

# **Action Research Report**

## **Improving Access**

### **to Legal Services & Health-Care**

#### **For People Living With HIV/AIDS**

##### **Who are Immigrants,**

##### **Refugees or Without Status**

**The Committee  
for Accessible  
AIDS Treatment  
(CAAT)**

**July 2001**

# Thanks.....

We are very grateful for the courage and generosity of the People living with HIV/AIDS who shared their stories with us.

The success of our research project has also depended on the participation & commitment of physicians and service providers and the broad-based support of over 25 community agencies that provide services to support immigrant and refugee PHAs.

## **Committee for Accessible AIDS Treatment (CAAT) served as the Project Advisory Committee:**

410 Sherbourne Health Clinic, Asian Community AIDS Services (ACAS), AIDS Committee of Toronto (ACT), African Community Health Services, Africans in Partnership Against AIDS, Alliance for South Asian AIDS Prevention(ASAP), Black Coalition for AIDS Prevention (BlackCAP), Casey House, Centre for Spanish Speaking People, Davenport-Perth Community Health Centre, HIV and AIDS Legal Clinic Ontario (HALCO), Parkdale Community Health Centre, Regent Park Community Health Centre, SHOUT Clinic, Teresa Group, Toronto People with AIDS Foundation, Women's Health in Women's Hands Community Health Centre.

## **Other Organizations and individuals who assisted with our research activities including data collection, Advocacy Think Tank, Immigration & HIV Skill Development Forum and Report dissemination:**

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# Summary & Recommendations

"Without papers you are nothing." *Person Living with HIV/AIDS (PHA)*

People Living with HIV/AIDS (PHAs) who are immigrants, refugees or without legal status in Canada face enormous barriers in accessing health care, HIV treatment, legal and community services. The Committee for Accessible AIDS Treatment (CAAT), a coalition of service providers from Community Health Centres (CHCs) and AIDS Service Organizations (ASOs), initiated a research project as a way to document and respond to the suffering of these PHAs. The Ontario HIV Treatment Network (OHTN) provided research funding.

The project gathered information and used a community development approach to involve stakeholders. Safe points of contact were found to interview 38 immigrants, refugees and non-status PHAs in Toronto. We spoke with 28 service providers and 10 physicians. We also reviewed relevant reference materials (See References).

## What We Learned

The project identified the barriers that immigrant, refugee and non-status PHAs face to access treatment, care and services. We were inspired by their courage and endurance, not only living with a life-threatening disease but many having had to flee persecution in their home countries. We were also inspired by the dedication of the service providers, physicians and the handful of lawyers who respond to the overwhelming needs of these PHAs. Solutions emerged from all their experiences that would be effective, practical and much more humane. We learned that with good community and legal support many of these PHAs can achieve legal status in Canada. However, we identified a clear need to create a more supportive environment in order to dismantle the barriers to services.

### 1. Access to Health-Care & HIV Treatment

"[I have been in Canada for 10 years applying to get refugee status]. Not having the proper papers made life a living hell. I was sick many times and didn't have anywhere to go because I had no OHIP. I was pregnant with my baby boy, was in labour, taken to the hospital. I was left in the hallway. I was sent home the same day I had the baby. It was terrible." *PHA*

" The route people have to go through to get care is often humiliating and degrading."  
*HIV Specialist*

People who are in the process of applying to be immigrants or refugees in Canada are often ineligible for any form of public health care. Over half of the 38 PHAs interviewed did not have health insurance. Of the 31 PHAs taking HIV drug treatments, 15 (48%) had difficulty accessing treatment due to their immigration status. Many had used recycled medications from caregivers or community agencies. Twenty (64%) were on drug treatments because they had completed their immigration process and/or had qualified for some form of drug benefits.

Uninsured PHAs are forced underground and often seek care only when very ill. We heard stories of PHAs who became much worse or died when they did not get timely treatment and care. Many of these stories have been lost with their lives.

**Health impact:**

- Delayed diagnosis
- Sub-optimal care
- No treatment or limited choices
- Disrupted treatments
- Increased viral resistance
- Increased severe illnesses

Untimely deaths **Psychosocial impact:**

- Loss of dignity
- Loss of Confidentiality
- Fear
- Stigma
- Stress
- Lack of support

Depression and despair

HIV affects immigrant and refugee families. Of the 17 participants (45%) with children, 6 said their children were HIV+. Many felt that their HIV+ children were receiving excellent care. However, some of the 11 participants who had HIV-children without legal status reported significant barriers in securing health care for their children.

**Current strategies:**

- Health care providers spend many hours searching for care for PHAs.
- Recycled drugs. A lifeline for some but difficult to ensure consistent treatment.
- PHAs risk their health by postponing treatment until they can get coverage.
- Drug companies provide supplies to physicians but only for the short-term.

“Volunteering” for clinical trials to get access to medications & health care. **Recommended Solutions:**

- Expand and support the informal networks of health care providers.
- Extend funding of CHCs.
- Coordinate/enhance HIV drug recycling through a Drug Depot pilot project.
- A hospital is needed which accepts this population into its mission & programs.

Expand the provincial pharmacare program to address the needs of this population and prevent illness and death.

## **2. Access to Community Social Services**

“The thing is, you don't go up to immigration and say I have AIDS, I am dying. So how do you go about it? It is like a puzzle. You struggle, you don't know where you go. It is not only coping with the stress of the illness, also coping with the stress of immigration status, financial status.” *PHA*

**Barriers & Impact:**

- ASO service providers lack knowledge on immigration/refugee processes and agencies serving immigrants/refugees lack knowledge of HIV/AIDS issues/services.
- The threat of arrest, detention, and deportation increases the vulnerability of refugee and immigrant PHAs, and increases their distrust of any social service.

