CAP))
    xii. Asian Community AIDS Services (ACAS).

- Individual interviews with representatives of 7 organizations involved in the pilot project. These interviews focused on participants' views on service access challenges affecting the target population, expected benefits of the case management pilot service, measures of pilot project success and possible roles of the case manager during the pilot

Interview and focus group results were analyzed for key themes and a draft report was prepared and submitted for review and feedback. Following a presentation of findings, the final report was prepared and submitted to Project staff.

3. Structure of This Report

The remainder of this report is structured as follows:
- Section 4 summarizes feedback from PHAs who participated in the needs assessment
- Section 5 summarizes feedback from services providers
- Section 6 outlines a set of other needs that were identified but may not be directly addressed by the pilot

o   Section 7 presents a set of conclusions that focus on the implications of the above feedback for the pilot project.

4. Feedback From PHAs Who Participated In The Needs Assessment

This pilot project will target people living with HIV/AIDS (PHAs) who are homeless and simultaneously living with mental health issues and/or substance use issues. This section sets out a brief description of the particular population of PHAs targeted for the Short Term Intensive Case Management pilot project. It also briefly describes the social and personal circumstances that have such a bearing on the social determinants of health that shape their lives.

For the purpose of this report, homeless will describe someone who has recently lived or currently lives without a permanent fixed address which may include people who live outdoors, people who use shelters or temporary daily housing (such as churches who provide "In From the Cold" shelter), or people who experience a regular instability of housing including, but not limited to a combination of "couch surfing" or sharing temporary room rentals or "squats" (living in abandoned buildings).

It needs to be stated at the outset that this is not a homogenous population. While there are many shared experiences of poverty, health problems, homelessness and exclusion for this population, there is much diversity in the circumstances of people's health and capacity to access services.

4.1 Homelessness Context

Framed by poverty, homelessness, stigma and discrimination, much of the ability of people to manage their lives depends upon the variable circumstances of mental and physical health, housing and income, and patterns of substance use. People described times of greater or lesser ability to manage their lives and health depending upon these changing factors.

Participants described that in periods of intense substance use or mental health difficulties, the ability to manage health and the activities of daily living can be seriously compromised.

Many of the people interviewed for this report described personal trauma histories of various kinds. All of them shared experiences of homelessness for varying periods of time from weeks, to months and in many cases, for years. Most were either former or current drug users whose substance use contributed to chronic housing, health and life instability and frequent daily crisis management. Many had long standing concurrent mental health diagnoses or struggles including periods of hospitalization. Some described or alluded to histories of survival prostitution. For others, periods of incarceration formed part of their personal histories.

The confluence of homelessness, poverty, problematic substance use and concurrent mental health issues contributed to ongoing critical health problems sometimes, but not always related to their HIV status. For many people, those same social circumstances directly contributed to contracting HIV.

A number of people were immigrants to Canada and had experienced the profound impact of social dislocation and barriers related to racism and exclusion. A significant number were Aboriginal people who had experienced the kinds of marginalization all too regrettably present for many Aboriginal people.

Some of the people interviewed for this report have developed complex survival skills and an in-depth practical knowledge of services and resources in the city. Many of these people described widely and generously sharing their knowledge with other homeless people as part of a shared code of honour for homeless people.

Some people described having developed highly tuned capacities to read people effectively. These survival skills developed partly from their experience of negotiating homelessness and also from numerous encounters with an array of service providers, organizations and institutions. Regrettably, many people described circumstances where they felt that genuine caring was absent in the provision of services.

Some of the key factors facilitating connection, trust and follow through for people specifically related to:
- o having felt really listened to and heard by a service provider
- o feeling not judged for choices such as substance use
- o experiencing a genuine sense of warmth, caring and concern from the individual service provider
- o feeling like action was being taken to help people get practical solutions to immediate problems.

Some were able to articulate and acknowledge that their own complex behaviours and interactions could complicate the service relationship and could be difficult for service providers.

