Canadian AIDS Society *Société canadienne du sida*

Care and Support Challenges and Issues in a Spectrum of HIV/AIDS Populations

Final Report

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Executive Summary

Since its first appearance in Canada, HIV has made significant demands on the health and social service system. Recent advances in the treatment of HIV/AIDS and the changing epidemiological profile have ensured that the AIDS epidemic will continue to present new challenges. The critical need for knowledge and understanding of the impact of these circumstances on community-based care provided the impetus for this research. The Canadian AIDS Society (CAS), with support from the University of Toronto HIV Social Behavioural & Epidemiological Studies Unit, joined to conduct this national multi-site research project to examine the capacity of the community to provide services to persons living with HIV/AIDS. The central purpose of this research was to understand how community-based care differs for HIV/AIDS populations currently in need of support, with a focus on examining how each population could best be served.

Specific objectives included:
> To develop an understanding of the community's capacity to provide care and support to current and growing HIV/AIDS populations
> To identify valuable lessons learned in the provision of services to under-served populations, and understand gaps in care and existing barriers to care for each population
> To generate strategies for providing care and support to each population

Research Design
A focus group methodology was employed to investigate care and support issues for under-served populations living with HIV/AIDS in five communities (Halifax, Montreal, Toronto, Winnipeg, Vancouver) across Canada. The research was undertaken by a team of five site coordinators, a research project coordinator, and two university-based researchers. Data were collected from the perspective of the care recipient, front line care provider, and informal care provider. Specific participant selection criteria were developed and a purposive sampling strategy was employed to select individuals most likely to generate productive in-depth discussions on issues directly related to the research objectives. In order to standardize procedures across sites a comprehensive Focus Group Guide was compiled and used for training of all staff. The data were transcribed verbatim, entered into the *Atlas-ti* software program for qualitative analysis, and blocked in such a way as to facilitate both site-level and national analysis. A total of 161 individuals participated in the study (88 care recipients, 37 front line care providers, and 36 informal care providers).

Results
What is care?
When care recipients were asked to describe what they envisioned as their ideal choices for care, three very strong themes emerged across all sites with all populations. Care recipients consistently identified the desire to have peers actively involved in their care. Peers were viewed as an essential source of support and HIV/AIDS-related information. Care recipients also sought empathic care providers who were compassionate and well-

informed about the challenges and life circumstances of individuals living with HIV/AIDS. Additionally, a range of practical supports were identified as essential components of care, these included assistance with every day practical tasks such as errands, transportation to appointments, food banks and clothing exchanges.

When care works well

Service providers across all sites were very clear on what was required to make services work effectively. First and foremost the service needed to be accessible. In circumstances where staff eliminated access barriers and allowed clients to get in the door on their own terms, services worked well. Providers either went out to clients or brought services in to suitable locations. Successful services were centralized, one-stop shopping approaches often offered collaboratively by a team of professionals or service agencies. These services frequently assisted clients in meeting their basic living needs such as food, clothing, housing, and financial support to cover basics. When client-worker interaction was successful, care providers described their approach as one of acceptance, where they met the client "where they were at" and remained supportive and non-judgmental regardless of circumstances. Staff also reported having the time to establish rapport with the client which in turn encouraged a trusting client-worker relationship. In many cases, effective programs had some component of peer involvement, where peers were available informally for social support, peer support groups or peer education sessions.

What stands in the way of care?

Care recipients described a variety of access barriers to "getting in the door" of health and social service agencies. Required waiting time for needed services or dealing with bureaucratic red tape and application procedures that were oppressively complex or slow were frequently cited as barriers to care. The need to travel when specific services were unavailable locally or travel within cities to various service locations presented barriers for many. In addition to facing access barriers, clients repeatedly found their own personal financial situation did not allow them to pay for such basic necessities as a phone, transportation to appointments, high protein foods, vitamins or medications. When clients found accessible services or support, instances of negative encounters with staff were frequent. Clients felt the negative interactions stemmed largely from discrimination related to their HIV status or the service provider having knowledge of their addiction. They also found care providers were ill informed about the needs of people living with HIV/AIDS and appeared to lack understanding about the illness or affected populations.

Front line workers described many aspects of their work environment as unsatisfactory, citing gaps in their knowledge and training to support current client populations as the primary concern. This was compounded by an absence of resources to acquire needed training, and inadequate inter-agency collaboration which resulted in limited sharing of expertise across disciplines. Front line workers at all research sites identified service provision policies and guidelines that were not flexible enough to accommodate the diverse needs or situations faced by current client populations as a barrier to care. Policies pertaining to a wide range of issues including access to medications, social assistance, home care, housing, and the scheduling of appointments were all found to be prohibitive.

What steps can be taken to enhance care provision?

Participants were asked to comment on how they would improve HIV/AIDS care and support if they had the opportunity to develop services with unrestricted resources. Strategies common across all research sites focused on improved access to services, enhanced inter-agency collaboration, the need for educational initiatives for the health and social service sector, supports to informal care networks, and the development of service provision policy from the ground up.

Policy and Program Implications

The following recommendations for policy and programming are grounded in the research results and reflect the ways those directly involved in HIV/AIDS care and support feel service delivery can be improved.

HIV/AIDS care and support can be enhanced through policy and programming that:

> builds partnerships and collaborative linkages with all stakeholders whose mandate is to assist those who are currently under-served
> develops innovative models of care and support provision that move beyond the status quo to more creative, flexible, integrated solutions specifically designed to meet the needs of under-served populations
> provides education and training initiatives for health and social service providers to be sensitized to issues related to HIV/AIDS, homelessness, addictions, poverty, and the accompanying care and support strategies that work effectively with under-served client populations
> is developed from the ground up and eliminates the rigid policy structures that hinder the provision of care to current client populations
> supports informal care networks and recognizes their contribution as an integral component of care

While care provision appears to be improving for certain under-served populations, for the most part front line workers struggle as they attempt to secure support for socially and economically marginalised client groups. It is essential to recognize the changes that have occurred within HIV/AIDS care and adapt to present needs. The challenge ahead is to understand how to provide system-wide care and support in a manner that is both respectful and well suited to the ever changing context of the HIV/AIDS epidemic.

Introduction

Since its first appearance in Canada, HIV has made significant demands on the health and social service system. Recent advances in the treatment of HIV/AIDS and the changing epidemiological profile have ensured that the AIDS epidemic will continue to present new challenges. People are continuing to be infected with HIV/AIDS, and are living longer with the virus. While there is still no cure for HIV/AIDS, increased longevity has resulted in the development of more complex clinical, social and mental health problems amongst persons living with HIV/AIDS. These evolutions in disease trajectory over the last decade have significantly impacted on the provision of HIV/AIDS care and support.

The increasing complexity of the epidemic is also making it more difficult to care for people living with HIV/AIDS. The epidemic has advanced primarily through a shift into younger, more marginalised populations. Increasingly, affected individuals exist outside the mainstream of our society - socially, economically and culturally. In these groups, traditional sources of support may be weak or nonexistent and alternative sources must be relied on. The critical need for knowledge and understanding of the impact of these circumstances on community-based care provided the impetus for this research. The Canadian AIDS Society (CAS), with support from the University of Toronto HIV Social Behavioural & Epidemiological Studies Unit, joined to conduct this national multi-site research project to examine the capacity of the community to provide services to persons living with HIV/AIDS. Information was gathered about existing practices in the delivery of HIV/AIDS care and support services with the goal to contribute valuable evidence to support future health and social service planning for the community support needs of populations affected by HIV and AIDS.

