

Executive Summary

The face of HIV/AIDS is changing. Some of the fastest growing HIV infection rates in Canada are among women, people from HIV-endemic regions, and intravenous drug users. In response to these trends, AIDS service organizations (ASOs) are working towards directing their programs and services to address the needs of these emerging and, often, underserved populations.

The Casey House Access Project, a community-based action research project, is one initiative that explored the challenges faced by these groups. Specifically, the Project sought to identify barriers that women, people from HIV-endemic regions (including sub-Saharan Africa and the Caribbean), and street involved and homeless people experience when accessing HIV/AIDS services. Because of the focus on action in the community-based model of research and because of a commitment to improving outcomes for communities that participated in all phases of the research process, findings of the research were meant to serve as a catalyst for change at Casey House: organizational, programmatic, and informational change.

Methodology

In the initial phase of the Project, a qualitative approach to understanding barriers was adopted. Barriers were identified through in-depth interviews with twenty-two (22) service providers representing fourteen (14) different organizations and twenty-seven (27) people living with HIV/AIDS (PHAs). Both service providers and PHAs were selected to represent emerging HIV-infected populations.

Results

Collaborating with relevant community-based organizations to access underserved PHAs was critical to the success of this Project. The need for accountability, in terms of both processes and outcomes, to the communities being investigated was particularly relevant amongst often over-researched service providers and PHAs.

A range of barriers were identified including both systemic barriers (such as lack of access to affordable housing, drug treatments, and employment opportunities) through to programmatic and organizational barriers (such as lack of services for families with affected and/or infected children). Barriers identified were often relevant across populations (such as lack of affordable housing, for example) yet there were barriers that were particularly unique to some communities (such as lack of access to linguistically and culturally appropriate information and services).

Recommendations

Based on the barriers identified by service users and service providers, the Project developed short-term and long-term recommendations for increasing access to Casey House services, programs and treatment. A community advisory committee with representation of both service providers and PHAs was actively involved in this phase and all phases of the Project.

Short-term recommendations adopted by Casey House include the following:

- Implement interpretation services for clients
- Establish services for child care provision for Casey House programs
- Continue to share Casey House's supportive and palliative care expertise with community organizations that serve target populations
- Provide ongoing education and training opportunities in culturally competent service delivery for staff and volunteers at Casey House
- Provide direct communications about Casey House to community organizations serving target populations
- Develop a Community-Based Research Network with organizations working on similar initiatives
- Maintain the Access Project Community Advisory Committee
- Disseminate barriers to accessing services and recommendations implemented

Long-term recommendations include:

- Develop staff at Casey House to become organizational resources with areas of expertise related to target populations
- Integrate cultural competency as a required core competency for all Casey House staff, volunteers and Board members
- Ensure Casey House's Mission Statement and Philosophy of Care are reflected in programs and services
- Revise client database, documentation and evaluation tools to reflect specific needs of target populations
- Create a community development/community partnership position
- Incorporate community resource education in orientation for staff, volunteers, and Board members
- Ensure staff, volunteers and Board members reflect populations living with HIV/AIDS

Outcomes

Community-based research, by definition, focuses as much on the process of doing research as on its tangible outcomes. During the course of the Access Project, Casey House:

- Developed partnerships with several community organizations that serve target populations
- Received a number of client referrals from community organizations that were involved with the Project
- Focused its efforts on working towards accessibility for new populations
- Learned about the barriers experienced by the target populations when trying to access services, and
- Developed a course of action and assigned areas of responsibility to follow up the recommendations of the Project.

Finally, the broad dissemination of this final report is critical so that the Access Project may serve as a model for other organizations and groups. The information collected and the recommendations adopted by Casey House all point to further areas for improvements in program, service and treatment delivery.

List of Acronyms

ACHES	African Community Health Services
ACT	AIDS Committee of Toronto
AIDS	Acquired Immuno Deficiency Syndrome
APAA	Africans in Partnership Against AIDS
ASAP	Alliance for South Asian AIDS Prevention
ASO	AIDS Service Organizations
Black CAP	Black Coalition for AIDS Prevention
CPP	Canada Pension Plan
CAC	Community Advisory Committee
CBR	Community-based research
CHC	Community Health Centre
FBA	Family Benefits Allowance (now ODSP)
GTA	Greater Toronto Area
HALCO	HIV/AIDS Legal Clinic (Ontario)
HIV	Human Immuno Deficiency Virus
IDU	Injection Drug Use
LCDC	Laboratory Centre for Disease Control, Health Canada
ODSP	Ontario Disability Support Program
OHIP	Ontario Health Insurance Program
OHTN	Ontario HIV Treatment Network
OW	Ontario Works
PHA	People living with HIV/AIDS
Toronto PWA	Toronto People with AIDS Foundation
TG/TS	Transgendered/transsexual

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1.0 Introduction

1.1 The Changing Face of HIV/AIDS in Canada

The impact of the HIV epidemic on the most vulnerable members of society is mounting. Some of the fastest growing HIV infection rates in Canada are among women, people from HIV-endemic regions¹, and injection drug users (IDUs). According to the most recent *HIV Epi Updates* (Health Canada, May 2001), estimates illustrate the changing face of the Canadian HIV epidemic. In 2000, women accounted for 23.9% of all positive HIV reports up from 9.9% before 1995. For women, the primary exposure categories associated with newly diagnosed HIV infection were heterosexual contact (55.9%) and IDU (38.5%).

The *HIV/AIDS Epi Updates* also demonstrate a steady increase over time in the proportion of adult AIDS cases attributed to IDU, peaking at over 21% in 1997-2000. Although the national estimates for 1999 show a slight drop in the number of new infections among IDUs, HIV/AIDS among IDUs in Canada continues to be a critical problem. Further, women, street youth and Aboriginal groups are particularly at risk for HIV infection through injection drug use.

The extent of the HIV infection rate among people living in Ontario who were born in sub-Saharan Africa or the Caribbean (HIV-endemic regions) was described by University of Toronto epidemiologists in the 1999 document, *The HIV/AIDS Epidemic Among Persons from HIV-Endemic Countries in Ontario, 1981-98: Situation Report* (Remis and Whittingham, 1999). Remis and Whittingham found that people from HIV-endemic regions accounted for an increasing proportion of cases in Ontario; while these populations represented about 3.1% of the population of Ontario, they were over-represented, at 17%, in terms of AIDS cases in 1998. Further, the majority of HIV-positive women, in a database of HIV-infected mothers and their infants, were born in sub-Saharan Africa or the Caribbean. At the time of this study, Toronto was resident to 75% of immigrants residing in Ontario from sub-Saharan Africa and to 85% of immigrants residing in Ontario from the Caribbean. As such, these populations are of critical importance to organizations that work in the Greater Toronto Area (GTA).

While the epidemiological data underscore the fact that HIV/AIDS has become another symptom of the social, economic and cultural inequities that exist in Canada, they also provide critical evidence for the planning and evaluation of HIV prevention, care and support programs. In response to these growing rates of infection among vulnerable populations, AIDS service organizations (ASOs) in the GTA have been compelled to work towards delivering more effective programs, services and treatment – ones that will address the unique needs of these emerging and, often, underserved populations.

1.2 Strategic Directions at Casey House

Casey House Hospice is an organization that is “committed to providing exceptional palliative and supportive care for people living with HIV/AIDS (Casey House Mission Statement).” In 1999, Casey House engaged in a comprehensive strategic planning

¹ The term “HIV-endemic regions” refers to regions in which the prevalence of HIV infection is greater than 1%.

process. This process involved significant community participation including a *Community Consultation Needs Assessment* (Joan Anderson, 1999) and a *Stakeholder Scan* (Pitters Associates, 1999).

The Casey House *Stakeholder Scan* (Pitters Associates, 1999) examined the trends that study participants anticipated over the next two years that would impact Casey House and other AIDS service organizations. This stakeholder scan highlighted changes in not only the disease itself but the people affected by HIV/AIDS and how care is delivered. Participants noted that an increasing number of people from diverse and, often vulnerable, groups are affected by the epidemic (including, for example, immigrants, refugees, women, and homeless people). Participants also noted that these shifting demographics require that the previous focus on medical issues must broaden to embody the increasingly complex social issues faced by these populations.

To complement the *Stakeholder Scan*, the *Community Consultation Needs Assessment* (Joan Anderson, 1999) was conducted. This consultation focused on hearing from people living with HIV/AIDS as well as from their frontline community service providers. This assessment found that there was a need to respond to diverse communities (including, for example, women, families, ethnocultural communities, people living in poverty, homeless people, and immigrants) by expanding outreach and by developing a service delivery model that integrates people from diverse communities.

All of these consultations pointed to the dire need to develop ways of responding to emerging populations of people living with HIV/AIDS. Guided by the *Stakeholder Scan* and the *Community Consultation Needs Assessment*, the *Casey House Strategic Directions, 1999 to 2001* were developed. Casey House developed five Strategic Directions (see Appendix A). It was the third Strategic Direction, ensuring Casey House “reaches out, welcomes and reflects diverse individuals, groups and communities,” that was the impetus for the one-year community-based research initiative, the Access Project.

1.3 Objectives of the Access Project

The Access Project worked towards developing a clearer understanding of barriers to accessing HIV/AIDS services (HIV/AIDS services in general and Casey House services in particular) experienced by underserved populations living with HIV/AIDS in the GTA. Specifically, the Project examined barriers as they relate to:

- Women living with HIV/AIDS
- People from HIV-endemic regions living with HIV/AIDS, and
- Street involved and homeless people living with HIV/AIDS.

The Access Project was an exploratory initiative that developed the evidence needed to substantiate making changes within Casey House. Interviews with both service users and service providers highlighted not only barriers to accessing services but also pointed to potential strategies for their alleviation. Consultations with the Access Project Community Advisory Committee (CAC) resulted in the development of a number of recommendations to ensure that barriers were addressed.

The Project focused on moving beyond conducting research to implementing long-term, sustainable and meaningful changes. The Project ensured the critical action component (so often neglected in the research process) was built in to the process and it sought to respond to the demands of the community members involved in the Access Project who insisted that Casey House take the next step and not leave the research “on a shelf.”

In planning the Access Project, it was critical that the exploratory work (or data collection and analysis) segue into action. As such, much of the Project focused on moving beyond identifying barriers experienced by the populations in question to working towards removing barriers.

The five main objectives of the Access Project were:

- 1 To establish linkages with and access to the targeted populations
- 2 To understand barriers that prevent targeted populations from accessing HIV/AIDS care and treatment in general and Casey House programs in particular
- 3 To improve access to Casey House programs for targeted populations
- 4 To provide appropriate information on Casey House services to targeted populations
- 5 To prepare and disseminate a final report

These objectives were operationalized in the five phases of the Access Project outlined in Section 2.1.

1.4 Principles of Community-Based Research

As a starting point, the Access Project drew on the principles of community-based research outlined by the International Network for Community-Based Research on HIV/AIDS. In the Network’s document, *Communities Creating Knowledge: A consensus statement on community-based research* (March 2000), the guiding principles include the following²:

Community benefit: Community-based research is research conducted by and for communities. Its purpose is to build community capacities and to provide knowledge with which to improve community conditions.

Capacity building: The aim of community-based research is to build sustainable capacities within communities for self-informed, self-inspired transformation.

Collaboration: Research initiatives must involve community participation from formation through to dissemination.

Equity: Relationships between those conducting research (those observing) and those participating (those being observed) must be negotiated in a collaborative spirit.

² Terry Trussler and Rick Marchand in *Creating Knowledge for Action: Evaluation of a national workshop on community based research* (1999) outline similar guiding principles (see Appendix B).

Inclusion: Community-based research must be broadly inclusive of community members in all phases, from the review of proposals, protocol development and data collection through to interpretation of findings and dissemination of results.

Accessibility: The language and methods used in community-based research must be broadly accessible to a diverse range of participants.

Empowerment: The conduct of research, the data it generates and the results it produces are tools of the community's empowerment and must be recognized as such.

These principles are complimentary to and support the health promotion movement described in the *Ottawa Charter* (World Health Organization, 1986). Health promotion, according to the *Charter*, is the process of enabling people to increase control over and improve their health; it encourages collective action to create supportive environments, develop personal skills, strengthen community, reorient health services and advocate health policy.

2.0 Methodology

2.1 Project Design

The Access Project was developed in five different phases during the course of the year. Each phase had specific activities as well as a timeline (see Appendix C). The phases guided the progress of the Project and included:

Phase I: Project Development, June to August 2000

Phase II: Data Collection, August to October 2000

Phase III: Data Analysis, October to December 2000

Phase IV: Recommendation Development, January to May 2001

Phase V: Dissemination, May to June 2001

2.2 Ethics Review

In addition to liaising with external ethicists, Casey House has an internal Ethics Committee. *The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (see <http://www.nserc.ca/programs/ethics/english/index.htm>) guides the review process of the Casey House Ethics Committee. This Policy Statement describes standards and procedures governing research involving human subjects and urges the sensitive and thoughtful implementation of the requirements and the spirit of the document.

The Guiding Ethical Principles in this policy include: respect for human dignity, respect for free and informed consent, respect for vulnerable persons, respect for privacy and confidentiality, and respect for justice and inclusiveness as well as balancing harms and benefits and minimizing harms and maximizing benefits. It was with these principles that the research process and tools of the Access Project were reviewed.