Participant's access to services often depended on literacy, communication skills, gender, race/culture and social class as key elements for successful negotiation of systems and services. Some people alluded to having been socialized to some degree of entitlement to service, while others, having experienced multiple experiences of marginalization from an early age, described no such sense of entitlement.

For many participants, HIV health management is not considered an immediate priority need. Daily priorities are most often dictated by the demands of an active addiction or substance use pattern or other immediate survival needs.

Priorities were frequently described more or less in the following order:
- o access to or money for drugs/substance of choice
- o food
- o dry or clean clothes
- o finding a safe sheltered place to use drugs or sleep after using drugs.

Looking after health or maintaining housing were not mentioned as typical priorities. Most described that planning was reduced to the more immediate needs of the moment, the hour, or the day at most. Long term health planning was not typically part of regular life for most people in these particular circumstances.

For many people, their HIV status was neither a central organizing identity (a "PHA" identity), nor their most immediate health priority or concern. Often, their street peers were unaware of their HIV+ status. Similarly, they did not always share their HIV status or drug use histories with all service providers.

Street survival has taught many people to carefully guard personal and health information from service providers and peers as a means of personal protection. Others have developed a fierce sense of independence to cope with homelessness, earlier life traumas or the experiences of stigma and exclusion in service provision environments. These factors, while understandable in origin, can often impede their ability to access service and get their health and life needs met.

Many, if not most, only sought active care of their health when their health or life was imperilled by an acute health crisis. For some, discovering they were HIV+ only occurred in the context of a life threatening AIDS diagnosis discovered in an acute health episode or hospitalization. Some had attempted to access medication for HAART (highly active anti-retroviral therapy) but found it difficult to adhere to drug regimens due to having their medication stolen while living in shelters. They described that other homeless people stole the medication thinking that it was narcotic or could be sold as such.

Many did not have regular health care providers such as dentists, doctors or nurses. Due to not having a fixed address, they were often unable to provide a regular phone number to service providers and were not available to hear back from service providers about possible appointments or follow up from tests. Due to the high risk of theft in shelters and other housing environments, many people were regularly without the necessary documents to access services, such as OHIP and hospital cards and proof of identity such as photo ID.

Similarly, given the frequent upheavals and instability of housing and life, few have the hallmarks of typical middle class life such as day planners, cell phones, or personal hand held organizing devices (iPhones, PalmPilots, BlackBerries, etc) to organize appointments or act as reminders. Some describe appointment cards being lost or stolen causing difficulties in following up with appointments.

4.2 Attempts at Accessing Services

"The services are all there. It really took coming close to death before I was able to accept help from others. When I did, people were very good to me and I'm alive because of it. I'm living inside for the first time in more than 10 years."

"You can tell by the way that people look at you and treat you that you don't belong. At one place (ASO) I just felt like the homeless girl with the drug problem that everybody was looking at. They made me feel like I didn't fit".

"The bed bugs were the worst part. It's a real issue. I'm really scared to go back, even though management has sprayed. I'm looking for a new place right now but it's really hard."

"How can a 48 year old devout woman talking to me about Jesus seriously expect to understand my problems and help me with my housing or deal with people who are angry and swearing? We need more peer workers and people with street experience."

" I deal with two drug dealers... my psychiatrist who drives a Ferrari and my crack dealer who rides a bicycle and both give me the drugs I need. Not much difference between them except what they drive".

"Workers only document your problem behaviour, never your good behaviour"

"After all the help I've received over the last year I have hope for the first time in my life. I'm not going to die of AIDS, I'm going to die of old age. I'm gonna be there to blow out the candles on my 80th birthday"

"When I was in trouble, I went to Emergency and I have a background of drug abuse. They refused to help me and called security that forced me to leave thinking I was only a drug addict. I was vulnerable and felt abused because I use drugs and I felt really bad".

PHAs who participated in interviews or a focus groups stated that the reasons for attempting to access health care usually occurred when an acute, potentially life threatening health crisis caused them to put health as an unexpected immediate priority. Consequently, the most frequent source point chosen for service access was hospital emergency rooms, usually the place least able to meet their immediacy needs.