Study Objectives

The central purpose of this research was to understand how community-based care differs for HIV/AIDS populations currently in need, with a focus on examining how each population can best be served. Specific objectives included:

> To develop an understanding of the community's capacity to provide care and support to current and growing HIV/AIDS populations

> To identify valuable lessons learned in the provision of services to under served populations, and understand gaps in care and existing barriers to care for each population

> To generate strategies for providing care and support to each population

Literature

The Canadian HIV/AIDS Epidemic

The epidemiology of HIV in Canada has been characterized as a series of overlapping epidemics moving in waves through different risk groups. The latest figures reveal there were an estimated 49,800 people in Canada living with HIV infection at the end of 1999, and an estimated 4,190 Canadians who became newly infected with HIV in the same year. Although the estimated incidence rate (number of new infections) was virtually unchanged between 1996 and 1999, there has been a significant shift in the distribution among exposure categories (Health Canada, 2002).

The most recent estimates indicate that women comprise an increasing proportion of reported HIV cases in Canada, and that both prevalent and incident infections amongst the heterosexual population are on the rise. There has been a 91% increase in prevalent infections between 1996 and 1999 in the Aboriginal population, and evidence of a resurgence of new HIV infections among gay men also exists. Injection drug users represent the only population whose infection rates have declined, however, the proportion of existing infections in this group is still unacceptably high (Health Canada, 2002).

It is clear that the epidemic has continued to evolve and affect different susceptible communities. The emergence of HIV infection in more diverse populations has prompted questions regarding the adequacy of existing resources to support community-based services, and has created a whole new set of issues for health and social policy.

Factors to Consider with Emerging Populations

The diversification to new and varied client groups has impacted directly on the community's capacity to provide care and support. Many of the newer populations experience multiple disadvantages leaving health and social service agencies struggling to meet diverse needs. The lives of emerging clients are more often in crisis, and services required range from attending addiction treatment centres and accessing emergency health care to finding shelter or food. Clients who are unstably housed may suffer from serious mental health problems and many come from impoverished, dysfunctional family backgrounds where they have experienced physical, sexual or emotional abuse (McAmmond, 1998). Those living on the street or in poverty may have poor social supports and tend to decline in health more quickly (Goldstone, 1995; Goldstone, et. al., 1995; 1999; Hogg et al., 1994; Schecter et al., 1994).

Since the advent of new drug therapies, the types of support people living with HIV/AIDS require has shifted considerably. Rather than addressing end-of-life issues, many are confronted with the prospect of prolonged life and seek supports around issues related to a return to work, adherence to medications, and financial problems (Bourdages et al., 2001; Jalbert, 2001). As they go on with their lives they face the prospect of living in poverty and dealing with the many accompanying psycho-social stressors associated with low income status such as inadequate housing, unemployment or under employment, and addictions (Adam, et al., 2001; Gill, 1998; Olivier, 2001). HIV is viewed as just one of many issues clients must encounter in daily living.

Current Community Health and Social Service Environment

At present, community health and social service agencies are under tremendous pressure as they strive to meet client needs in an environment of fiscal restraint. The growth in demand for community services is unprecedented, at a time when reductions in federal transfer payments, and decreased provincial support for community-based services have forced reductions in funding for welfare, hospitals and community agencies. This in turn has eroded the social infrastructure necessary to achieve health for many populations (Raphael et al., 2000; Steele, et al., 2002). A recent study of HIV/AIDS service providers in Ontario revealed how changes in public policy have impacted services on the front line. Workers are faced with a system riddled with bureaucratic procedures and a lack of training to adequately assist clients with the complexity of issues that arise. At a time when client needs are more complex and services most in demand, the availability of support has become increasingly scarce (Cain & Todd, 2002).

Injection drug users living with HIV/AIDS make up a significant proportion of the population needing HIV care, treatment, and support. The paucity of appropriate services in the continuum of care for this population has been well documented (Millar, 1998; Parry, 1997;Stajduhar et al., 2002; Whynot, 1996). The inflexibility of the system and lack of services designed to meet the specific needs of this under-served client group have frequently been cited as barriers to care. Workers often have difficulties defining the boundaries of their work and have reported "bending the rules" while attempting to access services for clients (Cain & Todd, 2002; Stajduhar et al., 2002; Strike et al., 2001).

Clearly we must move beyond conventional methods of care provision to enhanced models of community agency partnership and improved services specifically designed to meet the needs of marginalised populations (Anderson & Parent, 1999; Andrews & Macdonald, 2001). Support is building for safe injection facilities and more innovative harm reduction approaches, however, integrating these methods into traditional mainstream services will require considerable time and resources (Fischer et al., 2000; Kerr & Ibaez-Carrasco, 2001; Kerr & Palepu, 2001; Le Clerc, 1999; Millson et al., 2001, 2002; Wood et al., 2001). HIV/AIDS is more than just a health issue, and it cannot be solved by the health system alone. Many community-based organizations have come to this realization as growing demands have been placed upon them. Each community has a different context and each population at risk has unique needs. Any efforts to enhance the lives of individuals affected by HIV/AIDS must be developed in light of these changes. The spread of HIV infection to more diverse populations has created a whole new set of issues for health and social policy. The challenge ahead is to generate creative and flexible models that have high relevance to affected populations.

Methods

Design

For this research we elicited the expert perspective of persons living with HIV/AIDS and those involved in the delivery of HIV/AIDS care and support services. Because the issues under investigation were multi-dimensional and not readily quantifiable, a qualitative approach was selected to seek insight from those actually involved in planning, coordinating, delivering, and receiving care and support (Cresswell, 1998; Denzin & Lincoln, 1998). A focus group methodology was employed to investigate care and support issues for under served populations living with HIV/AIDS in five communities (Halifax, Montreal, Toronto, Winnipeg, Vancouver) across Canada. The research was undertaken by a team of five site coordinators, a research project coordinator, and two university-based researchers. The initiative was funded in two stages, an initial developmental stage, and a second follow-up stage during which the actual research was carried out. During development, site coordinators conducted environmental scans to determine populations for the research, piloted measures, and gathered details to inform the data collection process. This developmental work laid the foundation for the research, and was integral to the success of the study as it provided an opportunity to build partnerships and design an appropriate research methodology.

During stage two the research team worked collaboratively to address issues regarding criteria for study participation, recruitment strategies, and refinement of measures and data collection methods. The consultatory process ensured methods were well-suited for working with the selected populations, while at the same time maintaining the integrity of the research design.

Selection criteria and recruitment

Data were collected from the perspective of the care recipient, front line care provider, and informal care provider. A purposive sampling strategy was employed where individuals most likely to generate productive in-depth discussions on issues directly related to the research objectives were selected. The selection criteria and recruitment strategies were developed in consultation with the site coordinators and standardized as much as possible across sites.

Front line care providers were recruited through consultation with staff at site agencies and using specific selection criteria. Care recipient and informal care provider participants were identified through community connections and with assistance from a community assistant hired to support the site coordinator in recruiting marginalised participants. Potential participants were given study information and answered a brief set of screening questions to ensure they met the initial research criteria. More detailed descriptions of the field recruitment strategies and participants at each research site are available in the community reports at <*www.cdnaids.ca*>. Table 1 below lists the care recipient populations that participated at each site.

