



Toronto HIV/AIDS Community Planning Initiative (TCPI)
Final Report
March 2007

Message from the Toronto HIV/AIDS Community Planning Initiative Co-Champions

As Co-Champions of the Toronto HIV/AIDS Community Planning Initiative (TCPI), we are pleased to introduce this report outlining a strategic plan to improve the delivery of HIV/AIDS services in Toronto.

The TCPI process provided organizations in Toronto an opportunity to come together to plan for the future. Participating organizations and individuals brought their knowledge, commitment and expertise to the process. Together, we have created more opportunities to work collaboratively to address the needs of people living with and at risk of HIV/AIDS. New partnerships and initiatives, developed throughout the process, have already led to service delivery improvements.

The report outlines a 10-point plan for improving the system of service delivery in Toronto. We are confident that this plan will make a positive difference for people who are living with, affected by and at risk of HIV/AIDS. We hope that both HIV/AIDS organizations and those in broader health and human services will take up this plan as they do their own strategic and operational planning, building on the last two years of planning work that we have done together.

We wish to thank the AIDS Bureau, Ontario Ministry of Health and Long-Term Care, for the opportunity to do this work; the TCPI Steering Committee members whose commitment was reflected in the significant time and energy they contributed over the past two years; and all of the participating TCPI organizations who contributed ideas, time and effort in encouraging participation by people living with and at risk of HIV infection. Thanks also to Dr. Robert Remis of the Ontario HIV Epidemiologic Monitoring Unit at the University of Toronto and to our planning team of Deborah Leach, Dino Paoletti and Bonnie Simpson. Most of all, we want to thank those people living with HIV and those at risk of HIV infection who contributed ideas based on their own experiences of having navigated the system.

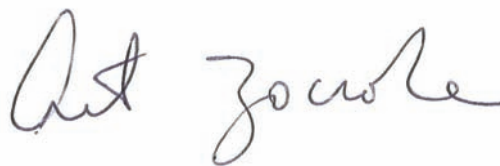
Sincerely,



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Toronto HIV/AIDS Community
Planning Initiative

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Executive Summary

EXECUTIVE SUMMARY

This report outlines a strategic plan for HIV/AIDS services in Toronto over the next three—five years. The plan was developed by the Toronto HIV/AIDS Community Planning Initiative (TCPI), a group of service provider organizations that included those specializing in HIV/AIDS, as well as a range of broader health and social service organizations that offer HIV-specific programs or other programs relevant to people living with HIV/AIDS (PHAs).

Purpose of the Planning Process

The Toronto HIV/AIDS Community Planning Initiative (TCPI) planning process was developed in response to guidelines issued by the AIDS Bureau, Ministry of Health and Long-Term Care (MOHLTC). This process required all communities in Ontario to develop a plan for HIV/AIDS and related services in their communities. The Ministry guidelines stemmed from recommendations of the Ontario Advisory Committee on HIV/AIDS (OACHA) and identified the following key objectives for local HIV/AIDS planning:

“To develop a community HIV/AIDS strategy that responds to local needs and reflects provincial goals and directions.”

To improve access to and co-ordination of services for people living with HIV and populations at risk.

To provide more integrated, comprehensive, effective, efficient care and support services.”¹

The planning time frame in most communities was 12 months, but because of Toronto's size and complexity, the local process took just under two years, from the Spring of 2005 until March 2007.

TCPI's efforts have focused on Toronto's HIV/AIDS services overall and not on individual organizations. It concentrates on system-level issues that can best be addressed through coordinated and collaborative community responses. The plan is not intended to replace the strategic or operational plans of individual organizations or programs, but rather, to inform these plans.

This plan is an initial step in ongoing planning and coordination in Toronto. The 10-point set of priorities recognizes that, in order to address diverse HIV/AIDS-related needs and service gaps, Toronto requires a broad-based, ongoing HIV/AIDS planning and coordination function.

¹ “Improving Services for People with HIV and Communities at Risk: Guidelines for Community Planning”, AIDS Bureau, Community Health Unit, Ministry of Health and Long-Term Care, May 2004.

Structure of the Planning Report

The report is structured as follows:

Section 1 outlines the purposes and context for Toronto's planning process.

Section 2 provides an overview of the planning structure and process.

Section 3 presents the values developed and approved by the large TCPI group to guide the process.

Section 4 presents highlights of relevant planning data (e.g., epidemiological data, social context).