When attempting to access hospital based services (emergency rooms, clinics) they described frequent experiences of stigma related to their homeless status, their history of substance use or the complex behaviours that they acknowledged could sometimes complicate the dynamic of service access.

The complexities of their lives, needs and sometimes difficult presenting behaviours lead many of these people to be identified as "hard to serve" by service providers. While this kind of descriptor is sometimes

used to identify some service users, it may more accurately describe service provider frustrations in attempting to address complex service needs.

Other people described how health crises that were causing acute physical pain, were often ignored or disbelieved by health care providers who dismissed their claims or disallowed access to narcotics or pain management medication due to the belief that people were engaged in "drug seeking behaviours" and did not experience an authentic health need for pain relief or pain management.

Other people talked about difficulties maintaining adherence to their HAART drug regimens due to shelter providers' medication policies. Some shelters demanded that shelter clients surrender their medications upon admission, thereby potentially increasing risk of their HIV disclosure to other residents. In one circumstance, shelter policy was such that medication was distributed to all shelter clients at the same time, despite the client having stated the importance of adhering to a regular time schedule to reduce of risk of developing drug resistance.

Another frequently mentioned factor creating barriers to access involved the relative isolation and lack of integration of various service sectors including health care, ASOs, addictions services, mental health, housing and shelter. In each of these settings people's needs were defined by the service provider and their limited service mandates versus looking more collaboratively at the broader and complex needs that this population experiences.

Participants described difficulties trying to remember the names of individual service providers, hours of service, dates of appointments and which service providers were working on what issues on their behalf. At best bewildering and frustrating, negotiating the intricate web of bureaucracies and services is complicated and time consuming for most people and many PHAs. For this particular population, it becomes almost impossible.

People also described significant barriers to housing included exclusion based on current substance use or substance use histories and wait lists for priority housing of up to ten years.

Many people described experiencing prejudice, stigma and exclusion from service providers based on their mental health status, substance use, incarceration history and homelessness. In some cases, frontline workers in government funded housing services were poorly trained to understand and meet the needs of this complex population. Participants described a need for greater access and availability of harm reduction based services in housing and health care.

While people were grateful for the range of services that are available, significant barriers exist to accessing those services for many homeless people. The regrettable outcomes for most people were manifested in significant HIV-related health problems and frustrating and infuriating experiences of service access barriers that perpetuated the endless and expensive cycle of emergency room visits and unnecessary hospitalizations.

People described the Monday to Friday, 9-5 hours of many organizations as being significant barriers. Given the regular instability and chaos that many experience, a 2:00am crisis on a Friday night leaves many people with few options other than hospital services.

5. Feedback From Service Providers

Interviews and focus groups were conducted with a range of service providers from various sectors (e.g., housing, health care, ASOs, community services) and different kinds of organizations (e.g., community services, hospitals) to seek their views on:

- o The kinds of service access challenges (including coordination challenges) facing members of the pilot's client group;

- o The pilot project itself, including suggestions about elements of the case management model, roles of the case manager and pilot project success measures.

Key themes, many of which reinforce those expressed by PHAs, are presented below.

5.1 Challenges and Barriers To Access and Coordination

- **Lack of Up-To-Date Knowledge About Other Service Provider Organizations Impedes Effective Service Coordination, Connections and Referrals.** Having an to-date and comprehensive understanding of services provided by other organizations is critical to the inter-organizational and inter-sectoral coordination that is so necessary to effective service delivery for PHAs with multiple and complex needs[3].

  The majority of interview participants felt they lack sufficient understanding of the roles, services, capacities and limits of other relevant organizations to coordinate effectively. This lack of understanding creates significant barriers to serving PHAs with multiple and/or concurrent (i.e., mental health and addictions) issues, affecting the quality of referrals made and received. Inaccurate information can lead to frustration of PHAs seeking service, conflicts between staff of different organizations and, ultimately, delayed response to health crises.