Table 1: Care Recipient Participant Populations

Research Site	Care Recipient Population
Nova Scotia	Rural Communities
Montreal	IDUs, Haitian Community, Gay Men
Toronto	People from HIV-Endemic Regions
Winnipeg	Women, Aboriginal Women
Vancouver	Women IDUs, First Nations IDUs, Active IDUs who frequent the open drug scene

Focus group procedures

In order to standardize procedures a comprehensive Focus Group Guide was compiled and used for training of all staff. The guide provided a detailed outline of all focus group procedures and responsibilities for the moderator, assistant moderator, and community assistant, as well as readings, the question guide, and instructions for audio recording, field note taking and debriefing. Selected readings from *The Focus Group Kit* by Morgan and Krueger (1998) were included as training materials in the guide.

Recognizing that a focus group methodology may not be suitable for all participant groups, site coordinators were given the option to collect data using an individual interview method. Only the Toronto site opted for individual interviews for some of the care recipient data, and for all of the informal care provider data collection. All other study data were gathered using a focus group method. In total 23 focus groups and 9 individual interviews were conducted.

Prior to focus groups and interviews, participants completed standardized demographic questionnaires and consent forms. Study participants understood involvement was entirely voluntary and were given the option to withdraw from the study at any time. Upon completion of the group, each participant was remunerated for their participation and out-of-pocket expenses were reimbursed.

Data analysis

The data were transcribed verbatim, entered into the *Atlas-ti* software program for qualitative analysis, and blocked in such a way as to facilitate both site-level and national analysis. The analysis examined data collected from the perspective of the three participant groups across the three central objectives of the study. Content analysis was used to explore the current status of care provision to different HIV/AIDS populations; examine factors influencing the community's capacity to provide appropriate care and support; and to identify community-based strategies to support the future health and social service needs of HIV/AIDS affected populations.

The analysts made several coding passes of the transcripts. On the first pass an initial set of codes were applied to the text of each transcript and a coding framework which captured key analytic constructs was established. Subsequent passes were used to refine and expand code categories and clean up manifest content categories. Analysis was conducted by forming categories, establishing the boundaries of each category, assigning

data segments to categories, summarizing the content of each category, and examining negative evidence.

The following systematic strategies were employed to ensure the validity, reliability, and credibility of the data (Lincoln & Guba, 1985; Sandelowski, 1986):

> The assistant moderator took careful field notes during each focus group. Field notes included: key points from the discussion, notable quotes, and important observations about the nature of the discussion as well as speaker frequency, extensiveness, and intensity. Flip chart notes were also used to cross reference the contents of field notes.

> A summary of critical points at the conclusion of each focus group was provided. Participants were invited to amend or change this oral summary, if suggestions were offered, the group was asked to confirm or correct the new ideas. This ensured that the researcher adequately understood the intent of participants and provided an opportunity for all participants to hear a summary while still present in the focus group.

> Immediately following the focus group, the moderator and assistant conducted a debriefing. This commentary was documented and used to capture immediate reactions following the focus group.

> All data were transcribed by the same individual and site coordinators cleaned and confirmed contents of all transcription.

> The data were independently analyzed by a team of three qualified individuals and consensus validation was used to confirm categories and the placement of transcribed quotes into categories arising from the analysis. Having two persons independently analyze the same raw data set and then compare findings (triangulation of analysts) served as a check on bias during data analysis.

> Following the initial examination of the data, the analysts were encouraged to look for rival or competing themes and examine outliers in the data. Attempts were made to understand disconfirming evidence, unusual cases or those that had a minority view.

> Following the initial analysis, category systems were examined for meaningfulness and accuracy following Guba's (1978) criterion for internal homogeneity and external heterogeneity. The criterion of internal homogeneity represents the extent to which the data that belong in a certain category hold together in a meaningful way. The data collected within a set should appear well-integrated and complete. The external heterogeneity criterion is also essential because it identifies the extent of differences between categories.

> Study participants were invited to provide feedback on draft summaries of each group following the initial coding pass.

> A final test for completeness involved the opinion of other qualified observers. If a competent judge can make sense of the category systems, and feels the categories are well represented by the data they contain, then this serves to further verify the accuracy of the analysis. The site coordinators, focus group moderators, and co-principal investigators were invited to verify the analysis.

Strengths and limitations of the study

Community research requires collaboration between the researcher, the support and care agencies serving the community and persons living with HIV/AIDS themselves. Community members have a wealth of practical information to share with researchers and a vested interest in research that can assist in meeting specific community needs (Allman, Myers, & Cockerill, 1997). Our research approach recognized expertise at the community level and included community members as active participants in all aspects of the research design. This in turn ensured relevant results that will assist organizations in meeting their service delivery goals. The community-based approach taken throughout this project must be considered one of the strengths of this study.

The limitations of this study are primarily related to the challenge of maintaining a standardized study protocol across diverse communities and populations. Data were collected by different teams (i.e., moderator, assistant moderator, community assistant) at each research site, introducing some variation in how focus groups were conducted. Given the budget limitations of the project, and sensitivity of the issues under investigation (i.e., peer involvement was critical to accessing populations), it would not have been possible to have a singular team conduct all data collection. The researchers attempted to compensate for this by training all staff and developing a standardized methodology well suited to each community environment.

Demographic profile of study participants

All demographic data were analyzed using the *Statistical Package for Social Sciences* software. A total of 161 individuals participated in the study, a break down by participant category is displayed below.

Table 2: Community Care Study Participants

Participant Category	n
Care Recipients	88
Front Line Care Providers	37
Informal Care Providers	36
Total Participants	161

Demographic characteristics of each participant group are listed below in point form.

Care recipients:

> 53% were between 30 - 40 years of age
> 41% of care recipients were male and 59% female
> 51% had incomes between $5,000 - $10,000
> 25% had incomes between $10,000 - $20,000
> 55% were diagnosed with HIV/AIDS between 1994 - 1998

Front line care providers:

> Formal education ranged from less than high school to post graduate degrees (PhD, MD) with 46% (17) having at least a bachelor degree
> 38% (14) worked in an AIDS Service Organization (ASO)
> 32% (12) worked in a hospital or community medical clinic
> 14% (5) worked in a combined ASO with housing support, medical or palliative care
> Approximately half (53% [19]) had worked between 9 -14 years in HIV/AIDS
> Those working directly with clients saw on average 28 clients each week

Informal care providers:

> Cared for partners/lovers (36% [13]), or close friends (42% [15])
> 66% (23) had received no formal training to provide HIV/AIDS care and support
> 56% (20) resided with the care recipient
> 40% (14) provided care on a full time basis every day, all hours of the day, while 46% (16) provided care on average 10 hours per week

Study Findings

Factors that Influence Good Care

The analyses presented here are national in focus; site level analysis is reported in the community reports available at <*www.cdnaids.ca*>. The first section of the analysis describes key components of care and contributing factors to successful care provision. Access barriers to care recipients as well as challenges faced by providers within the work environment are then described. Following this, an examination of the current status of informal care provision and suggested strategies to enhance future health and social service delivery are presented.

What is care?

When care recipients were asked to describe what they envisioned as their ideal choices for care, three very strong themes emerged across all sites with all populations. Care recipients consistently identified the desire to have peers actively involved in their care. Peers were viewed as an essential source of support and HIV/AIDS-related information. Someone who could listen and fully understand life living with HIV.

> ...a little support from people who are in a disease situation like I am...and that person can feel that way with you... because I find it hard to see always the people that don't have it...because really they don't understand (Winnipeg care recipient).

> It's better for me to give information to somebody who needs it because I'm in their shoes (Toronto care recipient).