2.3 Recruitment Strategy

Interview participants were recruited over several weeks. Interviews with PHAs from the target populations were conducted before interviews with service providers that work with PHAs from target populations.

PHA Recruitment: With the support of a number of community organizations that indicated an interest in being involved with the Access Project Community Advisory Committee and/or recruiting clients to participate in interviews or focus group discussions, recruitment flyers were distributed (see Appendix D). Information and flyers were sent to ASOs and other organizations serving the target populations, installed on bulletin boards and inserted into newsletters. Flyers outlined the purpose of the Project, the people that we were interested in interviewing and the flexibility that we had in terms of where and when to conduct interviews. Further, the flyer noted that participants would be compensated for their time. PHAs were advised to contact the Project Coordinator if

they were interested in participating. Another (unanticipated) method of recruitment was word-of-mouth; four (4) of the twenty-seven (27) participants interviewed indicated that they learned about the interviews through a friend or an acquaintance.

Service Provider Recruitment: Service providers were recruited by telephone, a process that took considerably less time as they were all accessible by telephone. Service providers were not compensated for their time with the understanding that the work of the Project would positively impact their clients by increasing their access to resources in the community.

2.4 Community Advisory Committee

The Access Project Community Advisory Committee (CAC) was established at the beginning of the Project. Initially, information about the Project was widely distributed to organizations that work with the target populations; this included AIDS service organizations as well as organizations that work with the target populations but not primarily on HIV/AIDS issues. Options for possible participation were outlined in this introductory letter and over twenty-five (25) organizations indicated that they would be interested in participating on the CAC. Ultimately, about nineteen (19) organizations and three (3) PHAs regularly attended CAC meetings (see Appendix E). While there was strong representation from a diverse range of ASOs (diverse in terms of the clients that they serve), and invitations to participate were quite broadly extended, very few non-ASOs participated on the CAC.

The role of the CAC, as defined in the Terms of Reference (see Appendix F), was to advise and support the Project and the Project Coordinator on project design, implementation, and dissemination. Members of the CAC:

- Attended Community Advisory Committee meetings
- Ensured that the Access Project effectively reached and reflected the populations of interest
- Promoted the goals and supported the work of the Access Project, and
- Identified strategies for creating change and improving accessibility both at Casey House and in the larger community.

2.5 Baseline Data Collection of Casey House Clients

For the purposes of designing an evaluation of this one-year initiative, the Project Coordinator attempted to establish a baseline of the clients that had been using Casey House services in the two-and-a-half years leading up to the Access Project. By collecting demographic information on clients that had used Casey House services in the recent past, we could then compare the changes in the demographic composition of clients during the course of and as a result of the Project. As such, a random sample of clients that had used Casey House services was manually recorded.

Data was collected from a random sample of 20 per cent of client charts between November 1997 and June 2000 – a period of over two-and-a-half years prior to the Access Project.

Casey House Community Programs: Of the 172 clients that were clients of Casey House Community Programs between November 1997 and June 2000, 34 client charts (or 20 per cent) were reviewed.

Casey House Residential Program: Of the 120 clients that were in the Casey House Hospice/Residence between November 1997 and June 2000, 24 client charts (or 20 per cent) were reviewed.

Here are some examples of information that was collected. Information about, for example, clients' first and second languages and ethnocultural background were not consistently documented and, as such, did not provide useful data.

	Casey House Community Programs (n=34)	Casey House Residential Program (n=24)
Gender		
Male	88% (30 clients)	96% (23 clients)
Female	9% (3 clients)	0% (0 clients)
TG/TS	3% (1 client)	4% (1 client)
Mean Age	47.0 years	42.8 years
Referral Source		
Hospital	29% (10)	63% (15)
GP	3% (1)	8% (2)
CCAC	21% (7)	0
HIV supportive housing	15% (5)	4% (1)
Community nursing agency	0	8% (2)
ASO/other community agency	6% (2)	8% (2)
Friend/partner/family member	21% (7)	0
Self	3% (1)	8% (2)
Not available	3% (1)	0

Casey House is currently implementing a client database to ensure that detailed client information is recorded and to facilitate future research initiatives. As such, accurate comparisons pre- and post-Project cannot be made at this time. This type of information will, however, be important to assess once the database is in place. The need to collect this information on an ongoing basis for the purposes of program planning and development and research is underscored in the Recommendations (see Section 5.2.4).

3.0 Description of Interview Participants

Interviews were conducted with people living with HIV/AIDS from the target populations as well as with service providers that work with the target populations.

3.1 PHA Respondents

In July 2000, a flyer calling for interview participants was widely distributed to both ASOs and other organizations that work with people from the target populations³. Interviews with people living with HIV/AIDS were conducted during a ten-week period, beginning in August 2000 through to October 2000. The Project Coordinator fielded over forty-five (45) requests to participate and, ultimately, twenty-seven (27) people were interviewed.⁴ Inclusion criteria, assessed during the initial contact, was broad. The potential participant was required:

- to be HIV positive
- to identify as one or more of the following: a woman, a person originally from sub-Saharan Africa or the Caribbean, and/or a person who is homeless, street involved or under-housed, and
- to be willing to meet to consider responding to either an individual interview or a focus group discussion.

Although both individual interview and focus group discussion formats were offered, only one focus group discussion was conducted and, in another case, an interview was conducted with a couple (a woman and her partner). Interviews were held in locations that were convenient and safe spaces for the interviewee; interviews were conducted at Casey House, in the homes of interviewees, at other ASOs, at a drop-in centre, at a needle exchange, at a coffee shop, and, for the focus group, at a weekend retreat. One interview was conducted over the telephone at the interviewee's request and three interviews were completed in the presence of the interviewees' support workers. Interviews lasted anywhere from forty-five to ninety minutes. Interviewees were compensated for their time (\$25) and those who traveled to meet the interviewer were given two public transit tokens.

Interviewees, before beginning the interview, were told the intent of the Access Project and they were then given and/or read an Information Form (Appendix G), and were asked to sign a Consent Form (Appendix H). It was understood that the people interviewed would not be identified in any reports. As such, efforts have been made in the following document to conceal any identifying information. Interviews were based on the Interview Guide for Service Users (Appendix I). There was some flexibility, however, in the flow of discussion as the interviewer was the same person each time.

Several of the people interviewed represented two or three of the broad target populations simultaneously. People were encouraged to define themselves, rather than

³ Inherent in this recruitment strategy is selection bias as all participants will have had some connection to participating organizations and, by and large, an ability to read English.

⁴ This discrepancy is due to a number of factors; for example, there were a number of people who did not turn up at the time of the appointment, contacting some people after an initial call was made was not possible, and one person who did turn up for the interview was not, it turned out, HIV positive.

the interviewer imposing labels. Based on the target groups identified for this Project, interviewees fell into the following groups:

Women: Of the twenty-seven (27) participants, fifteen (15) women, two (2) transgendered, and ten (10) men were interviewed.

People from HIV-endemic regions: Thirteen (13) of the twenty-seven (27) participants identified as being from sub-Saharan Africa or the Caribbean.

Street involved, homeless, or unstable housing: Fourteen (14) of nineteen (19) people identified as being street involved, homeless, and/or with insecure housing.⁵

Although the flyer did not specifically call for people of the First Nations to come forward for interviews, based on the rising incidence of HIV among these communities, it is not a coincidence that a number of people from the First Nations did come forward:

People of the First Nations: Three (3) of the twenty-seven (27) participants identified as being from the First Nations.

3.2 Service Provider Respondents

Interviews with service providers were conducted in a one-month period, beginning in October 2000, with twenty-two (22) service providers representing fourteen (14) organizations. Interviews were conducted with individual service providers and, in some cases, with two or more service providers. Based on feedback at a meeting with the Access Project Community Advisory Committee in November 2000, interviews with three (3) additional organizations were conducted. It was felt that some critical viewpoints were missing in the initial draft document that summarized interviews with service providers.

Of the twenty-two (22) service providers that were interviewed (including the three additional organizations), the fourteen (14) organizations with which they were affiliated represent and work with diverse populations. Of this group, there were eight (8) ASOs, two (2) CHCs, one (1) hospital, one (1) community centre, and two (2) population-specific organizations. Of these organizations, three (3) ASOs represented specific ethnocultural populations, three (3) programs focused primarily on women, and two (2) organizations worked with homeless and street involved people while the remainder served a range of populations.

Interviews with service providers were based on an Interview Guide for Service Providers (Appendix J) and lasted anywhere between forty-five minutes to one-and-a-half hours. Like the service users, service providers were given an Information Form and asked to sign a Consent Form. It was understood that the service providers themselves and the organizations with which they are affiliated would not be explicitly identified in any reports. Further, efforts have been made in the following document to replace any mention of specific organizations with generic terms.

⁵ Unfortunately, due to time constraints, detailed demographic information was not collected from focus group participants. As such, the denominator changes (from 27 to 19) for the numbers of people that identified this category.

4.0 Analysis and Findings

Interviews were taped, transcribed and reviewed for recurrent themes. While there were barriers to accessing care, support and treatment that were specific to some groups, discussions with service providers and service users highlighted the commonality of several themes across groups. As such, barriers are not divided by population but are pooled together and, when applicable, how this barrier specifically impacts a population is noted.

The barriers were also, of course, complex and often, intertwined. Barriers have, therefore, been divided into two (not mutually exclusive) categories: organizational barriers and systemic barriers. While the organizational barriers refer to issues that may be, at least to some extent, addressed by organizational strategies for their eradication, systemic barriers relate to the social determinants of health and pose a unique challenge for an organization. Systemic barriers are barriers to health in its broadest sense with accessing health care services as only one component of the resources for health.

Both sections present recurrent themes. Themes were verified by triangulation (presenting the draft analysis to selected interviewees as well as CAC members). The text for each theme represents direct quotes and/or paraphrasing from interviews with service users and service providers.

4.1 Organizational Barriers

Based on interviews with service providers and service users, this section lists organizational barriers as identified by interviewees.

4.1.1 Getting in the Door

When asked to describe their first experience of going to an ASO, respondents not only talked about their fears but the feeling that they ceded power over their own lives to some extent in doing so. And, despite their hesitation, it was their dire need for services that was responsible for getting people in the door:

I was nervous, afraid of the unknown and concerned about being rushed...it was intimidating. I like to do things on my own terms.

I was scared to go in to these organizations...but because your situation is so hard, you have to.

Further, access to services is compromised by the stigma attached to HIV/AIDS:

Barriers to reaching people or having people come to our ASO have to do with stigma around HIV, stigma around two-spiritedness, homophobia, and AIDS-phobia. Stigma is a huge blanket that covers everything.

Organizations need to deal with the difficulty some populations have with being identified with the gay population...some groups may feel doubly

stigmatized-their illness is stigmatized and then they are linked with the gay population.

4.1.2 Fear of Disclosure

PHAs talked about the difficulty of going to ASOs because they feared disclosure of their HIV status:

About having to be dragged [to ASOs for the first time], I can relate to that because you know about your disease and you can never be comfortable about the diagnosis with strangers. I had to be convinced by my support worker telling me I could be supported in different ways – I would be able to access food, I would meet friendly people who would relate to what I am talking about...

I know that when I first went to Voices of Positive Women, it was downtown and a lot of women were afraid to even go in because they thought people would see them [going in] and know they have HIV.

Fear of disclosure also impacted the use of treatments for two women and their children. One woman talked about the challenges of renting a room from a family who did not know that both she and her child were HIV positive while another was not comfortable having visitors in her home for fear that they will see the medications:

I had to wake my daughter up for her medications every night and she would cry. The family I was staying with wanted to know why she was crying so I had to leave.

At home, I can't have too many visitors because of my medication and my child's medication which is inside the fridge...I don't want anybody to know...so I just lock my child and I inside.

According to service providers, fear of disclosure takes many forms:

Our organization is a difficult place for women to come to because of the sign on the building...it is 'the AIDS building'.

When you have children, the fear of disclosure is even greater often because of fear of stigma to the children.

Disclosure amongst some ethno-cultural communities was also a prevalent theme:

There is a big issue around confidentiality - the community is small and everyone knows each other. They don't want to walk through the door and run into somebody they know or somebody who knows their family...Next thing you know, the news gets back home.

A lot of people are fearful to go to their own people. An advantage of a CHC is that people walk into the health center with the flu, HIV or whatever so it becomes more anonymous to come here.

4.1.3 Lack of Organizational Collaboration

Several service providers discussed their frustration with the lack of collaboration between organizations:

Organizations are not working together. For example, if someone comes to our organization to attend a meeting and they call another organization to get childcare, they say it's not our event so we're not providing childcare.

This lack of collaboration was attributed to inadequate funding by service providers:

The other organizations are getting very territorial. I don't know if it's because of funding...but a lot of people are being turned back. People are not working in partnerships but in isolation.

Some organizations are getting more money than others...agencies are fighting over funding. Funding goes to the big names or the well-known organizations but clients are not necessarily going through those doors.

Anything that isn't white and male is totally under-funded...and predominantly white organizations want to partner with cultural groups to make sure they are addressing cultural access issues but those groups don't have any time to do this other piece of work- they are barely meeting the needs of their clients.