- **Limits of Organizational Mandates and Resources Reinforce The Need For Coordination But May Also Constrain Coordination Efforts.** Several service providers spoke about how the scope of their service mandates (often prescribed by funders and/or legislation), along with limited service capacity (i.e., level of demand in relation to resources available) can limit the type and extent of support they can offer, increase the emphasis that is placed on the efficient use of time (so that as many people as possible can be served with limited resources) and, for some, lead to a concern that efforts to coordinate may involve more time than is available. Pressure on hospitals to move people through emergencies as quickly as possible is a major challenge. These factors can result in:
  - o Poor communication (often due to lack of time for telephone or in-person meetings) between service providers in different organizations and sectors
  - o People receiving fragmented and disjointed services
  - o People who are at very high risk being turned away because they do not meet service criteria. It was noted that in some cases these criteria may be used as a convenience to avoid "dealing with" complex people with complex needs
  - o People being discharged from various kinds of facilities on a Friday night with limited or no support
  - o Inter-organizational conflicts caused by concerns about clients getting different service than was expected, poor communication and lack of understanding about the mandates and service limits of other providers.

- **Reaching and Staying Connected To People Who Are Homeless and Leading Chaotic Lives**. Almost all the service providers who participated in the needs assessment emphasized the difficulties they have physically contacting people in order to schedule appointments, remind them about an appointment or refer them to other services. Sometimes people who are admitted to hospital for a 72

---

[3] A number of service providers stated, for example, that the need for coordination is underscored by the fact that PHA's with mental health issues may not know anything about HIV services and HIV services may not have the capacity to deal with serious mental health issues. Some in the health sector noted that they do not really have the time or knowledge to be effectively assisting people with housing-related issues.

hour stay want to leave at the end of that time, with the result that while they may have received an assessment and tests, they have not yet begun a treatment plan. In these circumstances, a support worker/case coordinator who is able to come quickly to the hospital to meet the individual will increase the likelihood of follow-up.

- **Need For Flexible Service Approaches**. In addition to the difficulties reaching people, access is hindered when services have limited and regular hours of service, require strict adherence to appointment times, do not offer (or work with others to offer) services in settings that are most comfortable for clients (e.g., in the offices of other providers, via mobile services, on the street). Integration of harm reduction and an ability to address some basic needs (e.g., food, clothing) were also seen as important elements of service flexibility and, thus, access.

- **Access To Limited Housing Supply.** Almost all participants emphasized the fundamental importance of quality affordable, subsidized and/or supportive housing in general, and as a central element of a coordinated case management service model in particular. Access to medication is largely dependent on having some form of stable housing. Ten year waiting lists through Toronto Housing Connections (and a need to ensure one's contact information with THC remains up-to-date), housing that is dependent upon the person being clean and sober and limited housing that is competent in both HIV and mental health issues are all significant service barriers.

- **Coordinated Support For Medication Access and Compliance.** "So many factors conspire to undermine drug compliance- no storage place, no housing, the need to treat mental health issues before beginning HIV medication, organizational policies and procedures that make compliance almost impossible … and so much more... " A number of issues were raised that relate to starting and managing medication when a PHA is homeless. These include:
    o the need for a place where an individual is able to start medication
    o difficulties getting prescriptions because of concerns about medication storage and ability to maintain a medication regime
    o protocols against prescribing pain medication to substance users and protocols related to pain management medication for people in drug treatment programs
    o reluctance of some shelters to modify medication-related procedures to accommodate the needs of people taking HIV/AIDS-related medication
    o experiences having medication stolen when living in a shelter.

All of these issues were seen to highlight the need for education, coordination and individual advocacy as key components of a case management service.

- **Access To Treatment Services For PHAs With Substance Use Issues Who Are Experiencing A Health Crisis.** Several individuals noted the reluctance of some psychiatrists to treat someone who is a substance user and experiencing mental health deterioration. Reluctance to treat is associated with concerns about determining whether behaviours are mental health-related or (illicit) drug induced. The need was identified for psychiatrists to trust workers when they report a difference in the person's behaviour, regardless of that individual's drug use. Other issues include people being turned away during an assessment when the substance use is discovered and delays accessing to detox programs.

