How HIV/AIDS impacts Immigrants, Refugees and those without Citizenship Status

People with HIV who are immigrants, refugees or without status (I/R/N-PHAs) are one of the most vulnerable and fastest growing populations affected by HIV/AIDS in Ontario. In 2005 alone, 668 immigrant/refugee applicants tested HIV positive through Citizenship and Immigration Canada, representing 15.7% of the total HIV positive tests reported in Canada that year. In addition, there are others who are not captured in government statistics and therefore cannot be estimated.

The changing demographics of people living with HIV/AIDS highlight the need to reorient existing health and social services to be responsive and accountable. Many I/R/N-PHAs have experienced HIV/AIDS-related stigma, racism, sexism, homophobia, trauma and loss throughout their migration process. For PHAs without status, their fear and frustration in negotiating the (Continued p.2)

What is CBR?

Community-Based Research (CBR) is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities.

Bridging Policy and Practice
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immigration system, the uncertainty of their future and the continual barriers in accessing treatment and care, all work to jeopardize their physical and mental health. Unfortunately, existing HIV/AIDS, settlement, and government sectors often work in silos so that HIV/AIDS issues become largely invisible. The lack of coordinated efforts among these sectors contributes to and reinforces multiple access barriers experienced by I/R/N-PHAs.

Building Collaborative Partnerships through CBR
Best practice evidence suggests that effective programs and services must be informed by relevant research and supported by inclusive policies. Most of the studies that I have been involved in or initiated are community-based. CBR plays an important role in informing practices that serve marginalized populations because it involves meaningful community participation and social action outcomes.

One example is the initial study I undertook on improving treatment access for I/R/N-PHAs. It started in 1999, when we found an increasing number of non-insured PHAs trying to access health services. A number of service providers came together to try and problem solve and it evolved into a community-based coalition that includes many health centres, hospitals, AIDS service organizations, legal clinics and PHAs, many of whom had a hard time participating because they were living underground. We attempted to support each other in providing care and advocating for access to treatment and health coverage.

A major barrier was the lack of documented evidence of the experiences of I/R/N-PHAs beyond our front-line experiences and observations. As a result, we developed a community action research project in 2000 with a grant from the Ontario HIV Treatment Network. We interviewed 70 service providers and I/R/N-PHAs. The preliminary findings were disseminated to the community for critique, analysis and action planning.

Work groups were established to follow-up on each of the key recommendations derived from the research findings.

Translating CBR Evidence into Action
First, our study identified the shortage of legal services as a barrier. There are few culturally competent and HIV-experienced immigration lawyers. We worked with the HIV/AIDS Legal Clinic of Ontario and developed a series of fact sheets written in plain language for PHAs and service providers so they could access appropriate legal help. We co-authored a chapter in the HIV legal advocate training manual on immigration issues and built a partnership with the Law Society of Upper Canada to educate members on the issues.

Second, a key problem was the lack of access to HIV treatment by PHAs without health coverage. We brought together pharmaceutical, government and community representatives to problem solve. The result was the “Drug Depot” that gives PHAs compassionate access to drugs while sorting out their immigration status. This program has since become the Treatment Access Program, a core program at the Toronto People with AIDS Foundation. Today, over 300 physicians and 300 PHAs have accessed this program to obtain medication on compassionate grounds.

Third, we identified the need to facilitate access to different services for I/R/N-PHAs. There are cultural and linguistic barriers, barriers in how to negotiate service access and how to best provide support to clients who do not have full coverage. We developed the HIV and Immigration Service Accessibility Training Program, for both service providers and PHAs. The program is housed at Regent Park Community Health Centre and is coordinated by an I/R/N-PHA. To date, seven series of training workshops have been conducted and over 150 PHAs and service providers from various sectors have participated. Many informal networks and stream-lined service arrangements were developed as a result.

“...I believe that best practices in CBR are not something to be taken for granted. Rather they need to be achieved through the application of a number of key principles. A cross-sector community partnership model that emphasizes community ownership and empowerment is very important.”