4.1.4 Getting Referred from One Organization to Another

A common experience among PHAs trying to access services was the tendency of organizations to send people on to other organizations because of the inability or, sometimes, what was felt to be an unwillingness, to help. This may be related to the lack of organizational collaboration discussed above:

Workers are always on vacation, always busy...you often get the run around where you are referred on and on.

I get a lot of obstacles with regards to referrals...you are referring people to an organization and then they call them and they're referring them on and it's this whole big referral game...as a client I would be frustrated. That's why I try to make the initial contact to make sure they get in.

We are talking about people here whose English is their second language, who have a lot of barriers, who experience racism, homophobia...and they're taking that step forward and asking for help and then they are being passed on to this service and then another service...

Why would [a service provider] tell someone who is looking for support and sharing their feelings that he can't deal with that because he doesn't know the issues. It is honest, but at the time, people don't need that.

It's hard enough to get there and you get there and now you can't move beyond. You were so close.

Service providers talked about their frustration when needs of certain populations were neglected by ASOs. Clients from particularly vulnerable groups were referred away from mainstream, well-resourced ASOs and sent to small organizations – organizations with less capacity to address their needs but with experience in working with particular populations:

People refer transgendered and transsexual people here but we are not an ASO...when asked why they don't deal with this population, they say they don't know how and we say, well, have some TG/TS volunteers.

My clients represent a smaller population...and I get upset when one agency calls and says 'when your clients are here they do this.' So, I say, if they are there, they are your clients.

4.1.5 Discrimination at ASOs

One barrier noted by service providers was the multiple levels of discrimination sometimes experienced by PHAs. People are discriminated against by non-ASOs because of their HIV status and, within ASOs, they are discriminated against because of their gender, ethno-cultural affiliation, sexual orientation, substance use, and socio-economic status. Service providers discussed covert examples of discrimination experienced by their clients outside of the ASO realm:

When we're not getting a service for our clients, I am not too sure what is going on. Is it discrimination because of HIV status? Or it is because you are calling from [an ethno-cultural ASO]...it's hard to tease out what they are discriminating against.

Women are often refused services because they have HIV. For example, when they try to get a lawyer and the lawyer refuses to help them - even though they are not necessarily saying the direct reason why they won't help.

I connect [my clients] with housing workers because when I call and say where I'm from, they know its AIDS and a lot of them don't want to rent to people with AIDS...and it's a hidden barrier. They'll never come out and say 'oh, we won't rent to someone with AIDS' but they'll say other things and find other reasons not to rent.

Shelters tell you there are no spaces available when they know what our organization is [an ASO] when, in fact, there are beds available...you want to protect the members' confidentiality and you also want to get the service for her.

Discrimination comes in many forms for people living with HIV/AIDS. Many PHAs talked about their experiences of exclusion at ASOs:

Some of [the ASOs] are not so good with liking women. That's just the way it is...not all of them are the same way.

White women get more services than they need and black women...do not get enough.

In the past, when we tried to access services [at one ASO], we were turned down but as soon as somebody who was gay walked in, they were able to access the service.

When I first went to [one ASO], the worker basically said that it's my fault for having HIV because I was a sex trade worker.

Having a history of substance use and being homeless influences access to health care and other services for PHAs, according to respondents:

Sometimes doctors, depending on the doctor, will not treat people who use substances with the HIV cocktail because they say that if someone is smoking crack everyday, they are not going to adhere to the schedule...but that doesn't mean they can deny them treatment.

One client went to talk to a housing worker and the housing worker said 'come back when you're ready' which is code for saying 'come back when you're not using drugs and alcohol.'

Within ASOs, PHAs also experience discrimination:

When trying to access the food bank at [an ASO]...I have had problems with being transgendered...you get called names sometimes and you're outed by other service users. So I just don't use the food bank anymore.

If a woman is HIV positive and she is trying to access HIV services, [some mainstream ASOs] are very male dominated...one HIV positive woman has had horrendous experiences using these services...men clients have made comments like 'what are you doing here, you shouldn't be here' and service providers aren't stepping in and addressing those behaviours.

Service providers talked about how they work around the issue of discrimination:

I don't have any problems sending anybody anywhere...if they're not receiving what they need and they come back and tell me...then I just make sure that they get what they need. I see it as part of my job.

If services are not set up for my clients, I keep sending them and sending them...[those services] will have to start responding if enough people keep knocking on their doors.

4.1.6 Inaccessibility of Support Workers and Services

Participants talked extensively about how inaccessible support workers and some services were:

When I go to an ASO, I wish people would show a little enthusiasm...I feel bad enough coming to see you. And then they say, be quiet, we are helping you. But, excuse me, you are getting paid for helping me.

It took me three years to understand that ...workers can be cold, they are very cold...whether it's intentional or not, it's just the way they are. They don't want to be nice to anybody...they are in their own little world.

[One ASO] is a very busy place...[clients] seem to be standing there waiting for five hours to see somebody.

I needed help. I was concerned that the Children's Aid Society was going to take my child from me so I met with support workers from two different organizations. They said it was not possible to help me and when my child was taken, they were both on vacation.

A lot of people are in a position...for the money. They are not allowing themselves to get closer and to know you...they just can't be bothered about you.

For substance users it's hard to trust anybody. You have to build that trust slowly. Sometimes it takes a long time...and [I don't think] the workers have time for that.

From the service providers' perspective, the accessibility of service providers is an important issue, but one that is compromised by lack of resources:

I had to get a cell phone because you realize quickly that the pager doesn't work with the homeless because they've got no place for me to call them back.

There can be a lot of hoops for people to jump through - forms to fill out, appointments that are not flexible or don't recognize peoples' life styles. Peoples' lives are chaotic. They don't have transportation, things pop up that are more immediate than a session with you...so you have to find ways to keep your door open so people know they can come back and that it is never the last chance.

The times when I haven't been of much service to clients are when I haven't been able to see them right when they need to see me and I haven't been able to see them right then because I've got someone I'm already working with.

4.1.7 Location of Services

The geographical location of services also proves to be a critical barrier to accessing services:

Women are so geographically isolated from each other but also from services. They live everywhere in the city and it is not likely that a woman would come from Scarborough to the downtown core.

A really big issue, for people who are poor especially if they are trying to access HIV support and they are living in my community, is transportation. TTC tickets are like gold here. Someone is not going to start to use HIV programs [in another part of the city] regularly from this neighbourhood because they're just not going to be able to travel there.

Mobile services and people coming out to see them is really appreciated by people on the street. It's like 'you're on my ground now and you're accepting where I'm at'...but when people go into some services then they have a different experience.

4.1.8 Misperceptions about Clients Served

Respondents had misperceptions about who ASOs and their programs were meant to serve:

I didn't even look at [The Living Guide]...I figured it was just for gay people because it is done by ACT.

I think, ultimately, when the organizations first started the gay people advocated to get the message out there but it has changed so much...it is a disease and that's all it is. It has nothing to do with sexual orientation. I think a lot of mainstream organizations have not tapped into that yet.

There was some acknowledgement of changes within ASOs to make their services more welcoming to diverse populations:

In the beginning, [my husband and I] weren't interested because to us, [some ASOs] were gay oriented, like you had to be gay to get in...and unless you were gay they didn't even look at you. In 1996, I got involved...because I had noticed that a board member and the speaker bureau coordinator were both straight.

4.1.9 Lack of Culturally Competency

The importance of culturally competency within organizations was highlighted several times by both service users and service providers:

You get into different cultural barriers in mainstream organizations and you are easily defeated when you get to the front desk...they sort of pre-

judge us as ignorant because we do not come from that singular culture which is the mainstream.

I consider myself bi-cultural...so I can go [into an ASO] and access their services and say, oh yes, this works. But, then, I see people I know from my community not being able to find their way around it because it is keyed to suit certain groups of people.

A lot of these places take care of your issues by saying 'you go and get services with your kind.' So I say, well let me go to 'my kind' and see what I can do...because they, too, are entitled to that access. These organizations need to know that these people have to be dealt with.

Time and time again, it has been said, if you want to work for our people, get one of us in there but then organizations respond by saying, we'll get a speaker from that community, give him \$30 and that will do.

Frustration about appropriate service provision was expressed by PHAs. In terms of culturally competent services, one respondent expressed the tension that exists between mainstream, often well-resourced ASOs and non-mainstream, less-resourced ASOs:

As opposed to going to mainstream organizations and educating them on how to service our communities, I think that what should be worked on is empowering us to service our own communities. Let's have some ownership of some of these things. Instead of pouring money into mainstream agencies, let's have our own and then we can access it.

Other interviewees advocated for peer run and peer staffed organizations:

[One ASO] is now starting to get people that are positive working there. It is a lot easier for somebody who has HIV or AIDS to talk with someone who is positive because they know exactly how they are feeling.

All of these agencies need peer programs...substance users feel really comfortable talking about stuff like that with somebody who's been there.

Service providers talked about the role of cultural competency in their work:

Our work is very culturally based. That does not mean that cultural traditions are automatically brought in to play but what it means is that I have enough competency and understanding of tradition and culture to work in a specific way. For other organizations, education around ceremonial practices, not actual instruction in ceremonial practices but an overview of what they are, should be provided to people working with our populations.

People are very conscious of the fact that if there are people from their community that are present they may not want to talk to someone from their own culture the first time...it's where they're at that needs to be recognized and respected.

Ethno-culturally specific services are so important...they call and they come because we understand, we live it, we empathize. We know what racism does to you, we know how it can silence you. Somebody said to me once that they go to one organization for their groceries but when they finish, they come here to connect, for their emotional support. There are certain services they can get at some ASOs but they cannot fulfill all of their needs.

Recognizing and integrating different religious and spiritual practices is critical:

Aside from being knowledgeable about spirituality there needs to be actual visibility of those traditions...there needs to be space for reflection and spirituality and that space needs to be reflective of various faiths in the community.

All levels of spirituality must be allowable. In other words, if we want an elder to come in, and that elder brings medicines that we burn, then we would like to be able to that.

There should be space for meditation, Muslim prayer and other spiritual practices within an organization.

4.1.10 Language Barriers

Language in its traditional sense and in terms of the type of language used were cited as key barriers to accessing or wanting to access HIV/AIDS services:

The language used to address HIV or the obscenity which is such a norm in some cultures, the crudeness in which the disease is addressed is, for me, culturally inappropriate...

When I went to [one ASO], at first, they used to talk about who they slept with last night and I had my children...I said to them one day, 'excuse me, there are children here and I bring my mother here'...I don't want to hear this.

Every service provider pointed to language as a barrier:

Language is probably the primary issue that our clients face in terms of accessing services in most ASOs that are not ethno-specific to their own culture and that limits their ability to make informed choices about their health care, treatment, and other issues like housing and social assistance.

An interpreter is a link between this system and other systems. We often send interpreters to other organizations to provide interpretation because it is an English-speaking system out there.

Of the nineteen (19) service users asked, nine (9) indicated that their first language was not English; of these nine (9) respondents, five (5) were comfortable and fluent in English. Presumably, however, most people who were not fluent in English would not

have volunteered to be interviewed. Several participants discussed the importance of language:

The first point of contact for a lot of newly diagnosed people is often mainstream organizations. But, if you speak a foreign language, very few times will you go in to one of these places and find any real help.

Part of the language barrier is, implicitly, knowledge. And it is a very key piece. If you don't know, you won't ask...it is knowing what you are entitled to. Knowledge is power.

One person talked about the challenge of addressing the language issue because of the number of languages and dialects amongst clients:

How many of the mainstream organizations are going to [translate brochures] because if you do it for my dialect, and everyone's dialect...you are going to get fed up. When you look at Africa, how many tribes, how many dialects. When you give our agencies ownership, when you give it to me, I can break it down the way I want it, the way to get my people, the way to reflect these communities.

Language goes beyond translation. Service providers highlighted the importance of culturally appropriate translation:

Information cannot just focus on language but must also focus on cultural content. The woman on a brochure has to look like me so that I will take it and look at it.

Information should be available in a culturally appropriate format. For example, in some cultures there is the concept of duty so that when a member of the family gets sick, they are required to care for that family member. To relegate that responsibility to an organization...they are going to have concerns around that. A partnership between the family and the organization, where the family is seen as decision-makers and participants in the care, should be conceptualized in the literature.

Handing out a translated pamphlet is not the only education needed. Especially for people from traditionally oral cultures...there is a need for personal contact.

Many times, we have a different way of communicating...it would be useful for organizations to connect with [our organization] so we can act as a bridge.

Ultimately, however, translation and interpretation are not the only aspects that need to be addressed:

If you are going to translate materials in different languages, you need to be able to support that with the services you provide.

4.1.11 Lack of Access to Information and Lack of Knowledge of Services

For people living with HIV/AIDS, access to information (compromised by all of the barriers cited) is critical to making informed decisions about all aspects of their lives:

I just found out that my treatment is not working. I overheard my doctor talking to another doctor and saying that my treatment was not doing what it was supposed to do and they still made me take it. I thought, should I take this or not, nobody is talking to me. I don't know about resources, I need to know about all of these things.