**Current Strategies:**

CAAT has consolidated pre-existing networks and expanded to include service providers, lawyers and activists in refugee and immigration services. **Recommended Solutions:**

- Develop information for service providers and PHAs.
- Develop immigrant advocate service to assist PHAs and train providers.

## **3. Access to Legal Services and Information**

“Immigration is not a do-it-yourself system – people need specialized help.” *Service Provider*

### **Barriers & Impact:**

- Twenty-two (22) of the 38 PHAs (58%) reported that a lack of information about the Canadian health care/immigration systems had impeded their access to health care.
- PHAs told us they were never informed of the services or care they could access.
- Lawyers and immigration officials gave inaccurate or misleading information. Long delays or rejection of applications were the result.
- There are very few lawyers with expertise in making immigration or refugee claims for people who are HIV+. They are often overwhelmed by the needs.

### **Current Strategies:**

- There are a few lawyers, and a couple of community legal clinics, who have expertise in both HIV and immigration. There are a few options to fill the gaps of information but they are not HIV specific.

### **Recommended Solutions:**

- Fund more staff resources in community clinics.
- Develop/support more lawyers in this field.

Develop HIV related resources on immigrant/refugee issues

## **4. Need for a Supportive Environment**

*This project has been shaped by these values that are also core Canadian values:*

- *The belief in the inalienable human rights of all human beings, regardless of their immigration status*
- *The belief that that all health care which is provided in Canada must meet the same ethical standards and standards of care.*
- *The right to free universal health care*
- *The right to freedom from persecution and discrimination*
- *A recognition of the significant social and economic contributions of immigrants in Canada*

This research shows us that we often treat immigrants, refugees and non-status PHAs inhumanely. It would be more consistent with our values as Canadians to support people through these processes. In time, many applicants are accepted. Over the course of this project PHA participants were gradually achieving status given the appropriate support. Why did they have to go through so much fear, pain and suffering in the process?

" If people are tested without fear of exclusion and deportation, we can start treatment early and minimize the cost to the system and maximize people's health and [their] contributions [to Canada]. " *HIV Physician*

# Action Recommendations

Although our recommendations for change have been developed in response to the needs of PHAs, they speak to the need for changes in health care delivery for all immigrants, refugees and people without status who are living in Canada. The solutions that this project has identified could be a model for broader reforms.

## 1. To Improve Access to Health Care & HIV drug treatments

### Immediate Action:

- Compile resource list of HIV specialists and primary care physicians who are willing to serve immigrants, refugee or undocumented PHAs.
- Develop fact sheets that outline the health benefits and drug coverage eligibility for people at various stages of the immigration process.
- Enhance existing recycling mechanisms for HIV antiretroviral drugs such as the development of a pilot “Drug Depot” project.

### Longer term Recommendation:

- Advocate with the provincial governments to develop a chronic and catastrophic prescription drug program for all residents without status in Canada.
- Develop formal arrangements between Community Health Centres and hospitals to facilitate access to care for PHAs with no coverage.
- Advocate with specific hospitals to adopt the care of non-insured PHAs as a core goal in their vision and mission.
- Develop networks with other centres across Canada that are struggling to provide services to HIV+ immigrants and refugees. Develop joint advocacy strategies for national change.
- Advocate with Immigration Canada to :
  - shorten the initial response time on refugee applications.
  - expand services covered by Interim Federal Health Plan.
  - eliminate the 3-month waiting period for OHIP coverage for newly landed immigrants.
  - grant amnesty for all PHAs who are living in Canada without official status.
  - to remove mandatory testing of HIV and remove HIV as an automatic ground for medical inadmissibility to Canada.
- Advocate to Ministry of Health & District Health Council to:
  - Ensure representation of communities affected by HIV & Immigration on their policy advisory groups.
  - Increase funding for Community Health Centres (CHCs) and other health organizations that provide service for PHAs without coverage.
  - Ensure funding for cultural interpreters at hospitals & health service organizations.
  - Increase funding for research on access barriers and health outcomes of immigrants, refugee and non-status PHAs.

## **1. To Improve Access to Community Support**

### **Immediate Action:**

- Develop an “HIV & Immigration Service Advocate” program to assist PHAs with no status in Canada to access health and legal services. The program will use a train the trainer model to train other service providers working in both HIV and immigration services.

### **Longer Term Recommendations:**

- Develop a comprehensive referral list of community-based health, legal, social, housing and income support services in the Greater Toronto Area that are available to immigrant, refugee and undocumented PHAs.
- Establish an ongoing network to promote networking, resource sharing, mutual learning and monitoring of HIV & immigration related issues and advocate for funding for staff resources.
- Advocate for increased funding for shelters who provide services for immigrant, refugee & undocumented PHAs and their families.
- To develop guardianship planning services for all babies of HIV+ parents.
- To increase funding for community awareness raising and mobilization to de-stigmatize HIV/AIDS in culturally diverse communities.

## **1. To Improve Access to Legal Services & Information**

### **Immediate Action:**

- To develop resource materials on frequently asked questions on HIV and immigration processes, and to integrate legal information and service listing in the “Living Guide”

### **Longer Term Recommendations:**

- Advocate for funding for increased staff resources at HIV & AIDS Legal Clinic Ontario (HALCO) and other legal clinics to enable them to provide legal services to immigrant & refugee PHAs.
- Advocate to Law Society of Upper Canada to:
  - develop training seminars and possibly a mentorship program on HIV and health related immigration and refugee claims for lawyers.
  - extend their pro-bono services to immigrant & refugee applicants with HIV or other health related issues.
  - develop a 'brief bank' for lawyers on cases relating to HIV, immigration, and health care issues.