Dr. Alan Li

Developing Best Practices in CBR
While “CBR” has become a buzz word in health research, not all CBR projects share the same principles of community empowerment and capacity building. In the past, I have participated in “community-based” studies that were academically driven. While some honor the spirit of equitable partnership and meaningful participation, many do not. Although these studies have had community advisory groups or collaborative partnerships on paper, the research questions, designs, implementation plans, data analysis and other research processes have all been pre-determined by the researchers. Community members feel like they are just asked to rubber stamp everything and their input is not valued. This has resulted in disempowerment, frustration and distrust among community members.

I believe that best practices in CBR can be achieved through the application of a number of key principles. A cross-sector community partnership model that emphasizes community ownership and empowerment is very important. Following the success of the Treatment Access Project, we are using a similar CBR model to research mental health service access for I/R/N-PHAs. We built a research team with members from ASOs, health service organizations and academic institutions. A specific component of the study involved recruiting and training I/R/N-PHAs to be co-researchers and to help analyze the data.

It is important to apply the Greater Involvement of People living with HIV/AIDS (GIPA) principle in all phases of...
Immigrant, Refugee and Non-Status PHAs: Innovative Think Tank Sets New Directions

Dr. Alan Li and Keith Wong

On June 7th, 2006 over 60 people participated in an innovative Think Tank focusing on HIV and immigration. The event, From Access to Equity: A Think Tank on Policies, Programs and Research Issues Facing Immigrant and Refugee PHAs, allowed participants to share varying perspectives on the challenges facing I/R/N-PHAS, and to identify strategic ways to advance collaborative action. Participants included PHAs, service providers, policy makers and researchers from various sectors.

A key challenge faced by these PHAs is the complex and confusing set of government policies from different levels of government that affect legal status, access to health care, social assistance, housing, education and employment. In many instances, these policies work at cross-purposes, sending mixed messages that further compromise self care, as well as economic and social engagement. Through cross-sector dialogue, the participants identified three key priority directions:

1. Ensure access to culturally competent and coordinated services.
   - The key challenge is the lack of accountable, culturally responsive and relevant service infrastructure. Research should monitor and evaluate the effectiveness and accessibility of current services and help inform standards of best practices in HIV testing, support and health care management.

2. Develop a holistic research agenda that addresses social determinants of health.
   - Major gaps exist in providing culturally relevant research that integrates various social determinants of health. Such research should also shed light on social norms and behaviours that impact on sexual practices, the impact of stigma and disclosure barriers to HIV prevention and care, and coping strategies and protective factors that promote resiliency in the face of compounded social exclusion.

3. Develop an effective evidence-based advocacy framework.
   - To effectively prevent further HIV infection and reduce barriers to care, governments and service delivery organizations need to work together with PHAs to identify discriminatory policies and practices that put them at risk, and to collaborate with broader campaigns that promote “access without fear” for all populations.

The Think Tank was co-sponsored by the Committee for Accessible AIDS Treatment (CAAT) and the Ontario HIV Treatment Network (OHTN) and also received funding support from the Public Health Agency of Canada and the Institute of Infection and Immunity, Canadian Institutes of Health Research.

“The Think Tank was an important step in bringing together multiple stakeholders to critically examine current policies, programs and research on HIV and immigration and to identify future strategic directions,” said Dr. Sean Rourke, Scientific and Executive Director, OHTN.

CAAT has conducted extensive and comprehensive literature reviews and focus groups with stakeholders, and released Status, Access and Health Disparities: A Review of Relevant Policies and Programs to Improve Access to Services for Immigrant and Refugee PHAs. It serves as a useful tool to engage stakeholders in the development of a joint focus for advocacy and policy development.