The issue of not even being aware of entitlements to services arose in different contexts:

A lot of times with drug users, they cannot even imagine that there is stuff for them so they don't even ask because they think that they deserve nothing. They can't imagine why somebody would want to help them.

Where I come from in the Caribbean, we don't have these services...When I came here, I could not believe that all of these supports existed.

Further, assumptions made by service providers about PHAs' knowledge about HIV/AIDS and ASOs was problematic, according to one participant:

Service providers assume people know information. They assume when you have [HIV], you know something about it, which is ridiculous. I don't think people can assume that people will ask questions either...People also assume that if you are there for a service that you know all about the services they provide and they assume that you know why you're there.

4.1.12 Lack of Childcare Services

In terms of limiting access to services and health care, childcare is a critical issue for families and, especially, for women. In this group, fourteen (14) of the twenty-one (21) people that provided this information had children, eleven (11) of which had children under eighteen years of age:

To access anything, I have to have childcare. I was invited to [the AGM of an ASO] to speak so I asked them if they had volunteers to provide childcare and they said they didn't. So, I asked if they were going to pay for me to hire someone to take care of the children and they said no...so what do they want me to do? Leave work, go home, get my kids dressed, and bring them back to the AGM so I can speak for them? That is what they forget - people have children and to educate and empower yourself you can't do that without childcare.

When I get sick, I have nobody. I have no family here [in Canada]. Alone sometimes, I have no energy. Sometimes with this sickness, you don't know how you are going to wake up feeling but I have to keep going because it's my baby and I have no one to do it for me...it's very hard for me.

When I had to go to the hospital, the daycare had to bring my child to me but they could not keep her [at the hospital] as well. There needs to be a place for people who are sick with HIV who have kids, a place where they can go and stay and feel comfortable. When I get sick, I don't know where to call.

Particularly when speaking with service providers who work with women, the issue of recognizing PHAs as parents with infected and affected children, is critical:

Women are often the caregivers of children and partners and therefore they are the last to get care. Many single moms do not have the time and energy to get care.

It is hard enough trying to cope with HIV status and women have to take care of their family and all that stuff too.

To ensure that people are able to attend programs, the need to provide childcare for short and long periods of time, was also emphasized:

Childcare and transportation are huge issues. Without them, you are not going to reach very many women.

For people with children, childcare is another barrier. One woman had to go to the hospital ...she could not stay and get treatment because who would look after her kids? She is alone here, an immigrant with no family...It's not one, there are many women out there in that position.

The need for longer-term childcare arrangements were also discussed:

If a woman needs a two-day break to rest, there is nowhere to go. In some cases, foster families will take children for the weekends for women to rest and so the child establishes a relationship in advance.

Parents put their children with the Children's Aid Society and then worry about not getting them back...another woman had a child who was HIV positive and taking medication and when she left for the weekend, her daughter did not get medication for the weekend because she did not want the people taking care of her to see the medication.

Some parents send their child back home [overseas] so that the child establishes a relationship with extended family to ease the transition if the parent dies.

What do women or men with children do if they need to go to supportive housing that does not accommodate children?

Service providers noted the importance of recognizing the links that people have with their families:

We need to keep looking at the needs of the whole family; we need to recognize that the family is the first line of care and that the rest of us are professionals that have to support the family as a whole.

4.1.13 Lack of Services for Women

Several women talked about the challenges they faced when trying to find services for women. Most acknowledge that the situation has improved in the last few years but, when some were newly diagnosed, there were virtually no services for women:

A couple of years ago, I wanted support and the hospital said they did not have enough women to create a group. It was difficult for me to access social, emotional support when I needed it. I was being passed around or it was like, oh, you are too fine, we will only do short term work. Why were they deciding what I needed? I knew what I needed and it wasn't there for me.

When I first got diagnosed, I walked into ACT and they did not have any services for women or services for gay women...So I got really involved...now they have a group for lesbians that are HIV positive...There are a lot of services now. The service industry has gotten better but in 1994, there were virtually no services for women other than Voices of Positive Women.

Some women talked about the specific types of support that women need:

Women come with baggage. They come with children, partners...they don't come alone. Supportive housing wants single people...but most people have something or somebody they need to include. Often services are designed only for that person...it's like they think people with HIV/AIDS have nothing or nobody.

Women need concrete support, not just talking and emotional support. I mean, that's good but if you don't have housing, you don't have food, you don't have clothes, what is the other stuff going to do?

Service providers also pointed to the lack of women-friendly environments as a barrier for women accessing services:

Not many women access [some of the mainstream ASOs]. They are not women-positive, women-friendly spaces.

Organizations are making the decision to include women but they are not including women with children or men with children. The face of HIV has changed. There are a lot of women. And when you have children, you put your children first when you make decisions about your life.

4.1.14 Lack of Holistic Approach

Another oft-cited barrier identified by service providers and service users was the lack of a holistic approach towards people living with HIV/AIDS:

Service providers need to take a holistic point of view...we need to look at a woman as a woman first and a woman who has this disease second. Organizations should provide opportunities for women to come together and not just about HIV, although HIV is definitely there.

The needs of the client depend on their situation, their health status at the time. And when their health is good, other issues take precedence. HIV seems to be the last thing on the list. Only when they are ill does it become a problem. They have so many other issues; they are emotionally needy, lonely, isolated, family and friends abandon them. HIV is not always on the front burner.

HIV does not stand alone. There is a need for a comprehensive approach. The less HIV is isolated, the more it will become part of addressing health. Health professionals should be responsible for clients' health in the broadest sense.

Because of the complexity of the lives of clients, service providers (particularly in non-mainstream ASOs) are required to fulfill several functions:

Whatever I can do for our clients, I just do it. Whichever area.

4.1.15 Lack of Harm Reduction Approach

Particularly with service providers working with street involved populations, the issue of failing to address harm reduction within organizations was cited as a barrier:

ASOs need to figure out harm reduction...It is incumbent upon the service provider to make it clear that [clients] are not going to lose services...If people can't fully be who they are...they cannot come.

There is a need for a commitment to harm reduction. We cannot do appropriate harm reduction in this country with the existing laws...but you can take a harm reduction attitude, you have to find a way to work with it.

We've got to get better at dealing with the new population who are in really high need. These people have mental health issues and they have substance use issues...we are really good at [some kinds of care] but we don't know what to do with the crack addict who is bouncing off the wall with schizophrenia...that's why they're not making it through our services. There's a role for people who are working with an HIV positive injection drug user to incorporate good harm reduction; harm reduction that doesn't deny the person's choice around use but keeps them healthier, keeps them engaged and open to treatment and counseling issues.

4.1.16 Power Imbalance Between Care Recipient and Care Provider

Service providers also talked about the power imbalance between health professionals and PHAs:

Some clients come from a culture where physicians and other health care workers are considered persons of authority and so when a physician tells them to do this or take that prescription, that is not something that is usually second guessed.

If they're a new immigrant they may assume that these practitioners are knowledgeable and that the advice they are giving is correct so they won't question it.

There are pressures to go on medication. Some women are not really sick and are taking vitamins and the doctor kind of forces them to go on medication and if they are not ready for medication, they don't get treated the same way at the next appointment.

Sometimes doctors don't respect that women know their bodies and don't respect the right of women to choose whether or not to go on medication.

4.1.17 Service Providers Not Reflecting Communities

Service users and service providers asked again and again, who are the clients that ASOs should serve and are those clients reflected in the composition of service providers?:

If women don't see themselves reflected in the service providers and volunteers [of an organization], then they will be less likely to access services.

The lack of visibility of South Asians in ASOs is a barrier. Not having a staff member who is South Asian or Black influences the way that particular organization positions itself around various issues.

In our organization, the staff is almost all white. This can be both an advantage and a disadvantage. When the staff reflects clients, it is a plus and a minus. If a client is concerned that their status not be divulged, people not reflecting their community are sought.

When you come to [our organization] and you are a person of colour you will feel more comfortable seeing people like yourself.

There needs to be people of colour everywhere so people don't have to come here to get what they want...If I go into a place and I see another person of colour, I feel good.

There are also many service providers in the HIV field who are highly competent, highly motivated, energetic and enthusiastic people who can break those barriers...it doesn't matter what culture they come from.

4.2 Systemic Barriers

Systemic barriers are those barriers, as identified by service users and service providers, that function on a system-wide basis. These barriers are those that are the social determinants of health.

4.2.1 Lack of Affordable Housing

Housing was considered the most significant barrier to health for most of the people interviewed. Of the nineteen (19) service users asked, three (3) were homeless and/or staying in a shelter, five (5) were living with friends or family, three (3) were living in supportive housing, and five (5) were living in subsidized or co-operative housing. Three (3) interviewees lived in apartments. Further, seven (7) of the nineteen (19) people indicated that they had applied for and were waiting for subsidized housing:

I get \$490 a month [after a deduction for a previous overpayment plus interest] on FBA, that's what I am supposed to live on. How are you supposed to find a half decent place and pay the rent?

If you are homeless and you are in a hostel, there is nowhere for you to go. And hostels are not a good place when you have HIV or AIDS because there are so many people living together and there are flues and colds.

One respondent talked about the challenges of living in supportive housing, after waiting for several years to get in:

You think it's easy living here? It's not an easy place to live...there are problems with people who do crack and other drugs. You can't even get in or out of the building without running into all these other people who don't even live here.

Another participant, now living in a shelter and receiving ODSP, talked about losing her housing:

I had an apartment and everything and then I lost that – I had a roommate living with me who wasn't paying any of the bills and I was paying everything. So I said forget that, I am not going to pay rent anymore...then I got a room at the back of a restaurant but there was a fire so I had to leave.

Every single service provider mentioned the lack of affordable housing as a barrier and, inevitably, lack of such a basic necessity impacts access to other services:

There just isn't housing for our people. The money that they need to get housing, they don't have. The greatest need of our members is housing.

Housing is not available to them [homeless clients]. If they can get Ontario Works - and some of my clients have problems with that - it is

only \$520 a month; most of the rooms you see are \$450. There isn't enough affordable housing.

Housing was also discussed in the context of children:

Housing for PHAs often does not take children although there are some co-ops that set aside spaces for HIV positive people with children.

4.2.2 Employment

Employment was often cited as a major challenge for PHAs. It is an area of concern not only because of discrimination because of HIV status but also because, it is felt, government assistance is designed to provide disincentives to employment:

I want to go back to work but then the government is not encouraging me simply because of the fact that you go back out and your CPP is lost and it is another four years before you can re-access it and your benefits are cut. The government is not doing anything to encourage you back out there, to be part of Canada as a productive member of the community.

Because I work, that is a barrier. I cannot get childcare because I work and I should be able to pay for it. As for food, they figure that I cannot access the food bank because I work. If I was on welfare, I could get the food bank. But because I work I cannot access it.

[At my last job] I was let go once I told them I am HIV positive. They said they couldn't take a chance, that there might be customers who come in and recognize me and that might be bad for business. This has happened on several occasions...I have decided I don't want to look any more because I am fed up with it. Welfare tells me I have to keep looking...

Finally, one PHA detailed the impact that she felt the disclosure of her HIV status would have on her employment and how this was impacting her access to drug treatment:

If you work, you can't buy the drugs even if you have drug coverage because if you use the drug coverage, because the drugs are so expensive, your insurance company will raise a red flag...when my employer finds out, I know that I could lose my job. So, I will stay off the medication because I need the job and my children need to be fed and clothed...that's my sacrifice.

4.2.3 Immigration Status

The impact that immigration status has on people living with HIV/AIDS is a profound and, with large immigrant populations in Toronto, growing issue. PHAs talked about their experiences of HIV as they related to their immigration status:

If you know you are not landed, you are afraid to go forward [to get help].

I went through two years of hell. I didn't have OHIP. I lost all of my documentation [while homeless]; I didn't have my Canadian citizenship, I lost my landed immigration papers. Finally I got my birth certificate [from where I was born] and they still wouldn't do anything...so I had to get a lawyer and now I have my identification and everything. But I didn't have blood work done for two years.

My landed status papers are ready but they are waiting for me to get my birth certificate but I can't get it. There was war, everything was burned. But I am going to get it.

One woman, a single parent and a refugee in Canada who does not speak English, has not had access to a physician or any other health care services. Her interpreter relayed the following:

I do not have status so I don't have an OHIP card...I cannot go to the doctor because they ask me to bring an OHIP card so I do not go to the appointment. I cannot go anywhere without papers or status; my immigration papers have expired. Because I am denied refugee status, I do not get any medication.

According to service providers, the immigration status of people who are HIV positive is a growing issue:

Immigration status is the biggest barrier. Whether needs are being met depends on their immigration status...all those other things tie in with how and whether they get those services that are available.

There are people who have been living here 'underground' as we call it, for a number of years that haven't seen the need to apply or couldn't apply for status and after they get sick and they go to the hospital, they have to do something. That's when they realize they need an OHIP card and a doctor. You see, people with immigration issues may wait until they are really sick because they don't have access to health care.

I have clients who are uninsured and are here illegally. They have no status in the country. For them to access health care is tricky and they can't access welfare services and even working is really tricky so they are remaining in poverty.