## **1. To Create A More Supportive Environment**

- To continue working in partnership with other groups concerned about issues affecting immigrants and refugees such as the Coalition for a Just Immigration Policy, Canadian Council for Refugees and the Canadian HIV/AIDS Legal Network to monitor and respond to policies and regulations affecting immigrants, refugees and people with HIV/AIDS.



# Introduction

## 1. Why a Research Project?

Front-line service providers and physicians in Toronto have witnessed growing numbers of people living with HIV/AIDS (PHAs) without access to care and treatment. They identified, in particular, the struggles of immigrants, refugees and people without status in Canada:

- These populations are forced underground and not connected to service or support.
- They lack OHIP or drug coverage.
- They cannot advocate for themselves due to stigma and fear of deportation.
- These populations and their struggles remain invisible to larger community.
- Individual service providers have worked hard to assist these groups, but due to the systemic barriers, the results have so far been discouraging.

The Committee for Accessible AIDS Treatment (CAAT) began as a coalition of front line service providers from Community Health Centres (CHCs) and AIDS Service Organizations (ASOs) The research project was developed as a way to document needs and to explore solutions. The Ontario HIV Treatment Network (OHTN) provided funding for a community research project *Improving Treatment Access to Marginalized PHAs (ITAPHA)*. The project:

- Documented barriers to treatment and care and their impact.
- Documented existing strategies by PHAs and their providers to ensure some level of health care for themselves and their families.
- Explored improved solutions to address these barriers.
- Increased dialogue and action among stakeholders.

## 2. How We Gathered Information

The project was designed as participatory, action research. The project used a community development approach to involve stakeholders in the research and to expand the initial coalition. We also reviewed relevant documents (See References).

**Advisory Committee:** CAAT served as the Project Advisory Committee and hired and advised the Project Coordinator. CAAT invited experts in HIV and/or immigration to Advocacy Think Tank sessions to review and recommend advocacy strategies.

**Service providers:** The project collected information from 28 community service providers in ASOs and CHCs. They provided services to a wide diversity of communities including the African, Caribbean, Black, Asian, South Asian, and Spanish, Portuguese, and French-speaking communities. Some services targeted specific gender, ethnic, or language populations, while others were available to all communities. The information was summarized in a preliminary report and circulated to service providers. They provided feedback and advice to ensure our research tools and methods would be sensitive to the PHAs' concerns and experiences.

**PHAs:** Due to the deep fears about disclosure, safe points of contact were identified. All PHA participants were recruited and interviewed by service providers with whom they had a trusting relationship. Ten service providers from agencies were trained to conduct a survey with 4-5 of their clients. The project has no record of people's names or identifying information.

Thirty-eight PHAs participated in the survey, including people at every stage of the immigration and refugee application processes, those with no official status in Canada and a few who have become Canadian citizens. The range of ages was from 26 to 49. They came from Africa, Asia, Latin American, the Caribbean, and Western and Eastern Europe. We conducted in-depth interviews with 8 of the 38 PHAs. They were 4 women and 4 men, from Africa (2), Latin America (2), Asia (1), and the Caribbean (3).

**Physicians:** Three physicians on the advisory committee conducted interviews with 10 HIV primary care physicians and specialists. They helped us document cases of PHAs not receiving optimal care and the negative impact this has on physicians, health care providers and the community at large.

**Analysis:** All interviews were transcribed and all the survey responses and interviews were analysed by the research coordinator and supervisor. Themes were then discussed and validated through the advisory group of CAAT.

## What We Learned

The PHAs had all made the choice to risk coming forward despite fears of discrimination and deportation. We heard stories of terrible suffering because people could not get care or proper, timely treatment. We have not heard the stories of people that received no care or support at all. We can only assume that their suffering is intensified by their isolation.

The project identified the barriers immigrant, refugee and non-status PHAs face to access treatment, care and services. Recommended solutions emerged that would be effective, practical and much more humane. We learned that with good community and legal support many of these PHAs can achieve legal status in Canada. However, we identified a clear need to create a more supportive environment.

### 1. Access to Health Care & Treatment

There was broad agreement among the physicians that, despite their best efforts, the care they can provide to PHAs who are uninsured is sub-optimal:

*"The care is fragmented, people are being bounced around from place to place. We are putting out fires and not dealing with long term issues." HIV Physician*

Only half (19 out of 38) of the PHAs had any form of health care insurance in Canada. Yet, most (35 out of 38 or 92%) had accessed some form of health care. People accessed health care at CHCs (24 or 63%), hospitals (21 or 55%), private physicians (16 or 42%) and through clinical trials (2 or 5%). Almost half (18 out of 38) have paid 'out of pocket' for health care. ASOs and CHCs were the most common places that people went to get help to connect with health services. Twenty-one (21) PHAs ( 55%) reported that fear of disclosing their HIV status or immigration status and/or social stigma was a major barrier to accessing health care.

Most of the PHAs surveyed were currently accessing HIV drug treatments in Canada (31 of 38 or 82%). Many (20 out of 38 or 52%) were accessing HIV treatments because they had completed the immigration process and/or had qualified for a form of drug benefits. Of the 31 people who were taking HIV medications, 15 (48%) reported that they had had difficulty accessing treatment due to their immigration status.

#### a) Who is Affected and How?

##### Immigration Applicants

People who apply to immigrate to Canada are not entitled to medical coverage. Immigrants who have been granted landed status must wait 3 months to get OHIP. Some PHAs said that even when they are able to obtain OHIP they do not

access care. They are afraid the immigration department will access their health records and reject them due to their HIV status.