The organizers are committed to the dissemination of the Think Tank Summary Report. They wish to actively seek partnership opportunities to move forward with the strategic directions identified, and to develop further action. The Summary Report can be downloaded at www.HIVimmigration.ca/thinktank

For more information, please contact Keith Wong, Training Coordinator, Ethnoracial Treatment Support Network (ETSN) keithwong@inspiract.com
Displacement and Empowerment: One Man’s Journey

Josephine Pui-Hing Wong

Five years ago, Victor Inigo came to Toronto from Mexico. A person living with HIV/AIDS who had experienced discrimination, harassment and violence in his homeland, Victor knew no one in his adopted city. He met someone with whom he felt deeply connected, but the relationship ended as soon as he disclosed his HIV positive status. He felt extremely isolated until he connected with the Centre for Spanish Speaking Peoples, where he received counselling and support and was encouraged to get involved in the community. That advice turned out to be extremely valuable, to both his community and to himself. He volunteered as an interpreter and accompanied individuals living with HIV/AIDS to medical appointments. “After we finished at the doctor’s, these people would always ask to talk. Sometimes they cried, sometimes they told their story ... when I started to learn more in my training ... I realized that what I had been doing was peer counselling.” Without a doubt, Victor touched the lives of many refugee people living with HIV/AIDS.

Later, he worked as the HIV and Immigration Service Access Project Coordinator for the Committee for Accessible AIDS Treatment. He also served as a research assistant for a study on improving mental health service access for immigrant, refugee and non-status people living with HIV/AIDS, as a peer counsellor for the Ethnoracial Treatment Support Network, and as a support counsellor at the Hamilton AIDS Network. For five years, Victor’s life as a non-status refugee person living with HIV/AIDS was dominated by the harsh reality of loneliness. For Victor, and for the many people living with HIV/AIDS he worked with, this loneliness became strongly associated with fear. “The fear of opening up, of disclosing, of being hurt, of being rejected ... all these fears, sometimes they just immobilize us ... the fears of being deported ... it’s all fear.” The prospect of returning to Mexico invoked additional fear: “Believe me, I am terrified, I am totally scared. But then I think, if we don’t face our fears we can’t move.” In June 2006, the Canadian Immigration and Refugee Board (IRB) rejected his refugee protection claim, in spite of his employment experiences and his invaluable work in supporting immigrant, refugee and non-status people living with HIV/AIDS in Toronto. He could have reapplied on humanitarain and compassionate grounds, but he didn’t. Instead, he kept the IRB decision to himself.

Reflecting on that decision, he said, “I felt so depressed, so lost. Never, never in my life had I felt that bad. But at the same time, I had never felt more empowered or more recovered, because of the work I was doing. I connected with all the real things about myself, all the good things about myself, all the strengths in me. This is something that has truly changed me.” In the summer, he continued serving others by working with his colleagues and peers at the International AIDS Conference in Toronto. He made connections with AIDS activists from Mexico, and became determined to continue his work there in the years ahead. In October, Victor left Toronto for Mexico. He wanted to leave Canada with dignity rather than ‘being deported.’ “I want to live ... I am forty-something, I am HIV positive, I want to live ... five years is a long time ... I really think I have waited long enough. But when I think of Canada, I will always remember the people who supported me to rediscover my heart.”

For more information, please contact Josephine Pui-Hing Wong, Doctoral Fellow, CIHR-IGH and CIHR-Health Care, Technology and Place Collaborative Program jph.wong@utoronto.ca
The HIV discourse affecting immigrants and refugees from diverse ethno-racial communities tends to focus on issues of screening and the identification of risk factors. There have been very few studies that have examined the lived experiences of immigrant, refugee and non-status people living with HIV/AIDS (I/R/N-PHAs) in Canada. Fewer still are studies focusing on this population that meaningfully engage them throughout the research process.

The Committee for Accessible AIDS Treatment (CAAT) conducted community-based research in 2001 that has since led to innovative strategies in facilitating access to legal, health, and community social services for this population. Building on this success, CAAT initiated another community-based research project in the fall of 2005 to better understand mental health needs, and to improve access to mental health services.