> Yeah! I sat in the waiting room [after receiving the diagnosis], I asked for an HIV+ person, I'd rather have somebody come that was positive and had more understanding (Winnipeg care recipient).

> Some people are scared they can't accept it...it would be nice for someone that has it to talk to the other person whose just caught it and you know, often (Vancouver care recipient).

When care recipients accessed the health and social service system, again they were looking for understanding. They sought empathic care providers who were well-informed, compassionate and knowledgeable about the challenges and life circumstances of individuals living with HIV.

> I have heard of so many times, where you go needing help, and these people are supposed to help you, and they look at you and they're like, they don't understand you, what you are going through...I want somebody who understands you, and from the experience I've had not everyone understands HIV and what you are going through and how it affects you (Toronto care recipient).

A range of practical supports were also identified as essential components of care, including assistance with every day practical tasks such as errands, transportation to appointments, food banks, clothing exchange, and help around the house. Those with children requested assistance with child care, particularly when they were experiencing ill health.

> Yeah, [help with] grocery and cooking, because one day I had a high fever, I went shopping and [the support worker] looked at me and said "You're sick, what are you doing out?" I said I have nobody to look after my baby and I have to do grocery shopping because if I don't do it my baby will starve. I have to cook for her (Toronto care recipient).

> ...there was like a shuttle...some driver would come in a van and pick everybody up and take them all shopping...which I thought was cool because you can get everything done, you don't have to carry all this stuff home, and I was tired (Vancouver care recipient).

> ...someone to come, go shopping, or to bring you home, instead of struggling you know, that's the support I need (Toronto care recipient).

When care works well

Care recipients reported many instances of positive interactions when they accessed the health and social service system. These descriptions of good care reiterated the choices for ideal care described previously. When things went well they received care from well informed empathetic service providers who understood their needs, and in many instances the care provided was of a practical nature and involved assistance with basic living needs.

> So I called [my worker] ...and she brought me some food, she came and we went to take me to the daycare. To walk with me, to stay with me for a while, to talk with me, she asked me, should I do your dishes...and [she] decided to leave her name at the daycare so if I am sick she can pick up my daughter because I don't know anybody (Toronto care recipient).

> Well, like they don't judge you, but you've gotta be open. They help, they understand... they're like your best friends. That's what I like. They understand, even though they don't have it (Winnipeg care recipient).

> ...the [agency name] has been really good to me...if I cancel too many appointments...they'll actually be calling me and telling me I've got to get in there...they've been pretty well on top of my situation (Nova Scotia care recipient).

> They give me everything...I get food once a week...we have coffee, we talk to people there. And, people are understanding (Vancouver care recipient).

When care works well, how is it delivered?

Service providers across all sites were very clear on what was required to make services work effectively. First and foremost the service needed to be accessible. In circumstances where staff eliminated access barriers and allowed clients to get in the door on their own terms, services worked well. Providers either went out to clients or brought services in to suitable locations. Child care and transportation costs were covered, and in many cases a flexible, informal drop-in style approach was employed. Successful services were centralized, one-stop shopping approaches often offered collaboratively by a team of professionals or service agencies. Again, successful services frequently assisted clients in meeting their basic living needs such as food, clothing, housing, and financial support to cover basics.

> Some of the most powerful connections, seem to be, in those kind of informal, casual... you're having a cup of coffee or whatever...and a conversation starts and pretty soon it grows...you can see the kind of support that people get there and it's all an accident...it's just a forum, a safe forum for that kind of thing to happen (Winnipeg front line worker).

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Negative encounters with the system

When clients found accessible services or support, instances of negative encounters with staff were frequent. When asked why these negative interactions were occurring, two main themes arose from the care recipient responses. Clients felt the situations stemmed largely from discrimination related to their HIV status or the service provider having knowledge of their addiction. They also found care providers were ill informed about the needs of people living with HIV and appeared to lack understanding about the illness or affected populations. In some cases negative encounters were attributed to staff simply responding in an uncaring, disrespectful manner. In these cases care was attainable, but the delivery was such that clients left the agency feeling undeserving of support, thus depleting their willingness to access care again.

> I sat there in the waiting room for like 10 hours, and I had come in long before these other people. They double up on their gloves, they wear face masks, you know, they don't really want to touch your skin...if you're not knowledgeable about the disease, why are you in the profession you're in (Winnipeg care recipient)?

> ...when you go to talk to them, they go Humph!...you're a drug addict. You do drugs? They move further away (Vancouver care recipient).

> I realized when I go to the hospital just how behind they are with HIV...you know the mask, the gloves, the whole nine yards...I don't have leprosy, I'm tired of being treated that way...because, you know, I use drugs (Vancouver care recipient).

> ...it's hard you know...you have the disease and you're an addict you know, and you're trying to go out, and you don't realize how much pain you're in, and they [the doctors] don't know it because they don't have the disease, and you're trying to tell them and they won't give you nothing (Vancouver care recipient).

> People think it's a chronic illness now...and we don't suffer...but you tell somebody your HIV positive. Oh, that's just like diabetes now, so let's focus on something else that's worse (Nova Scotia care recipient).

> I wish social workers would, you know, wouldn't treat you like a leper every time when you walk in to pick up your cheque, or talk to them about what your financial needs are (Winnipeg care recipient).

Current work environment

Front line workers described many aspects of their work environment as unsatisfactory, citing gaps in their knowledge and training to support current client populations as the primary concern. Their proficiency around issues related to medical, legal, immigration, addictions, harm reduction and the overall life circumstances of different client groups was insufficient. This was compounded by an absence of resources to acquire needed training, and inadequate inter-agency collaboration which resulted in limited sharing of expertise across disciplines.

> And part of our education is keeping ourselves caught up. I guess reading is our responsibility. No one is helping us. We have to organize our own workshops or fund raise to go to care conferences...and it's so important to social workers, social services or assistance workers who are working with our patients, it's important that they know something about HIV/AIDS services, they haven't had an in-service for about 10 years (Winnipeg front line worker).

...we need to know about the legal matters because somebody's dealing with immigration, and you need to know about the medical stuff because they're deciding to go on medications and they're having problems...and it's really difficult because there are so many aspects of one person's life. But you might be the only person they trust. And you might not have those skills. Or might not know, and that means they're not getting it (Toronto front line worker).

I would say one of the gaps is educating people and resourcing people in order to be able to accomplish [care]...here's a scenario, I'm working behind the desk of a housing project, somebody comes in starts swearing at me, throwing stuff...[I say] Here's your eviction notice, threatening behavior...what I'm talking about is training the person to see that, when a person is angry and screaming at them, it's not about them (Vancouver front line worker).

I think that's something across the board, I mean that's something that needs to be in nursing schools, and in social work schools, and in doctor training...anyone that's working with this type of clientele...Yeah, and that it has that harm reduction component (Vancouver front line worker).

Front line providers described services as fragmented, with unsuitable hours and a lack of vision or long term planning. In their own day to day interactions, they had little time to assist clients with their issues or establish the human connection so essential to good client-worker interaction.

What happens is everything gets split off and divided, so you have your addiction, your HIV...you have your food needs, you have housing needs, and all that gets spread all over the map (Vancouver front line worker).

We're not only talking dual anymore, we've got triple and quadruple issues...and we've got these type of individuals that need our help. That being said, we've got a system [where]...we have funding for a head that's called mental health, a head that's called addiction, and a head that's called HIV...and then we need to bounce the patient back and forth...[and then] we talk about engaging the client, case managing a client and working within a more global approach, holistic approach...[well] we've got a problem (Toronto front line worker).