The time and handling of immigration applications can have a harmful impact. One woman immigrated to Canada with her parents as a child over 30 years ago. She had a social insurance number and voted all of her adult life. When she tested HIV+ and decided to go on medications she found out she wasn't a citizen. The government took her OHIP away and threatened to deport her. It took 2 1/2 years for her immigration application to be processed. For all of that time she had no medical coverage and no drug coverage.

## **Refugee Applicants**

People apply for refugee status due to persecution in their home country. Once their application is acknowledged, they are eligible for "essential and emergency" health-care through the Interim Federal Health (IFH) plan. There is no coverage until the claim is acknowledged. The acknowledgement usually takes 1 or 2 weeks if refugee claim was filed at port of entry (border or airport), but it may take 3 to 6 months if filed later at an immigration office.

The coverage provided to refugee applicants changed from a provincial responsibility (OHIP) to a federal responsibility (IFH) in 1995. Therefore, many health-care providers don't know how to submit claims, and won't accept IFH as a method of payment. Physicians complained that some of their claims were lost or ignored and requests for pre-approvals and payments take lots of phone calls and letters. Several PHAs reported they had to pay in advance for care and seek reimbursement from IFH. One client did this and waited over a year before getting reimbursed.

## **Minister's permit**

For people who fall between the cracks, for example, visitors who are found to be inadmissible, they may seek a Minister's permit granting them permission to stay in Canada. However, people on a Minister's permit due to medical inadmissibility are generally ineligible for medical care and are expected to get coverage through private insurance.

## **No Status**

PHAs in Canada without official status are not eligible for health care or assistance. Some people who start in Canada as an immigrant, refugee applicant, on a working permit or as a visitor can end up here with no status. Even so, for many PHAs, living illegally in Canada is a better option. The alternative may be going back to their home country to face persecution and death.

## **Children**

Of the 17 participants with children, 6 reported that their children were HIV+. Fortunately, none reported major barriers in securing health care and treatment for their children. Many felt their HIV+ children were receiving excellent care. However, some of the 11 participants who had HIV- children without legal status reported significant barriers in securing health care for their children. Several women reported receiving inadequate pre and post-natal care. One woman, who was unaware of her HIV status when her son was born, told us:

*"Even when he was born I had to pay the hospital, \$3000...[he was] born about 3am, they let me out the next day because I didn't have coverage. I was breastfeeding him because I didn't really know much about [HIV]... Maybe that is what is a miracle because I don't know when I brought him for testing he wasn't [positive]."*

Another woman expressed her pain and wonder that her children weren't covered while with her, but she knew that they would receive medical care if she surrendered them to the Children's Aid Society.

PHAs without health coverage may be eligible for care at CHCs, but many do not seek care due to fear of deportation or because they are unaware of the services. When they do seek care they are often gravely ill at which point the health care system is obliged to care for them. Ultimately this is an inefficient and inhumane use of health care resources.

## **b) Barriers & Impact according to types of health care:**

## Primary Health Care

PHAs often reported paying for primary health care. They access care when they have money and stop accessing care when they run out of money. Many uninsured PHAs accessed primary health care at CHCs. However, CHC resources are severely stretched by the large number of uninsured HIV+ clients as well as the demand for other services. Many CHCs are unable to accept new clients due to limited resources. One refugee found out that she was HIV+ in her eighth month of pregnancy. She didn't have a health card so went to a CHC at 6 months but “ *They were full, over-stretched, they had a waiting list.*” Only after she got a yeast infection and went to a women's clinic was someone able to advocate successfully for her to see a doctor at the CHC.

Furthermore, few CHCs have developed expertise in treating HIV. After being diagnosed with HIV, one refugee applicant from Africa reported that his doctor at a CHC told him that he could no longer see him. The doctor offered no referral but simply told the man that the public health would contact him and tell him what to do.

## Specialists

While many of the HIV specialists would waive their fee to see uninsured PHAs, making referrals to other sub-specialties is a major challenge. Physicians confirmed that they must often use personal connections and ask colleagues for favours to see patients without coverage. One woman reported that a specialist, who agreed to see her as a favour to her doctor, treated her with contempt. When she asked for more information, he replied that she should be thankful that he was seeing her and that he didn't have time to explain the details of her treatment. Several PHAs reported that specialists have refused to treat them.

## Hospital Care

Several PHAs reported being turned away from hospital emergencies, although seriously ill. One man described how they would not admit him so he went home, became worse, returned 3 weeks later and was finally admitted. One physician indicated that when his hospital admits uninsured patients, they keep the stay as short as possible to minimize the hospital's cost. He felt that uninsured PHAs generally received compassionate care but also felt there were varied attitudes to uninsured patients. Another physician reported that her hospital usually ends up covering the costs of uninsured patients. The accounting department sends collection agencies to the homes of those with bills to try and collect some portion of the bill.

Accumulating large hospital bills was a coping method and a burden for several PHAs and their families. They had bills they can't ever pay off ranging from \$8,000 to \$30,000. The hospitals send collection agencies even if people are on social assistance. PHAs sacrifice to provide small payments to hospitals.