In this partnership project involving Toronto’s five ethnoracial AIDS service organizations, I/R/N-PHAs originally from South Asia, Southeast/East Asia, Africa, the Caribbean, and Spanish-speaking countries in Latin America are the focus of this study. The entire project consists of six interconnected components that are grouped into two phases. In the first phase, the research team conducted focus groups, interviews, surveys and a peer empowerment exercise to examine social determinants affecting mental health, the capacity of existing services to address these determinants, and elements considered as best service delivery practices. Grounded by these findings, the second phase of the study seeks to promote inclusive mental health support by developing a training curriculum for service providers, pilot-testing and evaluating best practice models, and facilitating inter-sectoral collaboration and policy changes.

Guided by the principles of Greater Involvement of People living with HIV/AIDS (GIPA), this study engages I/R/N-PHAs in every aspect of the research process. Through their presence on the Research Advisory Committee, community members play an important role in setting strategic directions for the study from the onset. I/R/N-PHAs will be recruited for paid positions to undertake the day-to-day research activities. As well, a group of 20 will be involved in data analysis and the synthesis of best practice guidelines. The study will not only build the capacity of people living with HIV/AIDS from these ethno-racial communities, but situate I/R/N-PHAs at the centre of the HIV-immigration discourse as active contributors.

“The CAAT project has been an eye opener and a great learning experience ... I have been impressed with the research team as a whole for the complete dedication and enthusiasm towards the success of the project. The project has recognized the greater and meaningful involvement of people living with HIV/AIDS and included ethno-racial communities of diverse backgrounds; to me it is a milestone in Community-Based Research.”

Henry Luyombya,
Peer Research Assistant

Preliminary analysis of the study data has pinpointed a number of interconnected mental health stressors faced by I/R/N-PHAs including their HIV condition, experiences with the migration and settlement process, and social stigma and discrimination. Like the ethno-racial community at large, cultural beliefs play an important role for I/R/N-PHAs by influencing their understanding of mental health and subsequently dictating the strategies they use to cope. When accessing formal support, they often report experiences of ill treatment from service providers that are perceived to be rooted in the ignorance and
Researchers from the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) and the HIV Social, Behavioural and Epidemiological Studies Unit at the University of Toronto recently completed a research study to understand how African and Caribbean communities in Toronto experience and respond to stigma, denial, fear and discrimination associated with HIV/AIDS. The research grew out of efforts by ACCHO to respond to the disproportionate impact of HIV on Toronto's African and Caribbean communities.

Data was gathered through in-depth interviews and focus groups with 30 HIV positive participants and 74 participants who were HIV negative or who did not know their HIV status. Participants were drawn from Ethiopian, Kenyan, Somali, Guyanese, Jamaican and Trinidadian communities in Toronto. Participants identified stigma as a serious issue with several sources. They highlighted the need to raise awareness about HIV, combat stigma, and tackle systemic issues such as racism and unemployment which impact on the overall health of their communities.

The study, funded by the Ontario HIV Treatment Network and titled HIV/AIDS Stigma, Denial, Fear and Discrimination among People from the sub-Saharan African and Caribbean Communities Living in Toronto, benefited from substantial involvement of community members. The research team included representatives from community-based organizations who participated in all aspects of the study. A Community Advisory Committee provided assistance and advice throughout the research process, and members of the communities were hired to assist with study coordination, recruitment, data collection and dissemination. An important achievement was the development of a partnership agreement between ACCHO and the HIV Social, Behavioural and Epidemiological Studies Unit that guided how the university and community-based organizations were going to proceed in the research process.

A community report is now available. Fact sheets are also being prepared and consultations are planned with community members and other stakeholders to share the study findings and prepare responses to the issues identified. A community forum was held in November 2006 and another forum is planned for February 2007. For copies of the community report, please visit www.accho.ca.


Community Advisory Committee: Vuyiswa Keyi, Beatrice Nday wa Mbayo, Senait Teclom, Hiwot Teffera.

For more information, please contact Dr. Liviana Calzavara, HIV Social, Behavioural and Epidemiological Studies Unit, University of Toronto.