One more thing is the absence of communication between agencies and services...I still see gaps where people aren't communicating or referrals aren't happening...I guess just people working together better, that is a very simple thing (Nova Scotia front line worker).

The fact is that people...often fall through the cracks. Why are there cracks? Because the system is piecemeal...we think today that if we get a piece of paper that people understand it, but we're taking away the human contact along the way, in the name of efficiency and cost cutting (Toronto front line worker).

The health system is in an uproar and it's just a processing of people really...the quicker the better, and these people need a little more time, more quality time (Toronto front line worker).

Policy barriers

Across all sites, front line workers identified service provision policies and guidelines that were not flexible enough to accommodate the diverse needs or situations faced by current client populations as a barrier to care. Policies pertaining to a wide range of issues including access to medications, social assistance, home care, housing, and the scheduling of appointments were all found to be prohibitive. Specific to the IDU population,

policy related to pain prescription, and palliative or transitional care were fraught with obstacles. Methadone maintenance programs, designed specially for the IDU population, had operational guidelines that created serious difficulties for clients wishing to enter programs.

> I think something that also doesn't work are systems that are very rigid and aren't open to people coming late, or having bad hours...I could see that would be a real barrier with people coming in and having always to be on time (Toronto front line worker).

> [If I have a patient who has AIDS] I can get them housed rather quickly...the flip side is if they're only HIV I can get them nothing. So you'll get people who are HIV positive...but don't fit the criteria of AIDS-defined and they have no special housing whatsoever (Toronto front line worker).

> My program is a B.C. wide program, so it's not just for IDU...so that the rules of that system are more for a stable person who will be home...if you're not home 3 times, you're not visited anymore. (Vancouver front line worker).

> [The] more traditional health care policies [are not addressing]...the more controversial things, that people don't like to hear, which is, sometimes you can't do anything, or sometimes you do just have to leave a person alone, or sometimes you do have to watch something be really ugly, and messy and hurt, and people have a lot of pain, and there aren't neat solutions...people want the simple solutions, so policies tend to be designed to fit the simplest case scenario, rather than taking on some of the challenging ethical issues (Vancouver front line worker).

> People do use in all sorts of unsafe places because they're not allowed to use where they live, so they're marginalised into alleys or unsafe living conditions, and people are told not to call 911 when friends of theirs overdose because...they'll get kicked out...like people get found dead in shower stalls or dumpsters, because even social housing traditionally has not been inclusive of this population (Vancouver front line worker).

Table 5: Work Environment Barriers to Care Provision

Front line providers face barriers to care provision when:

> they lack opportunities for training to support current client populations
> they lack resources to access training and education
> agencies do not work collaboratively to provide a continuum of care
> they do not have time to build good client-worker relationships
> they are forced to work within overly restrictive service policies that are inflexible and not well suited to current client populations

Informal care provision

Both care recipients and front line providers recognized the integral role that peers, friends and family members play in the system of HIV/AIDS care. Given this reliance on informal networks for care and support, the research team felt an examination of the status of informal care provision was pertinent to our understanding of the community's capacity to support current client populations. For many individuals living with chronic illnesses, informally-provided care is a key variable in determining whether or not they can remain in the home setting. The tendency has been to use informal caregivers as much as possible in these situations with minimal consideration for the caregivers contribution of time and energy (MacLean, et al., 1998; Stajduhar, 1997; 1998).

What is informal care?

Participants in both the care recipient and informal care provider groups were asked to describe the activities they engage in when providing care and support for a friend or family member with HIV/AIDS. Responses from both groups mirrored one another with companionship and support for the care recipient emerging as the predominant theme. Informal care givers also provided support through practical tasks (i.e., assistance getting food, sharing shelter, help with errands, transportation), information sharing, medication support, and advocating on behalf of their loved ones.

> I go to his doctor's appointments with him...I prefer to go because he doesn't ask the proper questions...just recently he started a new cocktail...I wanted to know what the side effects were and so on. Because he would just say "Ok, just give it to me" sort of thing (Toronto informal care provider).

> At night, if he can't sleep at night, he calls and I sit up and talk to him on the phone... sometimes until 3, 4 o'clock in the morning (Toronto informal care provider).

> I always let people know that if they don't have a place to stay that they can always come over and sleep on my couch and watch TV, and if there's food in the cupboard, they can help themselves (Vancouver informal care provider).

> I've been a care provider...for over the last 3 to 5 years. It's a variety of girls I help out on the street, that literally have no one including themselves to look after themselves...I just do what I can to help them because I've been where they are...and I do what I can to help them through information, just somebody to talk to, clothing...clean drug usage (Vancouver informal care provider).

> I do errands, local errands, running around, cooking meals, freezing stuff for people who cannot make it themselves. Getting them out to movies, or going to get an ice cream, something kind of just to get them out of the house (Nova Scotia care recipient).

> He [informal care provider] was a big support to me...he talked about his struggle and I was down that day and I talked about mine [he gave me a ride home]...By the time I got home...we had stitches laughing at the whole thing. You know laughing about what we were talking about, which was good, we came up laughing instead of crying (Nova Scotia care recipient).

...you have a population of people that you just accept regardless, and then you attempt to bring in supports and services, of whatever nature, including food, and attempt to find funding to do whatever you can to basically improve quality of life where people are, in situ, not expecting them to go out...all that I have ever seen happen is people feel more empowered because they feel respected and they're getting a little bit more of what they need, where they need it and in a way that they can accept it. And then they can if they feel like it, venture beyond, where before they were kind of left to rot in a hotel room (Vancouver front line worker).

What works is like finally after I don't know how many friggin years of fighting about it, we finally got nurses in house [in the agency] who are actually providing flexible service on the basis of being around all the time and being able to develop relationships...being able to access people on their terms, when they want it, in the way they want it...and being able to be refused at their leisure, but knowing that there'll be someone the next day to try them maybe when they feel like it ...basically that's the only way it can work...to have huge flexibility, huge tolerance, and just adapt it, adapt, adapt (Vancouver front line worker).

Another thing that makes health care better is one-stop shopping, meaning having as much stuff in one building as you could possibly get. Also I find a lot of stuff is helpful for people who are impoverished ...stuff could mean clothing, tokens...because they're going to come back and visit me and that is effective as well (Toronto front line worker).

In my work at the [clinic]...what I've been doing is I've been inviting the people from other agencies to come there to the support group meetings...[the clients wouldn't go to other agencies] but they came to my support group and the [peer educator] was there and they asked him all the questions and apparently some of those women are convinced because now that they've got a face they're comfortable to go...so now I'm looking at how I can create keyholes into services that exist, as opposed to just "Oh, I can't go there" (Toronto front line worker).

When client-worker interaction was successful, care providers described their approach as one of acceptance, where they met the client "where they were at" and remained supportive and non-judgmental regardless of circumstances. Staff also reported having the time to establish rapport with the client which in turn encouraged a trusting client-worker relationship.

I also find too that on an individual basis, that when you see your client, you focus on the person and not focus on the disease...and you have that trust almost immediately (Winnipeg front line worker).

I think that there's ways that you can encourage people's strengths and hopefully see them...as beautiful people regardless of the drug use...it's not the drug use that defines the person (Vancouver front line worker).

...we talk a lot about meeting people where they're at, to me it means being able to sit down and be very very honest and open...I allow them to take the lead...for me for instance to enter into what is the "norm" in their world, rather than in some way expecting that they're going to come closer to me (Vancouver front line worker).