*“[My husband] had pneumonia and there [was] nothing, so he stayed at home until he was really helpless, I said, lets go to the hospital and they admitted him. (Interviewer: And the bill?) \$13,000. (Interviewer: What do you do?) This is after we have the baby and we would rotate and this month pay \$30 on your bill so that these people don't keep calling. So maybe next month he'll pay \$40, then \$20...The hospital would also call and say it is going into collections now because there is two people, my baby had a bill too.”*

Service providers reported that seriously ill PHAs have been turned away from hospitals and have then died at home or in the hospital because they did not get timely treatment. The sister of a man with HIV told the story of his death:

*“He was getting sicker and sicker, and weak. We decided to take him to emergency because he couldn't breathe. First thing they asked me [does he have OHIP] and I said, no he doesn't have any, I will have to pay. Oh, we'll have to see, they said. We waited there for hours...Finally they came. I paid \$150 for just a doctor to see him, plus I will pay the doctor's fee once inside. When another doctor came, the first thing he asked me was, ok I understand that you don't have OHIP. Well what is his status? The first thing. And I said he has applied for landed immigrant and we are in process. And he said, well you have to pay me because he's your brother. So he charged me \$60 for consultation and I paid him, it had to be cash. He pointed out to me that my brother may have TB...”*

*My mom called me saying my brother has been kicked out of the hospital because he didn't pay. He was kicked out with only the robe and the mask. No shoes, nothing, because we have taken everything with us, because they said he was going to stay. When I got there, he was in the waiting area, coughing and the nurse was screaming at him that he was going to contaminate the environment and to cover his mouth. My brother couldn't even breathe. By [the next] Monday [we took] my brother to [a CHC]. He was in pretty bad shape. As soon as we got to the [CHC, the doctor there] said, the first thing he needs is oxygen. So he put the oxygen on my brother. He called an ambulance and made arrangements for my brother to be taken to hospital, but my brother said, no I don't want to go to the hospital because of what happened. The doctor said he was going to see if we could get another place. So we ended up at [another] hospital.*

*We arrived there and the same thing...He doesn't have papers are you willing to pay? I said yes, just take him in. And when I came back to emergency my brother was being looked after. I stay with him all the time and I did like a nurse thing. He went in Monday and my brother died on Thursday. Complications. [Crying] He died."*

This story is only one of the many stories of PHAs who did not receive care in time to save their lives. Many of these stories have been lost with their lives.

## **Diagnostic Tests**

CHCs have small budgets to cover the costs of lab tests, x-rays, and other diagnostic procedures. PHAs often must cover these costs and often go without tests, because they have no money to pay for them. Within hospitals, the costs of diagnostic tests are usually covered by global budgets. Physicians reported tests are not always done to minimize hospital costs. One PHA confirmed her viral load tests were paid for, but were not done on a consistent basis.

Refugee applicants on IFH must prove that any tests they need are for 'essential or emergency' care but they cannot know how serious it is until they have the tests. One PHA nearly lost his sight because he could not afford diagnostic services:

*"I was supposed to go for a CT scan. It wasn't life and death and therefore I had to pay. One of the rules of the IFH was if the condition is not severe, they are not going to cover it. So they didn't cover it. So I suffered. They didn't know what it was, I suffered for about 6 months and finally the microbes spread and went up my eyes and I couldn't see; I lost three quarters of my eyesight. It was very painful. In the end [a CHC] had to pay for everything. (Interviewer: And did they ever accept that this was an emergency?) No. (Interviewer: And did the specialist tell you what could happen if it had gone untreated?) It would lead to blindness."*

## **Drug Treatments**

PHAs who are ineligible for provincial assistance with drug costs are thus denied access to standard drug treatments for HIV. For example, the provincial Trillium Drug Program helps people with low incomes cover the cost of medications for chronic or catastrophic illnesses. Trillium has been a lifesaver for many employed, low-income PHAs who are unable to afford HIV drugs. But it is only available for people who have OHIP so it is only an option for people who have achieved status as a refugee or as a landed immigrant.

The lack of a comprehensive pharmacare program for uninsured people has a negative impact on both the standard of health care that the individual PHA receives and potentially on the health of the broader community:

### *Compromised Standard of Care*

Some physicians indicated that clients without health/drug coverage receive a lower standard of care because there are fewer options for medications. Some physicians felt ethically compromised because they were unable to give uninsured patients the same choices that they gave everyone else. Physicians also expressed concern for patients who manage to get drug treatment but cannot afford to pay for regular tests to monitor the effects of the drugs.

### *Impact on Public Health*

One physician expressed concern about the danger of increasing drug-resistant strains of HIV, by denying treatment to those who need it. Another physician also talked of the risk to the public at large: *"You [create] a larger pool of people who are forced underground and not diagnosed and treated early... You also miss the chance of instructing people to*

*practice safer sex and safe behaviours.*" Physicians cautioned that there is an increased risk of people getting sick with opportunistic infections, such as TB and then passing on these infections.

### **c) Access to Health-Care – Current Strategies**

#### **Informal Networks of Care**

Health care providers manage to provide care for uninsured patients through informal networks with other providers willing to provide some services and through countless hours of effort, searching, connecting, etc. CHCs are a link between the uninsured PHAs and the networks of support but, as mentioned above, their resources are stretched beyond limit.

### **c) Access to Health Care – Recommended Solutions**

#### **Develop Local Health Care Networks for uninsured PHAs**

The informal networks have saved lives and need to be expanded. Information, support & training for health care providers involved is required. Enhanced funding would enable CHCs to meet the increasing needs of this population. A local hospital to champion the issue of immigrant and refugee PHAs as part of its core mission is also critical.

#### **Develop National Network**

Develop a broad-based network across the country that advocates for changes to policies by the provincial & federal governments.