Section 5 presents themes from the consultations conducted as part of the planning process.

Section 6 contains the plan for Toronto, composed of three elements: a vision of key features of a future HIV/AIDS system in Toronto; a 10-point set of priorities; and recommendations related to accountability for plan implementation.

Section 7 outlines key follow-up steps to begin implementing the plan.

The Planning Structure and Process

Toronto's process was divided into two phases, each approximately one year in length.

Phase One included organizations and programs that receive ongoing funding from the AIDS Bureau (MOHLTC) and focused on developing foundational pieces (e.g., values, vision) for the process, as well as data collection and analysis. During Phase Two, representatives from HIV clinics and a broader set of organizations relevant to the needs of people living with and at risk of HIV/AIDS were invited to participate, and the focus shifted to plan development (See Appendices A and B for a Glossary of terms and a List of participating organizations and programs).

TCPI planning was carried out under the following structure:

- Two Co-Champions, appointed by the AIDS Bureau, served as overall chairs for the process. These Co-Champions were Ruthann Tucker, Executive Director of Fife House Foundation, and Art Zoccole, Executive Director of 2-Spirited People of the 1st Nations. These individuals also served as Co-Chairs of the TCPI Steering Committee.

- A Steering Committee guided the process. Over the course of the process, those who served on the Steering Committee included: Art Zoccole (2-Spirited People of the 1st Nations), Barbara Macpherson (Toronto Public Health), Cathy Szabo (Etobicoke York Community Care Access Centre), Catherine Adams (Casey House), Don Chiro (Casey House), Eduardo Garay (Centre for Spanish Speaking Peoples), Juanita Smith (Black Coalition for AIDS Prevention), Lori Lucier (AIDS Committee of Toronto), Murray Jose (Toronto People With AIDS Foundation), Ron Lirette (community member), Rosemary Erskine (African Community Health Services), Ruthann Tucker (Fife House) and Stephanie Karapita (Casey House).
- A large group of HIV/AIDS organizations and programs participated in the process through interviews, questionnaires, focus groups and/or large group meetings.

The following were key elements of the planning process:

Development of foundational underpinnings

The initial stages of the work focused on establishing key foundational pieces. These included: values that should guide the process (presented in section 3); a vision of desired features of a future HIV/AIDS system in Toronto (presented in section 6, as the first component of the TCPI plan); a project Steering Committee and its Terms of Reference; and conflict resolution guidelines for the process (See Appendix C).

Meetings of the TCPI Large Group

Four large group meetings were held over the course of the project. On each occasion, participants received information about the TCPI's progress and were asked for their feedback and contributions on topics that would become key elements of either the plan or the planning process. A significant outcome of the large group meetings was the development of Working Groups to begin to address the Recommendations.

Information Collection: process

While the project was not intended to be a comprehensive needs assessment, information about system strengths and limitations was collected. Information sources included service users, service providers and existing epidemiological and demographic data and reports. Original information collected was qualitative and anecdotal.

Data collection took place over a 10-month period and consisted of the following:

On-line and hard copy questionnaires were completed

by service users and potential service users. Hard copy questionnaires were available in French, English, Simplified Chinese, Traditional Chinese, Spanish and Portuguese.

Eleven focus groups were held, involving people who use services of Phase One organizations and programs. Participants were primarily HIV+ people, although some were partners or family members of a person with HIV/AIDS and others were considered at risk for HIV/AIDS. Participating agencies promoted the groups and recruited members. Participants were offered an honorarium, Toronto Transit Commission (TTC) tickets and a child care allowance.

Three focus groups were held with front-line service workers (staff and volunteers).

An on-line questionnaire was provided to front-line staff and volunteers.

A focus group was held with representatives of organizations that joined the process in Phase Two.

Interviews were conducted with Executive Management (generally a senior management representative and a Board representative) of Phase One organizations.

Agency questionnaires were completed by Phase One participants about the services they provide.

Four meetings of the large TCPI group were held.

Overall participation levels were as follows:

People living with, affected by or at risk for HIV/AIDS:

79 focus group participants

89 questionnaires

Service providers:

27 focus group participants

23 individual staff questionnaires

28 interviews with Executive Management representatives (the number of people involved in each interview ranged from one to five individuals, with the majority involving one or two)

23 agency service questionnaires

Process Limitations

It is important to acknowledge the limitations of the information collection process:

- While efforts were made to hear from a wide range of people, those who participated were connected to services. The process relied on front-line workers' views about the

needs of people at risk of HIV who were not connected.