There are too few doctors that will provide care to non-status people...I have two clients who are new to the country and they aren't here legally and they don't have OHIP and I called quite a few physicians...I was told they were not taking patients and the one that I did get, the appointments are two months away.

People who have been in Canada for varying lengths of time as refugees or immigrants never expect to deal with HIV and the complexity of the issues of being immigrants, or especially refugees, and most are living in poverty and most are trying to find ways to work and live in really difficult isolation with their HIV and with children with HIV.

People tell you that once people know they don't have a health card, they are treated totally differently from somebody who does have a health card. They have to wait, they are passed over, and they talk about them when there are other people in the waiting room. So, that silences people and keeps them away.

4.2.4 Poverty

For many service providers, poverty is the primary barrier to accessing services:

Lack of basics are barriers to the people I work with. Poverty is a barrier...lack of education, lack of housing, lack of emergency shelters. The individuals that we work with live on such low incomes that they cannot provide for themselves in an adequate way. Sometimes the medicines they need are not available to them or they are but they cannot afford them.

People just don't have money. They can't afford food. They can't even afford TTC tickets to go and get information. So when we talk about barriers to services and barriers to information and treatment, you have to look at the biggest barrier, the financial barriers...if I don't have food, I don't want to go listen to anybody talk.

4.3 Barriers to Accessing Treatment

According to service providers barriers to treatment are manifold. Accessing treatment poses particular challenges for the homeless, for women, for people with literacy issues, for people in prison, for families with several HIV positive members and for people who are poor:

When you're homeless, doing the HIV treatment is virtually impossible. You don't have a lot of control over your environment so how do you remember to take meds regularly, how do you take them the way they are prescribed - with food, with no food, etc...how do you manage being sick on the street and how does self-medicating go against some of the HIV treatments. And what if things need to be stored in the fridge?

Medications are not appropriate for women...trials have been done on men. And women read this and they do not want to go on medications.

People have a hard time understanding the medication...they don't understand so they come here even though we don't specialize in that area. It is an intimidating process trying to understand treatment regimens.

When people are on HIV meds, they actually lose their independence. Because the meds are so expensive they can't work. The drug costs are through the roof. You have no choice but to quit your job and go on ODSP.

For people in jail, one of the biggest barriers is accessing HIV medications...you are sometimes outed when given the medication. And when I left prison and came to Toronto, I went off my medications because I didn't have a doctor here.

In one family, both parents and one of the children are infected. They have subsidized housing, subsidized day care, disability pensions and they want to work but...because their rent would go up, their day care costs would go up and they're afraid of losing drug coverage, they can't work.

People with no immigration status in Canada face particular barriers. A non-status refugee with no source of income talked about being part of a drug trial and the problems that ensued:

When I started treatments on a trial, I had problems...the medication was so strong that I had to go to the hospital for the first time since I had been in Canada. I was in the hospital and they sent me a bill for \$400. When I requested a test, they refused because it was not part of the study.

One PHA held pharmaceutical companies accountable for the lack of access to treatment and felt that the use of PHAs for clinical drug trials is unfair:

Another issue is the cost factor and the fact that the pharmaceuticals are making money, everyone is making money with the ridiculous price for these drugs...Even when you come off a trial, you have to turn around and buy the drugs when it goes onto the market...you are not given any consideration or special kind of access.

Finally, access to treatment, as articulated by some PHAs, was access to a basic need for people living with HIV/AIDS. That need is often not met for some of the most vulnerable populations:

Basic needs should also include treatment, your medication. But the fact that other basic needs are not being met, your treatment becomes secondary and, the way we understand it today, it's the only arsenal we have that keeps people alive.

4.4 Barriers to Accessing Casey House

Although ten (10) of the twenty-seven (27) service users interviewed knew nothing or very little about Casey House and its programs, two (2) respondents have accessed or are accessing Casey House services, ten (10) respondents had family or friends who had accessed Casey House services, and seven (7) respondents claimed to be familiar with Casey House services and programs. This group, however, when probed, had scant information about the range of Casey House programs, services and treatments.

4.4.1 Lack of knowledge about Casey House

As indicated, of the PHAs who participated, 37 per cent knew nothing or very little about Casey House. Many were not familiar with any of the programs and services and others mentioned inaccurate information.

4.4.2 Misperceptions about Clients Served

Misperceptions about clients served by Casey House programs abound. One of the most frequent misperceptions of Casey House by PHAs in this sample related to the clients that Casey House serves. Women, in particular, believed that Casey House only provides services for men:

I thought it was for men...It would be good if there were women at Casey House so they could get more support.

I just made the assumption that it wasn't for women - completely based on its past, I guess.

I never would have known that Casey House has services for anyone other than men. In the media, it is always men that are featured at Casey House.

Even PHAs who knew people using Casey House services had misperceptions of who the organization served. One interviewee had had three friends at Casey House and one currently in the residence, yet she had misinformation about the clients Casey House is serving:

It seems very nice but I read that there is only space for two girls and ten men.

Another PHA had just learned about the range of Casey House services:

I just found out this year about Casey House. I always thought Casey House was just a hospice but then I found out they do respite care and I found out purely by accident. I met someone on this retreat that I went to that was from Casey House.

4.4.3 A Service for People in the Last Stages of AIDS

Casey House's image as a place to go to die persists. Several respondents indicated that they believed that Casey House is the last step:

Casey House is where you go to die. It is the final stage.

Years ago, Casey House was a place where people didn't come out of...before new meds and people living longer. One woman said her husband went in there...Other people think that you go in there and they put you on a morphine drip and you're gone.

People had strong emotional reactions to Casey House because they had had friends or partners in the Hospice:

A few months ago, a friend passed away there...I don't like to remember because it's a déjà vu kind of a thing. I get very emotional because he was a good friend of mine.

They took two friends of mine from Fife House to Casey House on a stretcher and both of them didn't want to go...They knew they were very ill and probably dying and they wanted to die at home.

4.4.4 PHAs Felt They Were Too Well

Due to its image as a place for people in the last stages of AIDS, many of the respondents felt that they were not sick enough to use Casey House. Only in the event that their health did decline would they consider availing themselves of Casey House services:

If I ever get ill, well, then [Casey House] would be the perfect thing for me.

4.4.5 A Shift in Thinking about Health Care

Respondents also mentioned that Casey House would be a last resort if they did not have family to care for them. This speaks to the practice of some groups of providing care for family members. The notion of receiving care from strangers is not acceptable:

I would use Casey House only if I didn't have family here.

Let's go beyond how culturally appropriate Casey House is, let's look at cultural differences. Where I come from, there was no home for anybody - you stay with your family until you die. It is a different culture that has not integrated into the Caribbean or African cultures where you send your parents away to die or someone in your family. So Casey House, there needs to be a lot more integration into the African and Caribbean communities because that is not part of how we culturally take care of family members.

Another respondent talked about how for one of his clients, based on his experience in his home country in the Caribbean, the concept of accessing services was unheard of and required a shift in thinking to see access as a right:

One individual that I know asked, Why are they being so nice at Casey House? They paid for my cab fare. I said, "Wake up! It is your right! They are at work, they get paid to do this". Some of us need to know that these are services that are there for us, because of us.

4.4.6 Need for Greater Cultural Competency

The critical need for culturally competent service and program delivery was underscored by a number of PHAs and service providers. Food was one important piece of cultural competency:

I have seen Africans dying that are in those hospices, and yes, these people are being nice and sensitive to them because they are sick but it is not culturally appropriate. Two that I have spoken to just last week said "but I cannot eat that food." They are trying...but I don't think they are there yet. If I went, would I get my rice and peas?

Casey House does an excellent job but on cultural sensitivity, it is just bordering on it. I have people that have gone in to the hospice and...they say I am comfortable but there is a lack of cultural identification...you might want some special type of food or conversation.

If you are ill there are certain preferences about food... you may be able to eat only certain foods. If that recognition is there and you are sending someone who only knows how to cut celery...I don't feel respected and recognized because that is not the service that I require. Why don't you ask me what I would like to eat...If you are going to die, you want to enjoy food.

One PHA who praised Casey House from her recent experiences noted some skepticism about its level of cultural competency:

When a lot of my friends had no family or support, Casey House took them in...you go there and get better or die. Now I know that you can go there to pick up or energize and then you can go out on your own again...they have an outreach program that is coming out to you and I have found it very helpful to me...when I thought I was losing it, they came right to my door even though I could walk...Yes, I would recommend Casey House but I am not sure how culturally sensitive Casey House is.

4.4.7 Lack of Services for Children

As discussed, PHAs also talked about the lack of services at Casey House (as well as at other organizations) for people living with HIV/AIDS with infected and affected children:

We need a place for people who are sick with HIV that have kids, a place where they can go and stay. Please. Because I have a hard time when I get sick. I don't know where to call and I have girlfriends but they don't come to my home. I just talk with them on the phone and they say, when you get sick bring your daughter here but I can't bring her with her medication - I don't want them to know.

The most important thing is my daughter...that's why when I get so sick I still keep her with me...I keep her with me even when I was thinking I wasn't going to make it.

4.4.8 Lack of Known Harm Reduction Approach

One PHA talked about her frustration with accessing medical marijuana as part of her health care at Casey House:

One thing I don't like about Casey House...as a place where I am going to stay as a person living with AIDS, to get better or to die, is to be told I cannot smoke pot...how is it that an AIDS place doesn't understand the need to smoke pot? I don't understand because I use it as part of my health care.

4.4.9 Need for a Day Centre

Some PHAs also talked about a need for a day center and felt that Casey House was well positioned to provide such a needed service:

A day centre. We need it! We need an activity centre for people, they can get together and share information, have a coffee, find out the news, relax on a couch...And get some health care too.

4.5 Facilitators to Accessing Casey House

4.5.1 Positive Experiences

Certainly one of the most effective ways of learning about services is personal experience. PHAs talked about positive experiences of friends, family and partners that used Casey House services:

I have known tons of people to go to Casey House; the staff are wonderful, compassionate, and supportive.

They took good care of my husband. I was able to sleep there at night and I would leave in the morning and do things and come back and they even fed me. I also attended the bereavement group. I was the only

woman and the only straight woman but of the ones in charge, one was a lady so that made it better for me. It was also important that our kids got to come see their father at Casey House.

In the hospital, I had to go in early in the morning to feed [my partner] his breakfast and feed him his lunch otherwise he wasn't going to eat because the nurses had so many other patients to look after. But at Casey House he was never alone. There was always a volunteer in his room or to bring him outside to have a cigarette and I didn't have to worry about feeding him.

One service provider talked about her experiences with Casey House:

I had one client who was at Casey House and the Casey House social worker was genuine enough to share his progress...she kept up with him when I didn't see him. Casey House is one of the only places where I didn't get the sense that "it's my client, not yours" – the social worker was very open.

4.5.2 Alternative to Institutional Settings

Casey House is also seen as a viable alternative to an institutional setting which can be very intimidating for some PHAs. One PHA that was interviewed was homeless and on the Casey House waiting list:

Even though I am on the waiting list for Casey House I don't want to go to the hospital...I've had bad experiences.

4.6 Helping People Connect to Services

In addition to discussing barriers, service providers and PHAs suggested several approaches to ensuring that people living with HIV/AIDS connect with and find out about services.

4.6.1 Importance of Personal Connections

Service providers highlighted the importance of providing a personal bridge between services and service users:

People are more likely to have a successful contact if that contact is a personal contact and a personal connection is made. The most successful contacts with clients have been when the counselor has brought them here and introduced her...she is actually hosting or easing the transition into another service.

Orient them, make it clear that this is a service for them, introduce them to people so that the woman has contact with a human being and is less intimidated.

Service users underscored how important it can be, in some cases, for a trusted support worker to introduce clients to a new service:

My counselor at [one ASO] referred me to [another ASO] but I didn't go because I was scared...I did not want to expose myself to too many people that I didn't know. She referred me to [a third ASO] which I didn't go to. I had to be dragged there...she talked me into it and she said, "come, let's go and meet these people." So I went and sat down and talked and then I felt comfortable.

You have to be convinced by somebody that you already know...you really want to go to a place where you feel comfortable.

Through [a hospital], I learned about [an ASO]. Then I met someone from [another ASO] who came to meet me with my support worker at [the hospital].

4.6.2 Word of Mouth

The power of word of mouth as a way of learning about services was mentioned innumerable times:

Sometimes because they talk to another positive woman who tells them "you can get this at..." and if they know me, women will call me or drop in. If I am known in the community, I am going to get referrals.

Other people belong to agencies and they meet other women that say our organization is OK, it's safe to go there.

We see clients who are experts in accessing services...they know every service out there and every possible way of getting it... and they will often share their information with everyone.

Service users cited word of mouth most often as the way that people learned about services:

Mostly [I learned about organizations] through word-of-mouth.

I prefer to learn from a friend, then check with my doctor and then call.

Others preferred to or were forced to find services on their own:

For me, it wasn't about referral. I did my own research and found organizations.

4.6.3 Referrals by Physicians and Service Providers

Service providers indicated sources of referrals to their organization:

A lot of people find out about our organization from their doctor, the hospital, and the clinic where they get their tests. They find out from immigration workers, lawyers, support workers at shelters...

Most women find out about [our organization] through doctors.

Physicians that we know directly refer to us and those are the physicians that we have in the past targeted specifically.