### **e) Access to HIV Treatments - Current Strategies**

#### **Recycling Drugs**

Many stakeholders play a role in redistributing HIV drugs to PHAs who need them including community organizations, physicians, clinics and PHAs themselves. Of the 31 PHAs taking HIV drug treatments, 15 (48%) had difficulty accessing treatment due to their immigration status. Many had received recycled drugs. Several PHAs reported that recycled drugs provided a lifeline for them as they sorted out their immigration status. However, compiling a combination of HIV medications each month is a difficult task. This is one man's story:

*“That was the worst time of my life. Because I am having my fingers crossed to survive. Now the doctor told me, you need serious HIV medication, this is what everybody is getting...But the medication is only as long as I'm in the hospital. Because I survived the pneumonia, which was very bad, I left the hospital. I had to search all over, going to community places, phoning every place with any name with HIV. That's how I came to know about [the ASO]. When I called the office...then I spoke to him, he said, It is your own responsibility to find medication. He was sort of telling me to be more strong. We [get] these donations...sometimes it's people who don't survive and we get their medication, we recycle it. I say I'm available to come and collect medication. Several times I would go and they say, unfortunately we don't have anything. If you are told it is not there, what does it mean to you? It means you go back. I'm not a medical person, but it means that you [can develop] resistance.”*

Physicians expressed concern over the quality control of these drugs. Some patients got left over drugs from among their friends. Sometimes people will take these drugs with insufficient clinical supervision and without the guarantee of a continuous supply.

Service providers take on this role as a desperate response to the profound suffering that they witness. This work is very stressful and frustrating and may also pose legal and professional risks. Physicians often do not have the time or the support to do this work: *"There are more hoops to jump through, more advocacy work needed and nobody there to do it."* PHAs often have to endure a lack of privacy since many people must be involved to help them find treatment.

## **Postponing Treatment**

Many PHAs postpone taking HIV drugs until they can get coverage. One woman reported that her physician told her that she should be on a drug cocktail in 1996, but she didn't start taking one until 2000. One physician felt that the delays in treatment had led to increased hospitalizations.

## **Sharing prescriptions**

We heard stories of PHAs who have drug insurance that get prescriptions and give the drugs to a friend with no drug coverage. There were also cases where couples who are HIV+ share drugs because only one has drug benefits. Their health is compromised because they get less medication than they need.

## **Drug Companies**

Drug Companies may be willing to provide short-term supplies of drugs to physicians upon individual request. However, the requests need to be made over and over again and involve lots of paperwork. Some companies may provide larger drug supplies when they are close to their expiration date.

## **Clinical Trials**

Clinical trials may provide a year or more of regular medication, health care and diagnostic tests which can give people time to sort out their legal status. Uninsured PHAs without drug coverage may enroll in one trial after another to access HIV treatment. Some physicians expressed ethical concerns that people enter clinical trials because it's their only option.

## **f) Access to HIV treatment - Recommended Solutions**

### **Drug Recycling Depot**

Mechanisms for recycling drugs need to be coordinated and enhanced. Funding & drug supplies could come from recycled drugs, drug companies, and individual donations. St. Vincent's Hospital in New York City has developed a comprehensive care and treatment program for undocumented immigrants. This program may be a model to help plan a pilot project in Toronto.

### **Expand provincial program for chronic and catastrophic illness drug access**

The provincial government needs to expand its program to address the pharmacare needs of this population & prevent illnesses that require more complex, urgent care.

## **2. Access to Community Based Social Services**

### **a) Barriers & Impact**

PHAs come to ASOs and ask help to negotiate the immigration and/or refugee process. Service providers identified their need for clear, concise information about these processes and how people going through them qualify for health care, drug coverage, income support, and legal aid. Likewise, agencies serving immigrants and refugees often do not have a thorough knowledge of HIV/AIDS issues and services.

Both physicians and lawyers reported that when they try to refer people to ASOs, uninsured PHAs are often not willing to go because of fears of confidentiality. This puts added pressure on physicians and lawyers to co-ordinate a range of social service and supports that they are not able to provide. One PHA indicated that she only accepted service from an ASO when she really had no choice:

*“ I used to go to [an ASO] for the groceries. But that time I was off work. When I got a job again I stopped ... I don't want people see me and say, Oh my God!”*

This woman's comments are familiar to the staff of ASOs who struggle to provide services to PHAs who are unable to come to ASOs due to the stigma associated with HIV.

PHAs also have fears about asking for help because of their concerns about being 'discovered' and potentially deported because of the information sharing that occurs between government agencies. One participant reported:

*"I was not approaching Immigration, I was approaching the Health department. I need my health card so that I can access the medication. I go there to renew my health card, they punch the computer, and there is a warrant for me. They don't tell me. They say Ok, your health card, you sort it out in an office, number so-so, Airport Road. I do not suspect anything. I get there, the woman punch the computer. She say Ok, wait. One officer comes in the waiting room and says I have got bad news for you. I thought he was going to tell me they can't give me a card [instead he says there is] a warrant for your arrest. [They kept me] for seven days."*

Due to experiences such as this which are quickly shared in immigrant and refugee communities many people are nervous about accessing any type of help. Furthermore, many PHAs are unable to distinguish the roles of community and government agencies in helping them. The concerns of PHAs about disclosure and confidentiality must be taken very seriously by agencies working with this population.

## **b) Current Strategies**

The preliminary work of CAAT and this research project has facilitated the development of relationships and dialogue among community agencies. CAAT has consolidated these pre-existing networks and expanded to include service providers, lawyers and activists working in refugee and immigration services.

## **c) Recommended Solutions**

### **Support, Training and Referral Network for Service Providers**

A support and information network is an essential link in ensuring that information reaches clients. A referral list of services in the Greater Toronto Area that are available to PHAs without legal status, health insurance or drug coverage is a necessary first step to decrease access barriers. This list would need to pay close attention to the linguistic and cultural appropriateness of all services. Staff at ASOs and those working in immigration services need training regarding HIV and immigration issues.

### **HIV and Immigration Advocate**

The health, legal and social services systems in Canada are complex, contradictory, and confusing. The information needed to negotiate the immigration and health care systems is specialized information that takes time to learn and apply: *"Health, social and legal systems in Canada are difficult to negotiate for any newcomer. Negotiating can be an insurmountable obstacle when compounded by serious illness."*

There is a clear and urgent need to have an "HIV and Immigration Advocate" service. This service would advocate where care or services were being denied and would be a resource and trainer for service providers working with this population.