Some of our new members especially, need just to know that they're welcome and that they are understood and that they are not alone...it means so much to them (Nova Scotia front line worker).

It's more that you're developing relationships over time...and with this population it is essential, and if you can't do that, you can't do anything else (Vancouver front line worker).

> *It's more like the old fashioned social work set up...establishing good therapeutic rapport, and that takes a lot of time, a lot of patience...and chatting about nothing related to anything (Toronto front line worker).*

In many cases, effective programs had some component of peer involvement, where peers were available informally for social support, peer support groups or peer education sessions.

> *It's just amazing, you get three or four [HIV positive] people together, and someone comes in for a drink and says "How are you doing?" and there's a whole bunch of ears right there...it's just amazing the conversations that happen (Winnipeg front line worker).*

> *The [cooking program] has been going well. Women with HIV here like the social aspect of it, and the cooking, and deciding what to cook and doing it together. They also like the fact that we don't focus on their illness...we just focus on the social dimension (Toronto front line worker).*

> *I believe a success was...[the peer education workshops] and the reason I said it worked well is because I've had so many people come up to me and say they'd really like to do that workshop again (Nova Scotia front line worker).*

Table 3 : Components of Successful Care

Successful care involves:
>   support from peers
>   well informed care providers who are compassionate, knowledgeable and understanding
>   practical support in meeting basic daily living needs
>   accessible services where clients are accepted and treated with respect
>   services offered collaboratively by a range of providers in a centralized "one-stop" shopping model
>   workers with time to listen and establish rapport with clients

Barriers to Care and Support

What stands in the way of care?
Care recipients described a variety of access barriers to "getting in the door" of health and social service agencies. Required waiting time for needed services or dealing with bureaucratic red tape and application procedures that were oppressively complex or slow were frequently cited as barriers to care. In turn, the need to travel when specific services were unavailable locally or travel within cities to various service locations, combined with a lack of information about where and how to access services presented barriers.

> *It is bad enough getting the run around in the medical. But when you are worried about where you're going to live and what you're going to pay for food and medication... (Nova Scotia care recipient).*

> *Now that I want it [counseling] I really can't find it...it says 3 months from now it's so booked up...like what's my attitude gonna be in 3 months how am I going to feel about counseling (Vancouver care recipient).*

> *Sometimes the assistance takes so long...you end up getting sicker and sicker, worse than when you first called (Toronto care recipient).*

> *Yeah, having to feel your way in the dark...it is really difficult...bureaucracy (Vancouver care recipient).*

> *I don't know anything about what I'm eligible for. They [the service provider] don't tell you that type of thing (Winnipeg care recipient).*

In addition to facing access barriers to care, clients repeatedly found their own personal financial situation did not allow them to pay for such basic necessities as a phone, transportation to appointments, high protein foods or vitamins, medications, or clothing for themselves or their children. The cost of housing was frequently cited as an expense that depleted monthly budgets. Compounding the issue further were numerous barriers to employment. Clients had difficulties accessing job training, feared potential loss of benefits, and had no opportunity to job share or work when health permitted. Care recipients focused tremendous energy on simply meeting their basic needs and coping with the stress that stems from negotiating life as a low income person.

> *The apartments they are so expensive and the daycare for my daughter is too high (Toronto care recipient).*

> *It's too much. So let's say you get 4 prescriptions at $7 each that's $28. And then how much do they want for the HIV medications, and that dispensing fee...by the time you do the books at the end of the day you're in the hole (Nova Scotia care recipient).*

> *Well I just find that ridiculous, that's impossible to live at, even for a normal person, at $600 per month...that can't get me where I want to go with food and everything like that, the vitamins to stay healthy (Nova Scotia care recipient).*

> *But you gotta make sure the money you get stretches, you have two kids going to high school, have to get lunch, have to get food, you have to get shoes, and I be living so fast sometimes I find myself walking around like a refugee (Toronto care recipient).*

*If one does decide to go back to work, or go back to school and get a degree, or learn a
trade, you know, build a career for themselves, but there's only one thing that concerns
me..is how am I going to be able to pay for my medication (Nova Scotia care recipient)?*

Table 4 : Client Access Barriers to Care

Clients have difficulty with access when:

> waiting lists or oppressive bureaucratic procedures cause delays
> they must travel outside their community or between agencies for services
> they lack information about existing services
> their personal financial situation is so limiting they cannot meet basic living needs

Gaps in care

Both front line providers and care recipients noted multiple gaps in the system of care. For
workers, knowing that services were not available to support those in need of basic
necessities for living (i.e., financial assistance for travel to appointments, food,
supplements, medications) was a constant source of frustration. The shortage of decent
affordable housing or complete lack of supportive housing suited to the specific needs of
each population was also identified as a serious gap in the system.

*We have a woman who really wants to make a break from street life, drugs, the alcohol, you
know, and she can't...the location of where they can get an apartment is so restricted
[they're stuck] (Winnipeg front line worker).*

*[We need] treatment and recovery programs that aren't...not strictly abstinence-based...[that]
don't necessarily make somebody homeless if they fail in the first two weeks. So, I mean like
more realistic, long-term recovery, supported housing that's based on reality (Vancouver
front line worker).*

Care recipients reported a strong desire for increased peer and family support. In many
cases family members did not live in the vicinity, or clients reported tenuous relationships
with their parents and siblings. Many had no opportunity to link with support or peer
groups and were afraid to reach out to others for fear of stigmatization.

*I think this is for women and most of us are similar, if we can have like seven people get
together and talk...it's not easy. Sometimes you are so lonely you don't know what to do, you
just sleep at home, eating and that, you know (Toronto care recipient).*

*Because there is nobody to talk with you and nobody to care about you when you're sick
and when your down, nobody cares for you [like the family] (Toronto care recipient).*

*When I told my family, they hung up on me. They told me they specifically didn't want me to
come and stay there because they didn't want me around the children (Winnipeg care
recipient).*

Clients regularly found the services they required were simply not available, with notable
gaps in the availability of support workers with HIV-specific knowledge, counseling and
advocacy skills. More detailed descriptions of site and population-specific gaps in services
and support as identified by care recipients and front line workers are provided in the
community reports available on the CAS web site at *<www.cdnaids.ca>*.

Table 6: Components of Informal Care

Informal care providers give care and support by:
>   providing companionship and taking time to listen and support the care recipient
>   providing practical assistance with everyday tasks
>   advocating for their loved one when negotiating care, treatment, and support
>   providing support around medication issues
>   sharing information about HIV/AIDS services

What stands in the way of informal care

Informal care providers faced barriers similar to those of other participant groups. When they experienced difficulties it was due to the stigma associated with HIV or drug addiction, financial barriers to cover the cost of basic needs for the care recipient, or the frustration of complex bureaucratic procedures. Many informal care providers faced limitations when providing care due to their own personal health status.

For me I think the time I find it hard, I find it hard if I am sick...I'd feel like giving up sometimes. But then if I do that, nobody would be there (Winnipeg informal care provider).

Once you're health is no good, you know for yourself, then you cannot care for the person...because you're not able to provide what they need (Nova Scotia informal care provider).

Yeah, sometimes...my blood pressure...sometimes everything is stressed and everything come down on me and I end up in the hospital all the time (Toronto informal care provider).