4.6.4 Community Partnerships and Networking

Linking either formally or informally with other community organizations was cited as one way of ensuring that service providers and their clients learn about services:

One way women have found counselors here is through community partnerships. [Someone from our organization] spent one day a week at [another ASO] and through her work there, more women became aware of who she was and the services of our organization.

A presence at a network changes everyone's perception of an agency because there has been a personal link with other service providers. So, I am more likely and confident referring someone to a specific person rather than just an organization even if that person is not the right person but I know that that person is going to make sure that that person gets hooked up to the right service.

Ethno-culturally based organizations are particularly concerned about being involved with other ASOs to ensure that their needs are being addressed:

We sit on a number of committees in the HIV field to make sure that our voice is heard...that people understand what our concerns are. We go out into the community and work with mainstream ASOs and educate them.

Community partnerships and networking are, however, not necessarily a priority with organizations with limited resources:

My main concern and my main priority are the clients because I need to be here for the clients as much as possible.

4.6.5 Offering Practical Support

The need to offer practical assistance at ASOs was repeatedly mentioned. Practical assistance includes, for example, TTC tokens, furniture, clothes, financial assistance, and diapers:

Typically, women use the more hands-on, practical services.

Recently, a service provider from [an ethno-cultural ASO] came here with a client who needed support and money. The money is usually very helpful in helping people to get to know the agencies, the other things they offer and the people that work there.

We do a breakfast here...some type of activity that addresses immediate needs is a good way to draw people in.

4.6.6 Community Consultation

The need for community involvement at all levels of program development and implementation, to ensure relevance to the communities being served, was emphasized:

Programs need to be developed in consultation with the community. We will never overcome barriers if there is no community consultation. People will not access services if other community-based organizations are not involved.

4.6.7 Links Between Services

Service users were asked to outline how they found out about services and what they thought were the best ways to learn about services. There was the perception that the organizations all eventually linked together. One respondent mapped her route through several ASOs:

I found CATIE then, a year later, I joined APAA and then Black CAP. From Black CAP, I was introduced to the Teresa Group and from Teresa Group I was introduced to Toronto PWA and then ACT. I also went to HALCO and Voices of Positive Women...I found there was a chain.

5.0 Recommendations

In response to the barriers identified, recommendations were developed to increase knowledge of and access to Casey House programs and services. Recommendations were developed based on input from:

- interviews with people living with HIV/AIDS
- interviews with service providers
- interviews with Casey House staff, and
- feedback from the Access Project Community Advisory Committee.

Because of the emphasis on collaboration, community benefit, and inclusion inherent to community-based research, several HIV/AIDS service organizations were involved in the process of the work of the Access Project and, as such, much of the outreach work has already begun. Strategies suggested in this document speak to initiatives that will have been either implemented during the course of or initiated by the Access Project. Further, strategies often build upon efforts already in place at Casey House.

The following recommendations have been identified as concrete and measurable approaches to addressing barriers to accessing Casey House programs and services for target populations. Recommendations have been divided by short-term actions that can begin to be addressed in the life of the Access Project and long-term actions that require ongoing organizational efforts after the one-year Project is over.

5.1 Short Term Recommendations

5.1.1 Implement interpretation services

To ensure that the needs of diverse communities are met, Casey House will establish a contractual relationship with a community-based agency that provides trained interpreters. In the initial investigation of a number of organizations, Casey House has determined that interpreters provided by an agency must be:

- available at all hours
- proficient in a broad range of languages and dialects, and
- trained to address issues related to HIV/AIDS.

5.1.2 Establish services for childcare provision

While the organization has, in the past, made childcare arrangements on an ad hoc basis, Casey House will establish a formal protocol for accommodating children in the Residence as well as a relationship with a childcare service with trained childcare workers for Community Programs' clients. A working group will be established to develop alternative strategies for accommodating children within both of the programs at Casey House.

5.1.3 Continue to share expertise and resources with community organizations

Casey House will continue to share its palliative care, supportive care and treatment expertise with community organizations by offering educational and informational workshops not only at Casey House but also in the community among ASOs and non-ASOs (including, for example, Community Health Centres, Children's Aids Societies, and other ethno-specific organizations).

5.1.4 Continue to provide ongoing education and training opportunities in culturally competent service delivery

To facilitate ongoing learning and to improve skills for working with diverse populations, Casey House will continue to provide opportunities for staff to learn from community-based organizations. Several community organizations offer in-service training and education sessions related to working with specific populations. Existing workshops include, for example, a Prison 101 course offered by PASAN and a workshop on HIV/AIDS in South Asian communities offered by the Alliance for South Asian AIDS Prevention.

5.1.5 Provide communications to community organizations serving target populations

Casey House will enhance its communications strategy to include community organizations serving target populations. In consultation with community partners, publications and media that reach different ethnocultural communities should be identified as vehicles to promote Casey House programs and services and to share other relevant information.

Further, Casey House communication materials and resources will be revised to ensure that the populations being served and the programs available are explicitly identified including, for example, The Blue Book, ACT's Living Guide and the Casey House website.

5.1.6 Develop community-based research network

To support the ongoing community-based research efforts of Casey House, a community based research network will be established with other community organizations undertaking similar work with the goal of sharing resources and avoiding duplication.

5.1.7 Maintain Community Advisory Committee

The Community Advisory Committee will be maintained (with either quarterly or bi-annual meetings) after the completion of the Access Project so that it may:

- support the ongoing work of Casey House
- ensure that recommendations have been carried out
- maintain relationships that have been forged, and

- reflect on current and emerging issues related to accessing services for underserved PHAs.

5.1.8 Disseminate barriers to accessing services and recommendations implemented

Casey House will ensure that the barriers identified during the course of the Access Project are widely disseminated to organizations serving diverse populations living with HIV/AIDS. Dissemination will include:

- presenting at conferences (see Appendix K)
- hosting a community forum
- making the final report widely available to interview participants, CAC members, community organizations, and the Canadian HIV/AIDS Clearinghouse
- internal Casey House communications through workshops with staff, volunteers and Board members, and
- articles in newsletters.

5.2 Long Term Recommendations

Recommendations outlined in this section are ongoing initiatives that must be facilitated by Casey House and/or activities that require shifts in organizational practices:

5.2.1 Develop Casey House staff as resources with knowledge and skills related to target populations

Casey House will implement a program to ensure staff members develop skills to work with target populations including (but not limited to):

- women
- people from HIV-endemic regions
- street involved and homeless people, and
- First Nations people.

Staff will focus on developing 'pockets of excellence' in specific areas and will, therefore, act as resources within Casey house and in the larger community. This will entail:

- participation on relevant networks
- attending conferences, workshops, AGMs, and other educational opportunities, and
- creating relationships with relevant community-based organizations.

5.2.2 Integrate cultural competency as a required core competency for all staff and volunteers

To ensure appropriate care delivery, cultural competency will be a required core competency in hiring and in evaluating staff and volunteers at Casey House.

5.2.3 Ensure Mission Statement and Philosophy of Care reflect programs and services

Casey House will ensure that its Mission Statement and Philosophy of Care accurately reflect:

- programs and services that are offered
- clients that are served, and
- changing and emerging populations of PHAs.

5.2.4 Revise client database, documentation and evaluation tools to reflect specific needs of clients and target populations

To ensure that client information is collected for program and service planning, Casey House will implement a client database. Further, to ensure more reflective assessments and to provide appropriate information for data collection and analysis, admission/intake forms, quarterly Satisfaction Surveys, and client care plans will be revised to include more detailed information on issues such as ethnocultural background, interpretation requirements, religious considerations, substance use history, food preferences, childcare needs, and immigration issues.

5.2.5 Create a community development/community partnership coordinator role

Casey House will have a dedicated community partnerships coordinator for organizations to liaise with directly and to ensure representation and participation in community initiatives.

5.2.6 Incorporate community resource education in orientation for new staff, volunteers and Board members

To emphasize the importance of accessing community resources and developing partnerships, staff and volunteer orientation at Casey House will relay information about community resources.

5.2.7 Ensure staff, volunteers and Board members reflect populations living with HIV/AIDS

Casey House will continue its efforts to ensure that all staff, the Board of Directors, and volunteers are reflective of the target populations living with HIV/AIDS.

5.2.8 Continue harm reduction education

To ensure Casey House provides clients with appropriate care and support and following a review of its current harm reduction initiatives, Casey House will continue efforts to educate all staff on issues related to harm reduction. Casey House will also work towards adopting a universal working definition of harm reduction and a policy for addressing harm reduction in both of Casey House's programs.

6.0 Outcomes

6.1 Evaluation by Community Advisory Committee

One of the short-term goals of the Access Project was to increase knowledge about Casey House programs and services. As such, members of the Community Advisory Committee (CAC) who were actively involved with the Access Project, were surveyed mid-way (January 2001) through the Project and at the end (June 2001) of the Project.

The first survey, a process evaluation, asked members to respond to a number of questions to assess their knowledge of and reaction to both Casey House and the Access Project. The second survey, however, focused on assessing the potential impact of the short term and long-term recommendations adopted by Casey House in the second half of the Project (see Appendix L).

6.2 Community Forum Feedback

In June 2001, at the end of the Access Project, Casey House hosted a Community Forum. This was an opportunity to report back to community members at large, with Community Advisory Committee members in attendance, and to receive feedback on the Project. Of the twenty-one organizations in attendance at that meeting, many of the participants had been involved with Project in some capacity in the last year and were, therefore, knowledgeable about how the Project unfolded. Some of the areas of discussion at the Community Forum included:

6.2.1 Continuing the Community Advisory Committee

Participants felt that the CAC should be continued and that its most critical role, at this point, is to ensure that the recommendations are, in fact, carried out. The CAC was seen as an excellent resource to advise Casey House on its ongoing efforts to improve accessibility. The CAC should also be used to disseminate and deliver information about the findings of the Project.

6.2.2 Understanding cultural competence

The use of the term 'cultural competence' in the recommendations was disconcerting to some participants. This ambiguity led to a discussion about how participants have different understandings of the concept. As such, a request to include further information about cultural competence in the final report was put forward. For further reading, see Appendix M.

6.2.3 Access Project as a model

Participants saw the Access Project as a good model for organizations encountering challenges reaching and serving diverse populations. It was felt that the issues raised and the process of conducting the Project were relevant to other organizations.

6.2.4 Conducting workshops

Some discussion about disseminating information - beyond simply distributing the final report - was initiated; participants talked about conducting workshops to share the information and skills that were developed.

6.3 Follow Up to Recommendations

Casey House is committed to the short-term and long-term recommendations outlined in this Final Report. Recommendations will be followed up in a number of ways:

- Through a series of meetings with Casey House management, each recommendation has been assigned to relevant managers. This assignment means that the manager(s) will take the lead on ensuring that the recommendations are implemented within reasonable timeframes.
- Some recommendations have already been integrated into the day-to-day operations of the organization while other recommendations are currently being integrated into organizational operations.
- Proposals to fund some of the initiatives outlined have been or will be submitted to relevant funding bodies.
- The Community Advisory Committee will continue to monitor and assist the progress of the implementation of recommendations at Casey House.

7.0 Conclusion

The Access Project was a learning experience for Casey House and the organizations and individuals that were involved in the process. For Casey House, it was one of its first community-based research projects and, therefore, many lessons were learned:

- The Project was an important step in underscoring the relevance of evidence-based practice. It provided the evidence needed to continue some of our approaches to care delivery as well as to revise some of our approaches. It also provided a rationale to implement new services such as interpretation and childcare services.
- The Principles of Community-Based Research, as outlined in Section 1.4, guided the Access Project. Adhering to the principles of CBR and working towards meaningful community participation is a worthy challenge. Ultimately, however, doing so ensures that the Project will build capacity in communities and will be relevant to participants.
- It was critical to recognize and accommodate diversity within communities and groups particularly as the target populations were so broad. The notion of community was a challenging concept in this context and brought up questions of just who defines and represents community. For the purposes of this Project, we understood community to be those organizations and individuals that were willing to work on the issues at hand on behalf of different groups and populations.
- Taking action, beyond simply conducting research, was a demand made by community participants at several points in the Project. The commitment to action, as evidenced by building an action component into the Project design, was critical to its success.
- One of the objectives of the Access Project was to develop a model that could be employed by other organizations. While Casey House was determined to explore how it could ensure that the needs of emerging populations were addressed within its own programs and services, Casey House also hopes that its efforts would serve as a model for other organizations that were faced with the same challenges of providing care and support to increasingly diverse populations.

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Appendix A: Casey House Strategic Directions

In 1999, Casey House engaged in a comprehensive strategic planning process. Five strategic directions emerged from this process and the third strategic direction was the impetus for the Access Project. The Casey House Strategic Directions, 1999 to 2002 are as follows:

1. Improve access to and quality of existing programs and services.
2. Improve public awareness of Casey House's mission and programs.
3. Ensure Casey House reaches out, welcomes and reflects diverse individuals, groups and communities.
4. Provide leadership in research on HIV/AIDS palliative and supportive care.
5. Develop new programs and services to meet emerging community needs.