- **Literacy and Language Barriers.** Many homeless PHAs have life experiences of disenfranchisement, exclusion and marginalization. For some, service access is negatively affected by literacy and language barriers because they are unable to read, fully understand or complete necessary applications. Service access generally involves implicit expectations of literacy. The process of completing complex forms can be challenging for many of us. When compounded by literacy limitations (along with general experiences of not being seen or listened to) completing forms (e.g., for housing, coverage,

identification) can become even more anxiety producing and shaming. It will be noted later that assistance with form completion is seen as an important element of the pilot's case manager role.

- **Lack of Health Cards and Other Identification.** People who do not have status, lack health coverage or cards or have lost their identification face further challenges when trying to obtain health services.

- **Lack of Cultural Competency, Racism, HIV-phobia Homophobia, and Transphobia.** As noted earlier, homeless PHAs affected by substance use and or mental health issues are clearly not a homogenous group of people. Lack of understanding of diverse cultures and perspectives, and people being labelled or ascribed with certain behaviours because of who they are present significant service barriers. Few services that have an understanding of Aboriginal issues, staff who are not comfortable with or overtly discriminate against people from diverse cultures, people who are HIV+, trans, bi, gay individuals, drug users and sex workers all remain as significant barriers. Feelings of not being welcome and treated as "other" are frequently based in reality. Services that lack a harm reduction perspective, including long term care facilities that turn people away for drinking or smoking, also create barriers.

  Emphasis was placed on the need for services that reflect the changing face of HIV/AIDS and for all services (including the case management service) to become culturally competent within an anti-oppression/anti-racist framework.

- **Personal Impacts on Front Line Workers.** The personal effects of doing this work can be costly. Personal impacts are compounded by frustrations associated with trying to make a fragmented and under-resourced system work for vulnerable clients. Feelings of extreme isolation and anxiety can lead to staff burn out. Staff indicated that without a more coordinated approach, regular "clinical" supervision and time to debrief, staff turnover in the HIV/AIDS sector (particularly in community-based services) will remain high and the service system will lose knowledgeable and skilled resources. Individual PHAs will continue to experience the frustrations and gaps associated with a fragmented service system, undermining the potential for positive health outcomes.

- **Other Service Gaps and Limitations.** The following other service gaps were seen to make it even more difficult to adequately serve homeless PHAs with mental health and/or substance use issues:
  - access to mental health services (due to long waiting lists)
  - lack of female Aboriginal physicians
  - low staff-to-tenant ratios in supportive housing. This can limit supports available to help address crisis needs
  - harm reduction services, including safe injection sites
  - shortage of respite beds.

5.2 Suggestions About The Pilot Itself

Suggestions about the pilot are presented under the following headings:
  - the pilot's definition of short term
  - suggestions about the case management model
  - suggestions about the role of the case manager
  - measures of pilot success.

- **Service Definitions and Eligibility Criteria for Pilot Service.** During the focus group and in subsequent one-to-one discussions, it was noted that there should be some shared understanding about what "short term" would mean for the pilot. In general (and recognizing the importance of individual differences) most suggested that short term would be no shorter than three months. There was less clarity about when short term might become ongoing or longer term. However, the focus on

crisis situations was reinforced. Some suggested that after 6 months the service would no longer fall within the definition of short term. We understand, in fact, that 6 months is the general guideline that will be used by the pilot. Another question related to eligibility had to do with whether the program will only serve people who are already connected to service. Our understanding is that this is not the case.

- **Suggestions About The Case Management Model.** In general, feedback emphasized that the case management model most be one of real and active engagement with the individual and other service providers. Given the barriers identified, the focus was seen to be on connecting people to other services and advocating on their behalf, rather than simply making referrals. A well-publicized and mobile service (or involving extensive outreach), provision for 24 hour service, flexibility about where service is provided, accompaniment and direct assistance obtaining services (e.g., help filling out housing applications or hooking up to arrange a power of attorney or living will, appointment reminders) were all seen as important elements of the model. The need for a support worker/case manager who can meet on an immediate/rapid basis (i.e., when the person is still with the contacting service provider) was seen also seen to be critical. Emphasis was placed on a team approach and by some, an approach described as a "circle of care".