Personal characteristics of informal care providers

Particularly striking were the personal characteristics of informal care providers. In most cases care givers provided support alone and felt unsupported in their role. Care providers were self-educated about HIV and had accessed information by conducting their own research and maintaining close contact with health care professionals. Similar to front line providers, informal care givers felt they would benefit from additional training and expressed a strong need for up-to-date information on medications and available services. One of the most distinct themes arising from the informal care provider discussions were the descriptions of personal stress and exhaustion that resulted from their care giving responsibilities.

...when you have someone who is sort of in control of themselves, but is in desperate need of support systems that aren't there...you're it...and sometimes I feel really helpless. And, I am scared, sometimes I just want to avoid him, and I spend the whole night just feeling absolutely terrible because I know he's out there sick and hungry...(Vancouver informal care provider).

There were times when you know, you'd look around you and you'd say "God, what am I doing here?" Like, you felt like you walked into somebody else's nightmare (Nova Scotia informal care provider).

If I was in his position, I would want someone around me all the time too...but I'm thinking it's wearing me out...it played flip flop with my mind...you know, I want to be there, but I am tired, I am worn out, and I am getting depressed (Toronto informal care provider).

[My loved one] is a long-term, hardcore drug user, he's on the streets...right at the moment he's in jail...I have to say it's somewhat of a relief because it's somewhat of a respite from the general chaos that follows him around (Vancouver informal care provider).

Table 7: Characteristics of Informal Care Providers

Informal care providers:

> are experiencing stress and ill health as a result of their care giving
> provide care in isolation
> would like to receive more training in HIV/AIDS care provision
> are not receiving the support they need in their role as care provider
> are self-educated about HIV/AIDS
> show tremendous dedication

What steps can be taken to enhance care provision?

Towards the completion of each focus group, participants were asked to comment on how they would improve HIV/AIDS care and support if they had the opportunity to develop services with unrestricted resources. Strategies common across all research sites are outlined below and more site-specific strategies are described in the community reports available at <*www.cdnaids.ca*>.

Improved access and collaboration

Front line workers clearly identified the need to decrease access barriers to services. Strategies included broadening the criteria or guidelines of programs to be more inclusive of under served populations, and the development of population-specific programming. Improved access to HIV medications both within and across provinces, enhanced outreach, and the centralizing of services were frequently recommended. Workers also recognized the need to improve inter-agency collaboration with a focus on providing more comprehensive services.

> *I think outreach is important...I think getting out where they are is very important. [Outreach workers] are the glue to street-involved clients and that way you can build some trusting relationships with users...we need to put more into outreach...both money and human resources (Winnipeg front line worker).*

> *Well it's not their service, they didn't own it in the first place, it is usually designed for a different population...you're talking about adapting something that was intended to service a different population. It's like changing a leopard's spots...you need to design something specifically to meet the needs of a marginalised group that already have so much self-hatred and feel unworthy and don't access treatment of any kind ever. OK, give them the parameters of who this population are and what is realistic. How can we do things in a way that's going to work... [instead of] let's try and fit this group into this service. If we stretch it in this direction, maybe we can shove them in...it hasn't worked, it's not working (Vancouver front line worker).*

> *...in my wish list...a centralized drug depot with some way of accessing medications, and centralization of knowledge, everyone knows what clinical trials are available...and how do we make sure all of us know about where to go and who to call...the communication amongst agencies, connections are really important (Toronto front line worker).*

> *I really am one who wants to see a system that works hand-in-hand, and I know that's a very huge wish because there's so many variables that impede that...we could be building instead of fragmented, everybody grabbing for their two cents of work here and there...we could also share what we're doing and learn together (Toronto front line worker).*

Education

All participant groups identified enhanced educational initiatives as a priority. Front line workers emphasized the need for education of funders and providers across all health and social service sectors regarding changes that have occurred in the context of HIV/AIDS care.

> *I think education and awareness have to be brought to the table first. There are a lot of people out there working with agencies that have no awareness of resources for education in HIV/AIDS. Some of them, they shun them [clients] away...in my mind, these people who*

are professionals, counselors, they should have more decency, more information and better attitudes about HIV/AIDS (Winnipeg front line worker).

I think there needs to be more public awareness about what's going on...I think there's a misconception out there that people's HIV needs are getting met...people think because they are getting their drugs that their lives are fine. But I don't think people are aware of the realities...the economic and social realities of it (Nova Scotia front line worker).

[I think] just the education at the funder level, to understand the nature of the change in the disease...there are times when we actually need more staffing, but because...long-term care isn't aware of this added piece now, to who we're housing [more clients with addiction and mental health issues]...they're not motivated to make this extra funding...they could step up in terms of understanding the nature of the change (Toronto front line worker).

Now that the illness has changed the systems haven't changed with it. So we still have old systems in place where people are dying. [Clients are saying] "We need some stuff to help us, to help to live effectively." (Toronto front line worker)

From the care recipient perspective, the need for enhanced education was directed at health and social service professionals, and also included peer education for the newly infected, and prevention education for the general public.

One of the things that I would focus on would be, make it part, like a more intensive curriculum for health care professionals...that are going to school...[and the] social aspect to, make sure they are aware of what's going on as well as what are the issues surrounding it (Nova Scotia care recipient).

What I would do is, I would have...older people who have Hep C, HIV or AIDS, that have been living for a long time, and let the younger people know, people who just got it...what they can expect. Why they feel, what they feel, what goes around. What it's like down the road, because, you know, I'm sure that if we all knew that...we can live a good life...then we're going to try to work hard. Then we have a reason to get up in the morning (Vancouver care recipient).

Informal care providers recommended training programs for all those involved in the provision of care, including themselves, and noted the importance of learning first hand from individuals living with HIV/AIDS.

I think that more workshops held by [persons living with HIV] to care givers because nobody really knows what they're going through unless you're going through it. [People living with HIV] tell their stories and telling what they need to whomever is providing the care would be helpful...be it to volunteer groups or home care workers or whatever (Nova Scotia informal care provider).

Supporting informal care networks

Informal care providers also identified strategies to address the financial burden of care provision, and the need for counseling support for informal care networks.

Well, I think, you know, bus passes for people that provide support...to get to the hospital...it all comes down to money as usual but yeah, money would be nice to have there just in case you need gas to get this person somewhere or you know...Sinutab or something...so that you don't have to take it out of your own pocket...I'm sure each and everyone of you has done it, has taken $20 or $30 out of their own pocket (Nova Scotia informal care provider).

[I think] just even a debriefing session [with other informal care providers] on a regular basis where we can say "Well this is what I came up against"...I found myself in instances where I really truly did not know what to do and then I'd drop it by someone else that I trust, which is a critical element too, and [it would] open up a barrage of avenues to approach it (Nova Scotia informal care provider).

Working from the ground up

Finally, front line workers expressed frustration with policies and guidelines around funding and criteria for programming that appeared to be developed in the absence of stakeholder consultation. They emphasized the importance of decision makers consulting with clients and front line workers prior to establishing eligibility rules or policies for care provision to under-served populations. This approach would ensure that workers were informed of upcoming changes to funding criteria, and would assist in planning to maintain longer term programming.

How can I provide the best care and yet still really listen to what that person wished? And, I think that is what needs to happen to policy makers, they need to listen to the injection drug user. They need to listen to the staff that are working with injection drug users...they need to listen to the health care providers working with those people, because it's not good, what's happening now (Vancouver front line care provider).