## **3. Access to Legal Services & Information**

### **a) Barriers & Impact**

Twenty-two of the 38 PHAs (58%) reported that a lack of information about the Canadian health care and immigration systems impeded their access to health care. Lawyers and immigration officials often gave them inaccurate, misleading or incomplete information about the immigration process. Here is one family's story:

*"At the airport we did mention to the Immigration our reason for being here was to declare ourselves refugees. The Immigration Officer told me, You can find your way to your Immigration office in the town, which we didn't*



*know was wrong. It was a shock to the Immigration officer in the office. 'It is unbelievable that somebody asked you to come here when you were at the airport. They should have taken care of your case there...' which went against us because it was like we came to Canada as visitors in order to claim refugee status here..."*

Five years after arriving in Canada, this family was still waiting for their refugee application to be processed. For much of that time they have not had health insurance or drug coverage.

Several PHAs reported that they began the process of becoming an immigrant or refugee on their own, only to discover that they had failed to comply with an obscure requirement or deadline that resulted in delay or dismissal of their claim. It is at such points of crisis that people often seek legal assistance. Service providers explained that people are afraid to access legal aid, because they are afraid they will be reported to immigration.

Lack of good legal representation can result in long delays or in the rejection of applications:

*"We had one appeal but the lawyer changed jobs and he gave our file to somebody else... and the time lapsed when we were supposed to have done the claim...we found somebody else but by that time...they had already asked us to leave and they thought we had abandoned our claim. For a long time, maybe for two years, we didn't have any status and we were not doing anything, we were just sitting. And they had a warrant on us."*

Some lawyers and community legal clinics have mistakenly told HIV+ clients that nothing can be done. There are very few lawyers who have expertise in making immigration or refugee claims for PHAs. The number of clients and the urgency of their needs often overwhelm those who do have expertise in this area.

#### **a) Current Strategies**

Service providers refer clients to less than a handful of trusted lawyers who are willing to accept legal aid, and a couple of community legal clinics, who have expertise in both HIV and immigration issues. ASOs reported helping lawyers do some of the preparation that is needed to support a refugee claim or immigration application.

There are few options to fill the large gaps in information regarding the immigration process. CLEO (Community Legal Education Ontario) produces easy to understand fact sheets about the immigration and refugee processes. However, they do not address how to negotiate these if you are HIV+.

**a)**

## Recommended Solutions

### Staff & Information Resources

Funding for staff are needed so that expert services are available at HALCO (HIV & AIDS Legal Clinic Ontario) and other community legal clinics. A clear overview of the rules of the immigration system and guide to health services eligibility related to PHAs is a priority.

A referral list of lawyers who have expertise in HIV and Immigration is essential for ASOs and immigration/refugee services. PHAs expressed a need for information to make clear what to ask a lawyer when they need legal information. Community organizations must develop and distribute information that is clearly independent of government to increase PHAs' trust of that information.

### Professional Development - Training Seminars, Brief Bank, Mentoring Program

Seminars could be organized for lawyers who are interested in learning more about HIV and other health related claims. Ongoing professional development could be supported by a 'brief bank' that contains articles relating to HIV, immigration, and health care issues. CHAMP (Canadian HIV/AIDS Mentoring Program), was established to support physicians care for people with HIV. Similarly, lawyers with expertise in this area of law could be encouraged to mentor other interested peers and articling students.

## 4. Need for a Supportive Environment

### a) Guiding Principles and Values

This project was shaped by fundamental values shared by the Committee for Accessible AIDS Treatment (CAAT). These values include:

- The belief in the inalienable human rights of all human beings, regardless of their immigration status
- The belief that that all health care which is provided in Canada must be non-coercive and meet the same ethical standards and universal standards of care.
- The right to free universal health care.
- The right to freedom from persecution and discrimination.
- A recognition of the significant social and economic contributions of immigrants in Canada

These values are not unique to CAAT. The Canadian government promotes these as core Canadian values. In practice, however, the Canadian government and public are reluctant to extend the rights implied by these beliefs to people who are not Canadian citizens.

During this project, changes to federal law were proposed by the Minister of Citizenship and Immigration and being discussed in a parliamentary process. CAAT will work with its members and allies to monitor and respond to proposed changes and plans for implementation once made. During the course of this project CAAT initiated a local Coalition against Immigrant HIV Testing in response to the proposal of the federal government to test all immigrants and refugees for HIV. For more information on this issue see "*HIV/AIDS and Immigration: Final Report*," by the Canadian HIV/AIDS Legal Network and "*An Ethical Analysis of the Mandatory Exclusion of Refugees and Immigrants who test HIV-positive*" by Hoffmaster and Schrecker.

### b) Shelter from Persecution and Discrimination

Many PHAs who apply for refugee status flee their home countries due to the extreme prejudice and violence enacted against PHAs. A refugee from the Caribbean recounted:

*"And once there was a case where people were found to be positive, people were beaten and thrown out of their houses...houses were burned. Families would disown family..."*

Homophobia and discrimination based on sexual orientation are often prevalent in societies that are intolerant of people living with HIV. Another participant recounted the horrifying events that created the necessity for him to apply to be a refugee in Canada:

*"They called me to the army... [W]hen they called me to a physical I said besides being healthy I am gay. They give me a hard time and keep me in segregation. And I don't know if you can consider it rape or abuse by one of the sergeants for a whole week to prove that I was gay and that I wasn't just saying that to leave the army. They discharged me for medical reasons. The guys from the army knew of course what I did and they were coming and shouting in front of my house and trying to continue their sexual stuff. And so my Mom said, you have to get out of the country. Just from one week to the next I was on the plane, I was not allowed to tell anybody and just like that I came here not knowing what Canada was..."*

Canada welcomes refugees because we recognize the severe violations of human rights that occur every day around our globe. As a haven for those whose rights have been violated elsewhere, we are ethically compelled to protect their rights in Canada. However, this project shows that we often treat applicants, refugees and people without status inhumanely. We make people endure humiliations, long waits, deny access to basic health-care, deny the means to earn a living and we put the onus on them to understand and navigate our complex systems.