Appendix B: Guiding Principles of Community-Based Research

Terry Trussler and Rick Marchand (1999) outline principles of community-based research. This tool could be used as a checklist to consult while planning and implementing a community-based research project. The ten principles are as follows:

Partnership

- community/professional equity

Initiation

- community initiated, earliest involvement

Peer review

- community participation in funding review and publication

Community benefit

- research should improve community conditions

Capacity building

- instruct and employ community members in research procedures

Ownership

- lived experience belongs to the community

Interpretation

- community participation in analysis and interpretation of findings

Dissemination

- community right of review prior to publication

Implementation

- facilitate inclusion of findings into programs

Empowerment

- encourage community members to initiate own inquiries

Appendix C: Detailed Work Plan

Phase I: Project Development

Timeline:

- June to August 2000

Activities:

- Develop work plan for Project
- Conduct literature review
- Identify organizations that work with target populations
- Establish list of community organizations that agree to support the Project by being involved with the Community Advisory Committee and/or assisting with identifying PHAs to participate in interviews and focus groups
- Create research tools including interview and focus group discussion guide for PHAs and service providers as well as information and consent forms for interview participants
- Prepare and submit material for ethics review
- Develop evaluation tools including interim and outcome evaluation surveys
- Host a project launch for community members
- Prepare a draft of the terms of reference for the Community Advisory Committee

Phase II: Data Collection

Timeline:

- August to October 2000

Activities:

- Compile baseline data for Casey House Programs
- Recruit interview participants
- Pilot test interview questions
- Conduct interviews with PHAs
- Conduct interviews with service providers

Phase III: Data Analysis

Timeline:

- October to December 2000

Activities:

- Review and analyze data from interviews with PHAs
- Prepare preliminary report outlining themes for PHAs from target populations
- Review and analyze data from interviews with service providers
- Prepare preliminary report outlining themes for service providers that work with

target populations

Phase IV: Recommendation Development

Timeline:

January to May 2001

Activities:

- Meet with Community Advisory Committee and Casey House staff to determine recommendations
- Develop and disseminate short- term and long-term recommendations
- Meet with relevant Casey House staff to determine areas of responsibility for follow up to recommendations

Phase V: Dissemination

Timeline:

March to June 2001

Activities:

- Organize community forum to disseminate findings and discuss next steps
- Submit abstract to participate in conferences/workshops
- Present at conferences/workshops
- Present at Casey House to staff, volunteers and Board of Directors
- Prepare and distribute final report

Appendix D: Recruitment Flyer

We are looking for people to interview for the ...

Casey House ACCESS PROJECT

The Access Project will identify barriers that women, people from sub-Saharan Africa and the Caribbean and street involved and homeless people face in accessing HIV/AIDS services and a project that will take action to overcome these barriers.

We would like to interview:

Women

***People from HIV-endemic regions
Street involved and homeless people
who are living with HIV/AIDS.***

Meetings will be either individual interviews or focus group discussions, depending on your preference.

Participants will be paid.

To participate in the ACCESS PROJECT or for more information, contact Lea Narciso at Casey House at (416) 907-7180 Ext. 24.

All calls are confidential.

Appendix E: Access Project Community Advisory Committee Members

There was representation on the Community Advisory Committee from the following organizations:

- 2-Spirited People of the 1st Nations
- 519 Church Street Community Centre
- Africans in Partnership Against AIDS (APAA)
- AIDS Committee of Toronto (ACT)
- Alliance for South Asian AIDS Prevention (ASAP)
- Black CAP
- Casey House
- Fife House
- Maggie's: Toronto's Prostitutes Community Services
- Midaynta Association of Somali Service Agencies
- Nellie's Shelter
- Ontario Aboriginal HIV/AIDS Strategy
- Regent Park Community Health Centre
- Sherbourne Health Centre
- Street City
- Street Health
- The Teresa Group Child and Family Aid
- United Caribbean AIDS Network (UCAN)
- Voices of Positive Women

In addition to the organizations represented, there were three community representatives/service users that attended most of the meetings.

Appendix F: Terms of Reference for the Access Project Community Advisory Committee

Role of Community Advisory Committee

The Community Advisory Committee (CAC) will advise the Access Project Coordinator on project design, implementation, and dissemination.

The Casey House Access Project embraces the Guiding Principles of the HIV Community Based Research Centre which sees community action research as guided by the principles of:

- Community benefit
- Capacity building
- Collaboration
- Equity
- Inclusion
- Accessibility
- Empowerment

Accountability and Representation

Members of the CAC represent:

- women living with HIV/AIDS
- people from HIV-endemic regions living with HIV/AIDS
- street involved and homeless people living with HIV/AIDS
- organizations working with women, people from HIV-endemic regions, and street involved and homeless people living with HIV/AIDS

Responsibilities of CAC Members

- To attend Access Project CAC meetings
- To ensure that the Access Project effectively reaches and reflects the populations of interest
- To promote the goals and support the work of the Access Project
- To identify strategies for creating change and improving accessibility both at Casey House and in the larger community

Meetings

The CAC will meet every two months during the course of the Access Project. The first meeting is scheduled for September and subsequent meetings will be set at that time.

Chair

The Chair of the meeting will be the Access Project Coordinator who will be responsible for notifying members of meetings, recording and distributing minutes, and addressing all logistical issues.

Appendix G: Information Form for Interview Participants

What is the Access Project?

To respond to the changing face of HIV/AIDS in Toronto, Casey House is launching the Access Project. The Access Project is one way that Casey House is working towards improving accessibility of services to diverse communities both at Casey House and in the larger community.

The Access Project is a one year community-based action research initiative that will not only identify the barriers faced by women, people from HIV-endemic regions (such as sub-Saharan Africa and the Caribbean), and street involved and homeless people in accessing HIV/AIDS services but, more importantly, the project will develop and implement strategies to address these barriers.

How will barriers be identified?

To understand the barriers faced by the populations mentioned above, the Project Coordinator is conducting interviews and focus group discussions with people living with HIV/AIDS as well as with service providers that work with these populations. Service providers are able to provide a unique perspective as they see a number of clients with HIV/AIDS and they may be sensitized to the challenges that underserved populations experience when trying to access services.

What will the interviews be like?

In the current and first phase of the Access Project, people from each of the three populations will be interviewed in-depth for no more than one to one-and-a-half hours. Service providers that work on behalf of these populations will also be interviewed during this phase for in-depth interviews of no more than one to one-and-a-half hours. Interviews will be arranged at locations that are convenient for the person being interviewed and interviews will be taped with the consent of the participant.

How is confidentiality ensured?

The information discussed in the course of this interview will remain confidential. Names of individuals and organizations will not be identified in the Access Project interim or final reports. A consent form will be signed by the interviewee at the beginning of the interview.

How will I find out about the results of the Access Project?

At the end of the Project in June 2001, a final report will be written and available for those interested. Please indicate on the attached Consent Form if you would like a copy of the final report.

Who do I contact if I have further questions?

If you have any further questions about the Access Project, please contact either the Project Coordinator, Lea Narciso at (416) 907-7180 Ext. 24 or the Project Supervisor

and Director of Clinical Programs at Casey House, Joan Lesmond at (416) 962-7600 Ext. 209.

Appendix H: Consent Form for Interview Participants

I, _____(Name or Pseudonym)
understand and consent to the following terms of participation in the Access Project
interview:

I have received and read the Casey House Access Project Information Form for
Interview Participants. Yes No

All of my current questions about the Access Project have been answered.
 Yes No

I understand that the interview will be taped and notes will be taken.
 Yes No

I understand that tapes and notes will be stored for the duration of the Access Project (to
June 2001) in a secure and locked office. Tapes and notes will be destroyed at the end
of the Project and will not be used for further research.
 Yes No

I understand that I may discontinue the interview at any time and/or I may refuse to
answer any questions.
 Yes No

I understand that current services will not be affected in any way if I withdraw from the
interview.
 Yes No

I understand that the information that I provide will remain confidential and that I will not
be identified in the interim or final reports nor will any identifiable characteristics be
included in the interim or final reports.
 Yes No

I would like a copy of the final report when it is available in June 2001.
 Yes No

Please feel free to contact the Project Supervisor, Joan Lesmond, at Casey House (416)
962-7600 Ext. 209 if you have any questions or concerns before, during, or after the
interview. By signing below, I agree to participate in the interview:

Signature of Interview Participant

Date

Signature of Witness/Interviewer

Appendix I: Interview Guide for Service Users

Introductory Questions

1. How did you find out about the Access Project?
2. What, if any, organizations are you currently involved with?
For health care and treatment? For social support? For support for your family?
3. How did you find out about these organizations? What are the best ways for you to learn about services?
4. What made you decide to go to these organizations?

Defining Accessibility

5. What do you look for or want when you are deciding to use an HIV/AIDS service or any other health services for you or your family?
6. Can you tell me about your experience when you first went to one of the services that you mentioned?
7. Which organization do you find the most useful to you? What is it about their services that you like? What is it about their services that you do not like?

Describing Barriers

8. What are the most significant barriers or difficulties that you or people you know experience when trying to access HIV/AIDS services?

Improving Accessibility

9. What would make services better for you (and your family)?
10. Have you seen any examples of work that has been done to improve accessibility of services? Please describe.

Casey House Services

11. Are you aware of the services offered by Casey House? Please describe.
12. Why would you or why would you not try to use the services of Casey House?
13. How could Casey House improve its services? Or improve your knowledge of its services?

Role of Community Based Agencies

14. What can community-based agencies do to improve services, treatment and care for people living with HIV/AIDS?

Appendix J: Interview Guide for Service Providers

Introductory Questions

1. What is your role in the organization?
2. Describe the populations of PHAs that you work with.
3. What are the greatest needs of the populations that you work with? Are these needs met?

Defining Accessibility

4. What does access to HIV/AIDS care, treatment, and services mean to the populations that you are working with?
5. What services (including those offered by your organization and by other organizations as well) are your clients accessing?

Describing Barriers

6. What are the most significant barriers faced by the populations you work with in accessing health care and, specifically, HIV/AIDS care? Please list at least three.
7. How are these barriers unique to these populations?
8. What are the barriers that service providers face in trying to get health care for their clients?
9. Are there barriers that exist in your own organization that make your services less accessible to the populations that you do and do not serve?

Improving Accessibility

10. What would facilitate better access to services for the populations of PHAs that you see?
11. Have you seen any examples of work that has been done to improve accessibility of services to underserved PHAs (in your own organization or in another)? Please describe.
12. Has your own organization taken any initiatives to improve accessibility to diverse populations?

Casey House Services

13. Are you aware of the services offered by Casey House? Please describe.
14. Why would you or why would you not refer your clients to Casey House?
15. How could Casey House improve accessibility to the PHAs that you work with?

Role of Community Based Agencies

16. What can community-based agencies (specifically “mainstream” organizations) do to improve services, treatment, and care for PHAs from traditionally underserved populations including the populations that you work with?

Dissemination

17. What would you like to see happen as a result of this project?
18. Do you know of any other community based research or work that has been done in the area of barriers to HIV/AIDS services for traditionally underserved groups?

Appendix K: Conferences

The following is a list of conferences at which the Access Project was presented in workshop, presentation or panel discussion formats:

Opening Doors, Central East
March 2001
Toronto, Ontario

Canadian Association of Nurses in AIDS Care (CANAC)
April 2001
Quebec City, Quebec

Consumer Health Information: The Canadian Experience
June 2001
Toronto, Ontario

University of Guelph Sexuality Conference
June 2001
Guelph, Ontario

3rd Canadian HIV/AIDS Skills Building Symposium
July 2001
Montreal, Quebec

Appendix L: Evaluations by CAC Members

Survey One: January 2001

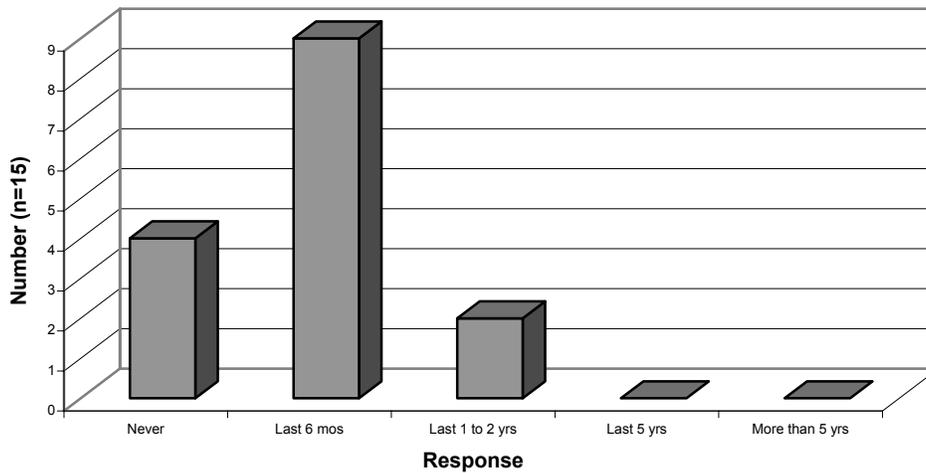
Respondents

Of the 23 possible respondents (Community Advisory Committee members who attended at least one of the first three meetings), 15 (or 65%) of the surveys were completed and returned.