  One individual stressed that coordinated case management should not be seen as a stand alone service. Rather, it should also be seen and integrated as an ongoing way of operating that results in better service and far fewer incidents of inter-agency conflict.

  Other features seen as important were:
    - a site with harm reduction supplies, needle exchange and ideally, a safe injection site
    - linkages to food banks, drop-ins, life skills (this was seen to be particularly important for people who are involved with the correctional system) and the primary care system and communications between the parts
    - provision for 24 hour a day cell phone access (staffing back-up was noted as an important to moving in this direction) with the number being known by all emergency waiting rooms across the city
    - a well advertised service
    - involving an integrated partnership built on inter-agency trust, understanding of each organization's roles, a setting for frank and open discussion and problem resolution
    - clear cross-agency protocols that all follow (i.e., to address/prevent issues of communications breakdown)
    - building in an opportunity for staff of participating organizations to come together on a regular basis to assess their practices and discuss how they can develop their skills and practices.
    - Inclusion of peer support.

- **Suggestions and comments about the role of the Case Manager.** In general, people saw this position taking on two major kinds of roles, i.e.,

    i.   those that involve serving individual clients

    ii. those that are intended to support other service providers

In addition, it was noted that the case manager would be involved in those that involve participating in systems level advocacy.

Roles in serving individual PHAs. The following suggestions were made about the case manager's role in serving individual PHAs:

- o "being the point person" (also described as 'the glue", "the go to person", someone who "knits together all of the services and supports")
  - with the initial intent of helping the client to stabilize during an acute phase
  - to whom any service provider could connect/refer
  - who would help an individual "get more grounded and focused", be involved in a critical assessment of client needs (with the client and the contacting worker) and in the development of goals and a service plan
  - who would organize services "at the front end" and connect an individual to services (e.g., primary care, speciality HIV clinic services, services for women, ASOs e.g., for benefits, programs to get identification, Social Insurance Numbers, OHIP cards) and advocate on their behalf, accompany people when necessary and assist in completing forms when required
  - who would "sweat the small stuff" (e.g., know when the person's appointments are, where they can be reached, know who all of their service providers are, help them set up a cheap telephone mailbox at a community centre)
  - must be well connected to all services, especially emergency departments at hospitals
  - have a role in monitoring/supporting medication compliance (some thought this was most critical for people who are unstable and leading chaotic lives)

  - who would serve as an alert system when someone is decompensating/to identify when someone is at risk.

Emphasis was placed on clear and timely communication by the case manager so that all providers are working together and doing their best for the client. For example, the suggestion was made that if a worker lets their hospital contact know ("gives them a heads up") that a particular client will be dropping by and the reasons for the visit, the hospital contact might be able to suggest how to best handle things so that the client receives the best service.

Role In Supporting Front Line Workers. This would involve activities such developing an up-to-date virtual compendium of the roles and services of the organizations involved and supporting the development of a working group/committee of front line housing workers.

Some individuals noted that the position would be a very challenging one and that longer term sustainability of the service would be dependent on having more than one case manager/coordinator.

The following were suggested as important **characteristics and qualifications** of the incumbent:
- o Someone who knows or is able to develop thorough knowledge of the services provided by all partners and other relevant services
- o Someone who is skilled at seeing when someone is decompensating and knowing who to call
- o Someone who is flexible about where they work and comfortable working from the streets
- o Someone who has a deep integration of a harm reduction approach.

- **Views On Measures of Pilot Project Success.** Both interviewees and focus group participants were asked how they would judge the success of the pilot. Key themes related to more immediate benefits to individual clients as well as views on how the Local Health Integration Network (LHIN) would likely judge success.

  - o **Benefits expected by the LHIN.** These consisted of:
  - reductions in the number and length of hospitalizations
  - reductions in the use of emergency services

- cost savings associated with the above reductions.

o **Output measures.** These included materials or initiatives developed by the Case Manager that would support front line workers (and ultimately clients). Examples included the development of a working group/committee of front line housing workers, an up-to-date virtual compendium of the roles and services of the organizations involved, anything else.

o **Outcome measures.** Suggestions included the following and are grouped under those for clients, those for staff and organizations and those that focus on systemic changes.