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HIV/AIDS Stigma in Toronto’s African and Caribbean Communities

Fauzia Gardezi, Liviana Calzavara, Winston Husbands and Wangari (Esther) Tharao

Understanding and Improving Access (continued from p.3)

personal biases of practitioners. Many also find a lack of information on services, long wait times, and language issues as barriers to their timely access to mental health care.

Improving access to mental health services for this population will require a comprehensive strategy that involves collaboration among all stakeholders, including IRINPs, service providers, and policy makers. It is therefore important for projects like this to continue being championed by funders so that the voices of marginalized populations will be heard and an action plan for an inclusive mental health service model can be properly developed and implemented.

“There is never a refugee or non-status person living with HIV/AIDS who doesn't have a problem and each and every story [that I heard] describes different versions of the same sad story. I personally would love to see some changes through our research project which could change and make a great difference to a lot of people.”

Amutha Sangamu,
Peer Research Assistant

For more information, please contact Y.Y. Chen, Research Project Coordinator, Committee for Accessible AIDS Treatment (CAAT)

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Top: Amutha Sangamu, bottom: Henry Luyombya

Understanding and Improving Access (continued from p.3)
The Youth Migration Project: Understanding HIV Vulnerability among LGBT Youth

Robb Travers and Suhail Abualsameed

The Youth Migration Project (YMP) was designed to assess the HIV vulnerability and health and social service needs of lesbian, gay, bisexual, transgendered (LGBT) and Two-Spirited youth who migrate to Toronto from other cities, towns and countries, including immigrant, refugee and non-status youth. The Project emerged out of an increasing concern for these youth, and sought to understand their vulnerability to HIV through a lens of the social determinants of health.

Led by Co-Principal Investigators Carol-Anne O’Brien and Robb Travers, the team included service providers, community activists and researchers with expertise in LGBT youth and HIV issues. Ninety youth and key informants were interviewed. The youth came from twenty-two countries and ranged in age from 16 to 25. While the YMP was conducted to help develop local prevention initiatives, its findings have broader implications, and can serve as a catalyst for other communities wishing to address similar issues.

The findings indicate that youth came to Toronto for a variety of reasons: to flee war, political repression, violence and discrimination; to escape homophobia in families and in religious institutions; and to search for safe LGBT communities that offer the prospects of freedom.

Most youth indicated that, on their arrival, they encountered poverty; problems attaining HIV medication for HIV-positive refugee youth; ethno-specific LGBT groups unfriendly to youth; and sexual exploitation.

In response to these situations, youth avoided their cultural communities, often leading double lives; and would visit relatives only when they were hungry, frequently discovering that relatives were very helpful until the youth’s sexual orientation was discovered. While happy to leave oppression behind, the emotional impact of migration was intense: many felt lonely and depressed, and described a profound sense of loss.

“"I had hell when I first moved here. I thought it was going to be easy. It was really hard. I needed somewhere to live. Money … God, you really need it here. When I moved here, I had no job."

For policy-makers and service providers, YMP enhanced understanding and awareness regarding:

- the impact current policies (e.g., welfare, immigration, housing) have on migrant youth;
- health and social service supports required by migrant LGBT youth;
- risk factors that may contribute to HIV vulnerability among migrant LGBT youth;
- HIV prevention needs for migrant LGBT youth.

In addition, the interviews and focus groups had the benefits of improving peer connections; increasing youth involvement in the community; and improving youth awareness and knowledge of community resources.

In terms of capacity building, the Project advanced the collaborative involvement of project partners in data collection, analysis, interpretation and dissemination; as well as in learning exchanges that helped participants better understand the nature of each other’s work.

A community forum was held on poverty and migration issues among LGBT and Two-Spirited youth. It brought together a national LGBT policy organization (EGALE Canada), a key LGBT community service provider (Supporting Our Youth) and a CBR project team (YMP). Approximately 90 community leaders, service providers, youth, and policy makers from federal and provincial governments and NGOs attended.