I know if I was in charge of any of these shifts or changes in policies or rules...that directly impact people with HIV and AIDS, I would basically have something in place...to prepare for the impact...when I see for example, the social assistance, the way rates are going down. What I am envisioning is, is that it's like sending somebody out in the rain without a raincoat, you know what I mean (Nova Scotia front line care provider).

Policy and Program Implications

While the findings from this research cite numerous cases of exemplary care, where clients accessed the system and were met by a well-informed team of compassionate professionals, these instances were countered by an equal number of examples of inappropriate care. Care where services were either inaccessible or incompatible with client populations seeking support, or where clients were treated in a disrespectful, discriminatory manner. The following discussion will focus on the policy and program implications as they relate to the major findings arising from the analysis. Some recommendations identified here can be incorporated into programming with relative ease, while others require either substantial reinvestment of dollars or new funding initiatives along with longer term program planning. The recommendations are grounded in our findings and reflect the ways those directly involved in HIV/AIDS care and support feel service delivery can be enhanced.

Supporting collaborative initiatives

There is no doubt the way HIV/AIDS care and support services are organized must change in order to meet the needs of under-served populations. Establishing an effective service delivery response involves providing multiple services to meet multiple needs, and building partnerships and collaborative linkages with all stakeholders whose mandate is to assist those who are currently under-served.

> In order to utilize existing resources effectively and develop collaborative efforts, community-based organizations should engage in an open dialogue with all local health and social service agencies working with or likely to encounter the more vulnerable populations. In many cases agencies may be well placed to extend services to one or more of the existing populations, however, there must be a commitment to explore the degree to which existing infrastructures are a best fit and where change must occur.

> Funding should be made available to support strategic partnership building and HIV/AIDS support and service coalitions that demonstrate how a multi-disciplinary response will provide a comprehensive continuum of services to under-served populations.

> Particular attention should be paid to coalitions formed to address the issue of poverty. Living in poverty curtails the ability of those affected by HIV/AIDS to preserve or improve their health status, and frequently increases risk behaviour. Unless underlying issues such as poverty are addressed, it will not be possible to enhance the system of care provision for persons living with HIV/AIDS.

> Ultimately change must occur at the systems level. Therefore it is essential to identify and document models of effective cross-sectoral care provision, where existing health and social services have been integrated and effective resource and information sharing is occurring.

Innovative models of care and support provision

New models and methods are required to deliver services appropriately with initiatives that move beyond the status quo to more creative, flexible, integrated solutions specifically designed to meet the needs of under served populations.

> Many innovative models of HIV/AIDS care and support currently exist, yet there has been little documentation to describe program successes, challenges and constraints, or to identify best practices arising from these approaches. Funding should be made available to gather evidence and conduct case studies on existing innovative models of HIV/AIDS care and support.

> Pilot projects on enhanced models of HIV/AIDS care provision should be solicited from agencies that have successfully formed HIV/AIDS support and service coalitions (as described above). The models must be developed with ongoing evaluation tools to examine the efficiency and effectiveness of service delivery. To the extent possible, all models and services should embrace the principles of harm reduction. These principles are grounded in respect for client choice and self-determination, and commitment to meet clients where they are at in their lives, allowing them to define their needs and goals, rather than imposing externally determined goals or requirements to receive care.

> Pilot projects should be solicited with particular attention to models of care that assist clients with housing. Secure affordable housing, well-suited to client needs, was identified as an urgent need and is a pivotal first step in establishing a stable environment and moving towards improved health and well-being. Pilot projects with a strong peer orientation (i.e., peers as community educators, trainers and support workers) should also be solicited.

Education and training initiatives

Opportunities for health and social service providers to be sensitized to issues related to HIV/AIDS, homelessness, addictions, poverty, and the accompanying care and support strategies that work effectively with these client populations need to be provided.

> Funding should be provided to support cross-sectoral training initiatives that allow for reciprocal learning across a range of health and social service issues and involve the full range of service providers (i.e., planners, policy makers, and front line workers) within each sector.

> A profile of best practice in successful care provision for current HIV/AIDS populations should be compiled. This documentation would be used as a standard learning protocol and educational tool for colleges and universities training health and social service providers and for staff training in health and social service sectors.

> At the program level agencies should be encouraged to work with existing resources on successful care and best practice in HIV/AIDS care provision, updating information where necessary, and disseminating broadly across sectors.

> Emphasis should be placed on peers as educators. Where possible, peer training and peer education programs should be employed with both formal and informal care providers and persons living with HIV/AIDS (i.e., experienced nurses supporting those who are new to the profession; those living with HIV/AIDS receive training to support the newly infected).

Developing policy from the ground up

Restrictive policies occur at the program and funding level, and within all levels of government. Front line workers face barriers providing care when they are forced to work within rigid policy structures that are not well suited to current client populations.

> Agencies should ensure that service policies promote rather than threaten access to care and support. At the community level, policies that disregard personal circumstances of client populations (i.e., no phone to call ahead or cancel appointments, no money for transportation, no place to call home) create barriers to care. Community based agencies must avoid blanket penalties applied to all regardless of circumstances.

> There should be consistent and effective consultation and collaboration between municipal and provincial government, different government departments, and between service providers, planners and persons living with HIV/AIDS during policy development. Public health and social service workers on the front lines must be involved at the planning stage rather than expending considerable resources attempting to ameliorate the impact of policy decisions after the fact.

Supporting informal care networks

Informal caregivers provide a wide range of skills, devote an enormous portion of their lives to care-giving, and are a critical link in the delivery of health care to persons living with HIV/AIDS in the community. This heavy reliance on family and friends, without acknowledging the health consequences or social and economic costs to them, overlooks an important component of care.

> Support for informal care providers is a major unresolved public policy issue that must be addressed. Resources should be directed towards accessible respite programs, skills training in HIV/AIDS care and advocacy, as well as counselling and peer support groups for care givers.

> Evidence from this research reveals that despite improvements in the health status of many persons living with HIV/AIDS, informal care providers continue to play a critical role in providing support. Community agencies must either renew, maintain or develop initiatives that reach out to informal care providers, and where possible include them as active participants in programming.

It is essential to recognize the changes that have occurred within HIV/AIDS care and adapt to present needs. The challenge ahead is to understand how to provide system-wide care and support in a manner that is both respectful and well suited to the ever

changing context of the HIV/AIDS epidemic. While care provision appears to be improving for certain under-served populations, for the most part front line workers struggle as they attempt to secure support for socially and economically marginalized client groups. It is imperative that HIV/AIDS services be developed in response to the nature of the population affected and to that population's unique set of service needs.

Next Steps

To date, findings from the research have been presented at the annual Canadian Association for HIV Research (CAHR) conferences in 2000 and 2002; the 3rd Canadian HIV/AIDS Skills Building Symposium 2001; the 2002 World AIDS Conference in Barcelona; the First International Conference On Inner City Health 2002; and the Ontario HIV Treatment Network Research Day 2002. The research team also made a presentation at the recent Community-Based Research Satellite Symposium at CAHR 2002. In total 10 conference presentations on the research findings have been made. It is expected that members of the research team will submit papers for journal publication based on the research.

Findings from the study will be distributed to all CAS member groups, individuals, foundations, and bodies identified as key stakeholders throughout the project. Dissemination will be facilitated through CAS's quarterly newsletter, monthly mail-outs, the CAS web site, and email listserves to the CAS network of over 100 member groups. CAS will be responsible for ensuring follow-up to recommendations from the research through ongoing core activities during 2002/2003.

The community reports available at <*www.cdnaids.*>, present local data in an accessible plain language format that clearly outline implications for community program development.

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