Questions and Responses

- a) When asked which of the target populations living with HIV/AIDS members represent or work with:
- | | |
|----|---|
| 12 | indicated that they represent/work with people who are homeless and/or street involved |
| 9 | indicated that they represent/work with women |
| 8 | indicated that they represent/work with people from sub-Saharan Africa |
| 7 | indicated that they represent/work with people from the Caribbean |
| 7 | indicated that they represent/work with other populations including transgendered/transsexual people, men, sex workers, families, children, youth and people of the 1st Nations |
- b) Other than meetings for the Access Project, members were asked when was the last time they had been to Casey House either in a professional or personal capacity. Significantly, 4 of the 15 respondents had never been to Casey House (see graph):

**Last time you have been to Casey House
other than for Access Project meetings**

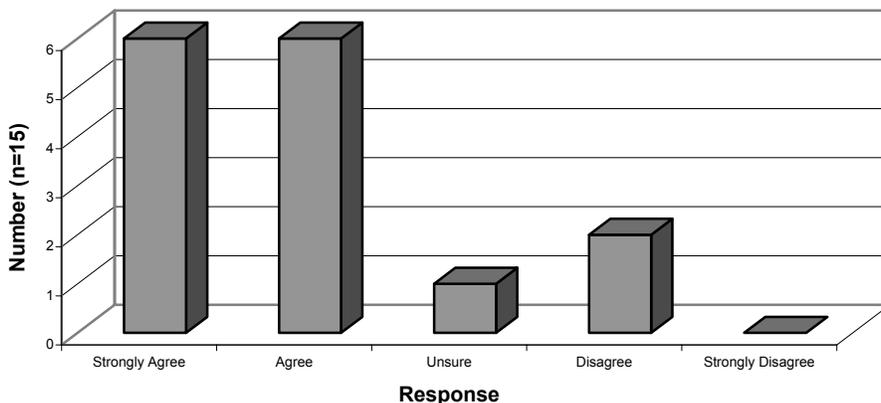


c) Members were asked to list as many programs and services offered by Casey House:

- 9 Residential program
- 7 Home hospice program
- 5 Counseling (including grief counseling, spiritual counseling)
- 4 Respite care
- 2 Research
- 2 Community education
- 2 Training
- 1 Discharge planning
- 1 Transportation
- 1 Referrals
- 1 Alternative therapies
- 1 Dispense treatment
- 1 TS/TG peer support project

d) Members were asked whether, since the Access Project started, they had learned something new about Casey House. Other the 15 respondents, 12 either agreed or strongly agreed that they had learned something new about Casey House (see graph):

I have learned something new about Casey House since the Access Project started



- e) Members were then asked, what have you learned? Many of the comments related to learning about Casey House services as well as services provided by other organizations:

More about services – I thought Casey House was just a hospice.

Outreach services – trying to match services with new clientele. Trying to accommodate other communities impacted by HIV/AIDS. Good intentions and an excellent effort.

That they want to try and change programming to include more women and homeless people.

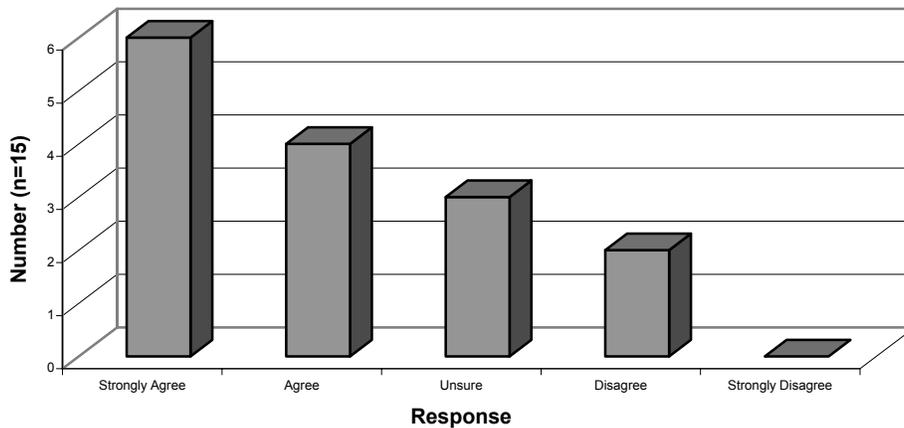
About the programs and services and about Casey House's commitment to accessibility.

That Casey House is not just a place for men.

Someone with HIV/AIDS can go to Casey House if they need a break. The various services that exist in the community. The need for agencies in our field to work together.

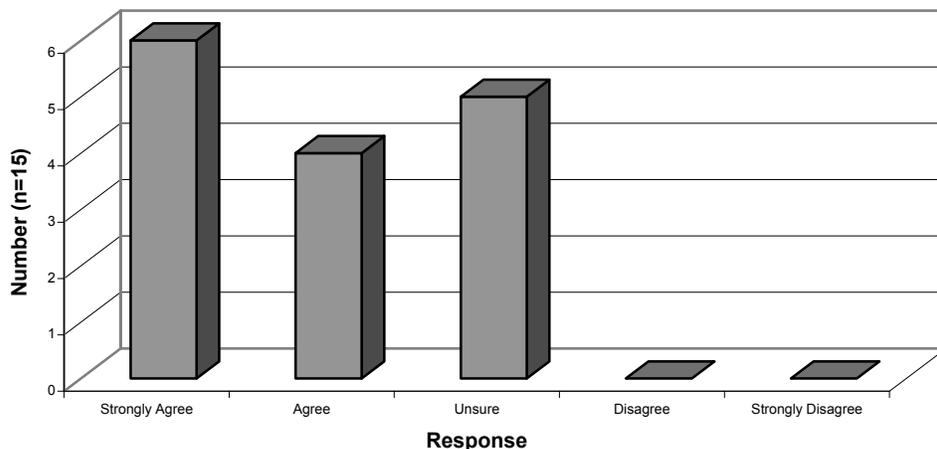
- f) Members were asked whether, as a result of the Access Project, they would be more likely to refer a client, family member or friend to Casey House and 10 of the 15 respondents either agreed or strongly agreed while 3 were unsure and 2 disagreed (see graph):

I would be more likely to refer a client, family member, or friend to Casey House as a result of the Access Project



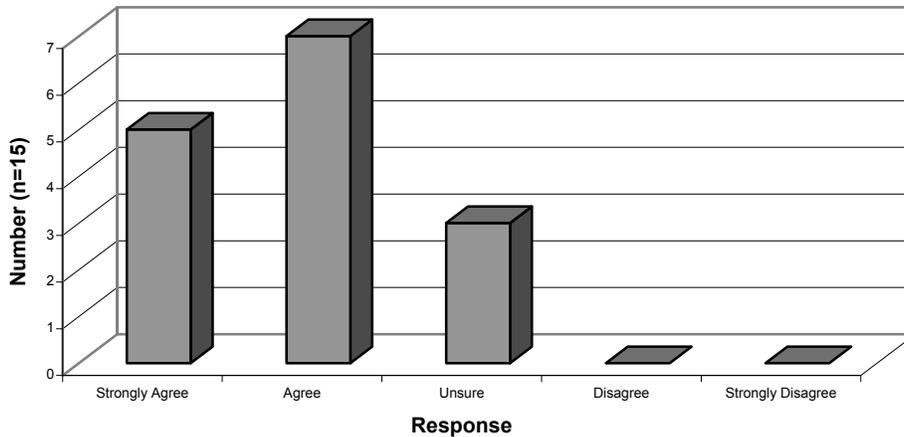
g) Members were asked whether they believed that the Access Project would contribute to ensuring that Casey House services are more accessible to the target populations (women, people from HIV-endemic regions, street involved and homeless people living with HIV/AIDS). Of the 15 respondents, 10 indicated that they agreed or strongly agreed and 5 indicated that they were unsure (see graph):

The Access Project will contribute to ensuring that Casey House services are more accessible to target populations



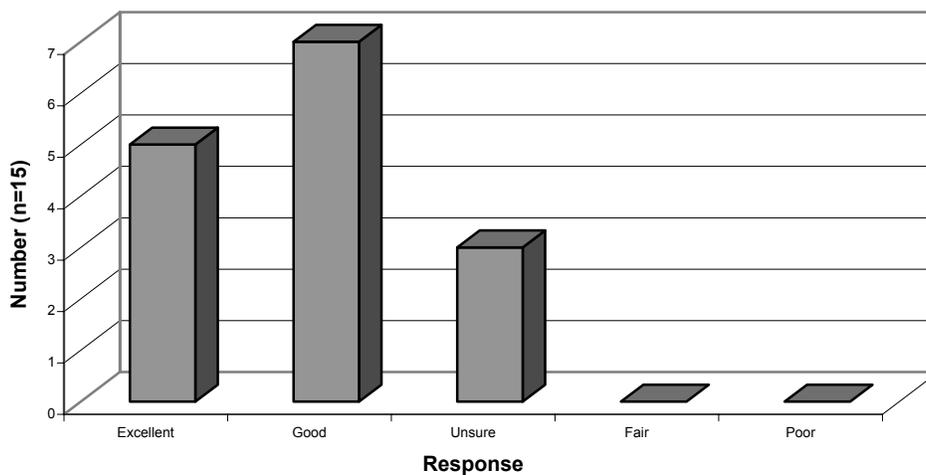
h) Members were asked if they felt that the Access Project may benefit their organization, work and/or clients (see graph). 12 of the 15 respondents agreed or strongly agreed while 3 were unsure:

**The Access Project may benefit
my organization, my work, and/or my clients**



- i) Finally, members were asked how they felt the Access Project was unfolding. 12 of the 15 respondents indicated excellent or good while 3 indicated that they were unsure (see graph):

How do you feel the Access Project is unfolding



- k) Members were given an opportunity to provide comments:

The Access Project has, in addition to addressing accessibility of the target populations, brought several ASO around the same table and has also brought to the fore many other pressing issues faced by PHAs that warrant changes in the way ASOs provide services, the dire need to address gaps in acculturation, adaptation and accessibility of HIV/AIDS education, materials and personnel, and to address existing barriers –especially systemic ones.

Research and general administration/organization of project is excellent. Staff have never been defensive but rather patient and open to comments and suggestions. Good job.

Dong an excellent job of identifying needs and developing a plan of action.

The group is representative of the target populations. The big part is being in touch with those people (workers) who are impacted by the services on behalf of their clients.

I feel that we will have a break through for how people feel about Casey House and the services. We can make it work if we all put our heads together. Good work!

The Advisory Committee is much too large. The group is so large I don't feel that I have an opportunity to speak and share my knowledge.

Trying to tackle too many issues. No indication of how the recommendations will be implemented. Coordinator seems to be doing an excellent job tackling this overly complicated project – such diverse needs between groups addressing, i.e. homeless and women.

Survey Two: June 2001

Following the final Access Project Community Advisory Committee meeting in May 2001, the second survey was distributed to solicit further feedback on the short-term and long-term recommendations. CAC members were asked whether they believed each recommendation would impact access for the target populations. Of the 17 surveys administered (to CAC members who had attended the majority of meetings in the second half of the Project), 9 (or 53 percent) were completed and returned. Responses indicated strong support for many of the recommendations.

SA: Strongly agree **A:** Agree **U:** Unsure **D:** Disagree **SD:** Strongly disagree

Short Term Recommendations	SA	A	U	D	SD
Implement interpretation services for clients	4	4	1	0	0
Establish services for child care provision both in the Hospice and in the Community Programs	6	2	1	0	0
Share supportive and palliative care expertise with community organizations	5	4	0	0	0

Provide ongoing education and training opportunities in culturally competent service delivery for staff and volunteers	6	2	1	0	0
Provide direct communications about Casey House to community organizations serving targeted populations	5	4	0	0	0
Develop Community-Based Research (CBR) Network with organizations working on similar projects	1	8	0	0	0
Maintain Access Project Community Advisory Committee (CAC)	2	4	3	0	0
Disseminate barriers to accessing services and recommendations implemented	5	4	0	0	0
Long Term Recommendations	SA	A	U	D	SD
Develop areas of expertise related to target populations among staff	4	3	2	0	0
Integrate cultural competency as a required core competency for all staff and volunteers	5	4	0	0	0
Ensure Mission Statement and Philosophy of Care are reflected in programs and services	3	5	1	0	0
Revise client database, documentation and evaluation tools to reflect specific needs of target populations	4	4	1	0	0
Create a community development/community partnership position	5	3	1	0	0
Incorporate community resource education in orientation for	5	4	0	0	0

staff, volunteers, and Board members					
Ensure staff, volunteers and Board members reflect populations living with HIV/AIDS	4	5	0	0	0

Appendix M: Cultural Competence

Cultural competence builds on the intention to be culturally sensitive by identifying the

- Knowledge
- Values
- Skills

that are imperative for helping in the cross-cultural encounter.

There are five essential elements that contribute to a system's ability to become more culturally competent. The system should:

- value diversity
- have the capacity for cultural self-assessment
- be conscious of the dynamics inherent when culture interact
- institutionalize cultural knowledge
- develop adaptations to service delivery reflecting an understanding of diversity between and within cultures

These elements should be reflected in attitudes, structures, policies and services.

See www.air.org/cecp/cultural/Q_howdifferent.htm

See www.associum.com