- **For clients**
    - **A Support System/Circle of Care**
        - connected to appropriate service providers and getting the services they need (including nutrition, shelter, hygiene, medical, housing, mental health, substance use, etc.)
        - aware of their community and surrounding
        - forming relationships with one or more service providers and has a "community of care"
        - knows where to go to get services minimize the potential for a crisis
        - gained an understanding of who provides what services and how to access them
        - want to have a primary support worker when they leave
        - have a doctor, know who it is and are coming for service.

    - **Housing**
        - housed in a setting that supports harm reduction and mental health
        - knows where (s)he will "put their head down"
        - experiencing greater housing stability.

    - **Health**
        - out of crisis
        - improved health status (e.g., viral load, CD count, symptoms inventory and severity indices)
        - increased weight
        - averted mental health decompensation
        - an emergency admissions prevented

    - **Ability To Stick To "Master" Treatment and Support Plan**
        - taking medication
        - attending appointments
        - complying with HIV, psychotropic and/or other relevant medication regimes.

- **For staff and organizations**
    - have a better understanding of the roles, services, capacities and limitations of other participating organizations
    - are involved in fewer inter-organizational conflicts arising out of lack of understanding of roles and capacities
    - are coordinating more effectively.

- **Systemically.** Suggestions here related to systemic changes having occurred as a result of systemic advocacy initiatives as well as improvements to inter-organizational

effectiveness (e.g., hospital staff receive increased advanced notice that someone will be coming for a hospital visit, fewer numbers of clients are falling through cracks and there is a reduction in worker burnout and social worker caseloads).

- o **Process measures** such as:
  - client satisfaction levels, such as feeling that there is an immediate response to their concerns and "feeling heard", feeling like they are not just being passed from place to place, that there is some hope
  - people are being contacted in ways that works for them
  - service providers feel some assurance that there is a plan in place to support the person
  - length of time for the case manager/coordinator to return phone calls (so that an individual might be connected to service before they leave, e.g., a hospital setting).

  In addition, an important process issue having to do with program design relates to determining which services should be available on a 24 hour basis.

6. Other Needs Identified

A number of other needs and service gaps were identified that may not be directly part of a case management service. They are listed briefly below.

- **Increased Housing Supply.** As noted earlier, most people described a need for more accessible housing. While some described living outdoors as a personal choice, most clearly defined a need for more housing options including dedicated beds for homeless PHAs in shelters and housing services inclusive of gender issues (male, female, trans).

- **Bed Bug Advocacy and Action**. Bed bug infestation in shelters and housing services was described as a significant barrier and needs to be part of more mobilized advocacy and action across this sector.

- **24 Hour Drop-In.** Due to the immediacy needs that this population experiences, creation and access to a 24 hour drop in service for homeless people was indicated as significant unmet community need and gap in current services. This kind of resource needs to be inclusive of food, health services, telephones, harm reduction resources and staff support.

- **Outreach.** Most participants also indicated a need for more outreach of services to homeless people where they live.

- **Peer Workers.** Hiring and training more peer workers with a lived experience of homelessness, substance use, HIV issues, mental health issues was also identified as significant priority.

- **Harm Reduction Resources.** The expansion of and access to more harm reduction resources was also identified as an important priority including (ideally) a safe injection site. This need acknowledges the complexity and diversity of needs experienced by people with current substance use issues and substance use histories.

- **Staff Training.** Due to frequency of frontline staff turnover and the complexity of service networks, a critical need was identified for ongoing regular training of service providers in the areas of shelters, housing, addictions, mental health, clinics and health care provision. This involves developing a shared culture of listening to and valuing experience and expertise from a variety of professional categories.

7. Conclusions: Implications of Findings For The Pilot Project

The following is a set of conclusions that relate to the final design and implementation of the pilot project. They are grouped under the following headings:

- The pilot's case management model
- Case manager roles
- Communication, promotion and outreach
- Pilot evaluation and monitoring.