The YMP research was a highlight of the forum, as was the keynote address by the Honourable George Smitherman, Ontario’s Minister of Health and Long-Term Care.

YMP Fact Sheets were launched at the forum. They contain a section entitled “What can we do?” that highlights recommendations for community and policy change. These are available online at: www.actoronto.org/website/research.nsf/pages/youthmigration

Partners:
- AIDS Committee of Toronto
- Asian Community AIDS Services
- Central Toronto Youth Services
- Trans Program at the 519 Church Street Community Centre
- Supporting Our Youth
- Two-Spirited People of the First Nations
- Black, Lesbian, Gay, Bisexual Initiative for Youth, Centre for Addiction and Mental Health
- School of Social Work, Ryerson University

Funds provided by:
Featured Organization:
The Committee for Accessible AIDS Treatment (CAAT)

CAAT is a coalition of more than 30 Ontario-based organizations from the legal, health, settlement and HIV/AIDS sectors. It was formed in 1999 to improve treatment and service access for marginalized people with HIV/AIDS. Since its inception, CAAT has been at the forefront of education, research, service coordination and advocacy on issues related to HIV, immigration and service access.

In 2001, CAAT undertook a groundbreaking collaborative community-based action research project: Improving treatment access for PHAs who are immigrants, refugees and without status. The study documented the challenges faced by these vulnerable PHA groups and engaged stakeholders from various sectors to develop a joint action plan to address these barriers. As a result of the study, several innovative initiatives were developed that continue to this day:

- The HIV Treatment Access Program at the Toronto People with AIDS Foundation that facilitates compassionate access to HIV treatment medications for immigrant, refugee and non-status PHAs.
- The HIV and Immigration Service Access Training Program based at Regent Park Community Health Centre in Toronto that facilitates provider and PHA skills development on HIV-immigration related issues.
- Providing accessible legal information on HIV and immigration in collaboration with the HIV/AIDS Legal Clinic of Ontario.
- A provincial working group on health care access for PHAs without full status in Canada.

Save the date! The OHTN is a proud sponsor of the Community-Campus Partnerships for Health’s 10th Anniversary Conference – Mobilizing Partnerships for Social Change, April 11-14, 2007 in Toronto, Canada. To register, please go to: www.ccph.info

The 16th Annual Canadian Conference on HIV/AIDS Research: Successes, Challenges and Opportunities is taking place in Toronto, Canada April 26-29, 2007. You can register at the following website: www.seatoskymeetings.com/cahr/

Community-Campus Partnerships for Health (CCPH), in conjunction with the Wellesley Institute, hosts an interactive list-serv which provides valuable information related to community-based participatory research. To subscribe, please go to the following website: http://mailman1.u.washington.edu/mailman/listinfo/cbpr

We Welcome Your Feedback Please feel free to send us any comments or suggestions about this newsletter, as well as any ideas on content you would like to see in future issues of Compass. Please email us at: compass@ohtn.on.ca

Ontario HIV Treatment Network (OHTN): Its mission is to optimize the quality of life of people living with HIV in Ontario and to promote excellence and innovation in treatment, research, education and prevention through a collaborative network of excellence representing consumers, providers, researchers and other stakeholders. www.ohtn.on.ca

Ontario AIDS Network (OAN): A network of community-based organizations formed as a grass roots response to the need for AIDS services and information. Through advocating, supporting and caring, the OAN enhances the ability of its members to continue to improve the quality and length of life of those infected and affected by HIV/AIDS and to prevent the spread of HIV/AIDS. www.ontarioaidsonetwork.on.ca

Community Linked Evaluation AIDS Resource (CLEAR): Through community direction and joint leadership, CLEAR provides the opportunity for equitable access to evaluation services and expertise to increase the effectiveness, efficiency and relevance of Community-Based AIDS Organizations and HIV/AIDS programs in their response to HIV/AIDS. www.fhs.mcmaster.ca/slru/clear

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