Until people have been accepted our systems are punitive. It would be more consistent with our values as Canadians to support people respectfully while they go through these processes. In time, many applicants are accepted. For example, over the course of this project PHA participants were gradually achieving status given the appropriate support. Why did they have to go through so much fear, pain and suffering in the process?

### **c) Universal Health Care**

Canadians place a high value on universal health care. From Health Canada's web-site:

*"The Canada Health Act, passed by Parliament in 1984, has become a cornerstone of the Canadian health system, reaffirming the federal government's commitment to a universal, accessible, comprehensive, portable and publicly administered health insurance system... [The concept of universality] requires that all residents of the province be entitled to public health insurance coverage."*

In principle, universality should apply to anyone residing in the province, regardless of immigration status. Sadly, the technical definition of resident excludes many groups, among them applicants for refugee or landed immigrant status and people who are homeless.

**a)**

## The Need for Balance

The social, human and economic contributions of immigrants, refugees and people without status are often not sufficiently valued in Canada. These groups are often portrayed only as a burden and used as scapegoats for home-grown problems. An exception is when the media catch on to an individual's or family's plight. In these situations they are portrayed and viewed as 'real' people and the treatment they endure offends our Canadian sense of fairness.

This project did not undertake an economic analysis as this was beyond its scope and resources. However, in our search for relevant documents there were a lack of studies in the North American context that did an economic analysis of providing treatment to non status immigrants or refugees. Of course, there would be huge difficulties in such research. We prevent people from making an economic contribution and then blame them for being a cost to society. By denying diagnostic tests and treatments, we ensure that PHAs become seriously ill which prevents their ability to contribute.

When decisions are made about providing early treatment or care to new immigrants, we need to balance the short-term costs of preventative care with the potential benefits of long-term contributions. Everyone we spoke with felt strongly that it made good economic sense for the government to be more active in providing preventative health care.

*"We need to recognize that immigrant and refugee PHAs do contribute to society and people are more than willing to do so if given a chance. The government should issue a temporary drug card to allow anti-retroviral therapy to all who need it. It would be cost effective because it will decrease hospitalization and other costs caring for people when they are very sick. There will be more potential work years lost if people don't get treated early. It's always better to give preventative treatment." HIV Physician*

The United Nation's [HIV/AIDS & Human Rights: International Guidelines](#) (1996 & 98) states:

*"In considering entry applications, humanitarian concerns, such as family reunification and the need for asylum, should outweigh economic considerations".*

Although our recommendations for change have been developed in response to the needs of PHAs, they speak to the need for changes in health care for all immigrants, refugees and those without status who are living in Canada. The solutions that this project has identified could be a model for broader reforms.

# From Research to Action

A major impact of the project is the network it has already built amongst the PHAs and service providers from different sectors (legal, health, social, immigrant, AIDS ). Based upon the project recommendations, CAAT is turning what we learned into action:

- On April 5<sup>th</sup>, 2001 CAAT cosponsored an “Immigration & HIV skills-building forum” for PHAs and service providers. Report from the forum is available through Asian Community AIDS Services (ACAS).
- Task Groups have formed to focus on 3 major action steps:
  - a) "Drug Depot" – develop pilot project to enhance recycling/donation program.
  - a) Information development - develop fact sheets on legal information and service eligibility of PHAs in various stages of the immigration/refugee process.
  - a) Service advocate program - develop resource listing of services available to immigrant/refugee PHAs, develop training module on access advocacy and train service providers/PHAs from target groups using train-the trainer model.
- Increased connections are being made with immigration and refugee lawyers and their associations including the Law Society hosting the launch of the project report.

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## Glossary of Terms

**AIDS**

Acquired Immune Deficiency Syndrome

<b>ASO</b>	AIDS Service Organization
<b>CAAT</b>	Committee for Accessible AIDS Treatment
<b>CHC</b>	Community Health Centre
<b>HALCO</b>	HIV & AIDS Legal Clinic Ontario
<b>HIV</b>	Human Immunodeficiency Virus
<b>OHIP</b>	Ontario Health Insurance Plan
<b>PHA</b>	Person Living with HIV/AIDS
<b>TB</b>	Tuberculosis Bacillus

## **Immigration terms**

<b>Immigrant</b>	Someone who comes to Canada intending to make their home in Canada and to live here permanently. An Immigrant becomes a Permanent Resident if they are granted landing in Canada.
<b>Permanent Resident</b>	An individual who has been granted landing -- the right to live permanently in Canada. Also called a Landed Immigrant.
<b>Landed Immigrant</b>	See "Permanent Resident"
<b>Refugee Claimant</b>	Someone who makes a claim to be a Convention refugee.
<b>Convention refugee</b>	People with a well founded fear of persecution in their home country because of race, religion, political opinion, nationality or membership in a particular social group.
<b>IFH</b>	Interim Federal Health Plan. Covers "essential and emergency" medical expenses for refugee claimants once their application is acknowledged.
<b>Permit holder/ Minister's Permit</b>	People holding a permit given by the Minister of Citizenship and Immigration which gives them temporary status and lets them come to or stay in Canada even though they would not normally be allowed to do so. Some medically inadmissible people are granted permits which allow them to stay in Canada.