The Pilot's Case Management Model

i. Finalization of the pilot's case management model should strive to incorporate many of the features noted throughout this report. However, likely the most important will be practices that impart a sense of caring and "being listened to", which so many PHAs said were most important to accessing and staying connected to a service. In addition, incorporation of harm reduction principles will be critical.

ii. The case management model should not only be a distinct "stand alone" service but also an ongoing way of doing business between all participating organizations. Consideration should be given to establishing clear expectations and standards related to inter-organizational communication. Supporting front line workers to coordinate and meet from time to time to talk about client issues is also seen as important here.

iii. Two key design issues that should be communicated to all partners prior to the initiation of service delivery are:
    - that PHAs do not need to be connected to a participating service provider to be eligible
    - the pilot's definition of "short term".

iv. Attention should be placed on ensuring active involvement of front line staff, including involvement in partnership development as well as in regular opportunities to come together to share information, including lessons learned about effective service practices. Opportunities for joint front line staff meetings will contribute to improved communication and trust building.

    The suggestion that a front line housing workers group be created should be communicated to the THN.

v. Efforts should be made to coordinate information sharing tools, including a consent to share information. Consideration should be given to enable mutual access to client charts or referral information.

Case Manager Roles

vi. The case manager should:
    - function as the key linkage ("point person") to coordinate and integrate service provision among all relevant providers (including access to long term case management) and ensure that necessary and timely communication occurs between all providers.

    - develop an extensive, in-depth and thorough knowledge of all potential referral resources and key contact staff in the areas of housing, shelters, clinics, drop-ins, other community and hospital-based health care services, addictions services, income supports, street outreach services, services for people with incarceration histories, food providers and mental health services. This would include understanding the limits of service and inclusionary/exclusionary criteria.

- o emphasize flexible service provision in office-based settings (PWA office), outreach to other community and hospital-based services and to other settings in which the client feels comfortable. Individual client advocacy in the area of organizing and attending key appointments such medical appointments, housing appointments and income support appointments, will also be a critical role.

- o offer supports to remind people about their meetings and appointments in order to maximize their ability to keep these appointments and support their health.

Communication, Promotion and Outreach

vii. It will be essential to communicate the specific services provided by the Short Term Intensive Case Management pilot project, including its service limits and inclusionary/exclusionary criteria. This should involve making direct contact with organizations from the range of relevant services and sectors where homeless PHA's are likely to access services.

viii. Priority should be placed on outreach that directly promotes and communicates about the service to homeless PHAs. Information resources about the project that are designed to reach homeless PHAs (e.g., posters and pamphlets) should respond to literacy, ESL and diverse cultural needs. Promotional and communications strategies should integrate and foster peer communication, knowledge exchange and networking.

ix. A key element of the pilot will be the development and communication of a virtual "compendium" of relevant service providers, including their mandates, roles and services, access procedures and criteria and any relevant service limitations. This compendium should be accessible to all participating pilot project organizations. The compendium may draw upon and be linked to ASO 411 and the HIV/AIDS Community Calendar. Implications to other working groups and committees of THN should be identified with the THN Coordinator.

Pilot Evaluation and Monitoring
The following are key considerations with respect to pilot monitoring and evaluation:
- o pilot project monitoring and evaluation should not only support funder accountability requirements but, to the extent possible within limited resources, collect information that will contribute to ongoing project improvement and knowledge development with respect to service needs and models

- o efforts should be made to include a focus and outputs (compliance), outcomes and process. Many examples of potential measures were provided by needs assessment participants and are outlined in this report. Selecting a small and manageable number of measures will increase the likelihood that the evaluation will be useful and "doable";

- o meaningful opportunities for client participation and feedback will be critical

- o opportunities may exist to collaborate with and/or draw upon relevant research initiatives (e.g., research being conducted about the use of hospital in-patient services by homeless PHAs) as part of the ongoing evaluation process

- o it is likely most cost-effective to build in as much ongoing data collection as possible rather than waiting until the end of the project to conduct a major data collection effort.