- Not all TCPI agencies completed the survey concerning their service offerings and some questionnaires were incomplete. In the end, the real value of this survey lay in the views expressed about current HIV/AIDS services and suggestions for the future.
- Developing the scope for Phase Two was challenging, particularly balancing the need to involve relevant organizations and sectors while keeping the process manageable in size. The Steering Committee focused on inviting into the process organizations or sectors identified by Phase One organizations as those used most frequently by their clients and others seen as critical to the future delivery of services in Toronto (e.g., Community Care Access Centres (CCACs)). As the process evolved, additional organizations continued to join.

Guiding Values

The process was guided by the following values, developed by the TCPI large group:

- Greater Involvement of People Living With and Affected by HIV/AIDS (GIPA principle)
- Driven by documented and expressed needs
- Inclusion
- Respect and integrity
- A social justice and anti-oppression approach
- Accountability

These values are described in section 3 of the report.

Strengths of Current HIV/AIDS and Related Services

An important assumption underlying the TCPI process was that it should build on strengths of the current HIV/AIDS and related service systems. The strengths, identified in discussions with people living with HIV and service providers, include:

- diversity of HIV/AIDS Service Organizations, programs and settings;
- strong community-based response;
- services that make a difference;
- harm reduction programs based in communities settings where other services are available;
- many informal inter-organizational partnerships and

working relationships;

- human resource strengths; and
- support to the sector through networks, funding, policy and research.

These are described in section 5.1 of the report.

Limitations and Challenges

Limitations and challenges relate to both HIV/AIDS-specific services and to broader health and social services. Themes concerning limitations and challenges consisted of:

- lack of access to up-to-date information about HIV/AIDS services;
- need for a system of services where access can be gained at any entry point;
- need for appropriate, safe and affordable housing and shelter;
- lack of responsiveness by broader (non-HIV-specific) health and social services;
- barriers to HIV/AIDS services;
- access to affordable, effective medications;
- the need to enhance income and employment-related supports;
- ambivalence about harm reduction;
- need for coordinated, targeted and innovative prevention education strategies;
- substantial service gaps remain.

These are described in section 5.2 of the report.

Growing and Emerging Needs

The following themes emerged in discussions about growing and emerging needs:

- population demographics: diversity and aging;
- need for supports to living well longer — whole person wellness approach;
- increasing poverty;
- children growing up with HIV/AIDS;
- impacts of long-term use of medication;
- HIV and drug use;
- co-infections.

These are described in section 5.3 of the report.

Plan for the Future

The plan consists of three main elements:

- Vision: key features of a future HIV/AIDS system;
 - Recommended Priorities;
 - Accountability: Implementation Monitoring and Reporting.
- The Plan is presented in section 6.

Vision: key features of a future HIV/AIDS system

The following were identified as desired features of a future system, set out as goals toward which we will strive:

- Client-directed services
- Needs driven
- Comprehensive and responsive
- Accessible
- Culturally competent and grounded in an anti-racist, anti-oppression framework
- Coordinated and collaborative
- A focus on ongoing system quality improvement
- Efficient and effective

Recommended Priorities

Ten recommended priorities were established for realizing positive changes in Toronto over the next three to five years. As noted above, the plan does not attempt to address all service gaps identified. It provides a framework through which issues and gaps that would benefit from coordination and collaboration can be addressed.

- 1 Establish an ongoing HIV/AIDS planning and coordination committee.
- 2 Develop an accessible, coordinated HIV/AIDS service information system.
- 3 Promote integrated, innovative and targeted prevention education strategies.
- 4 Improve the responsiveness of health and social services to people living with HIV/AIDS.
- 5 Enhance the capacity of HIV/AIDS-specific programs and services to serve more diverse communities across Toronto.

- 6 Improve access to a range of affordable and appropriate housing for people living with HIV/AIDS.
- 7 Advocate to address income and employment-related needs.
- 8 Develop a coordinated training strategy targeted at HIV/AIDS organizations and programs.
- 9 Promote infrastructure partnerships and address human resource retention issues.
- 10 Coordinate implementation of Toronto's HIV/AIDS Plan with Local Health Integration Networks (LHINs), provincial HIV/AIDS strategies and other emerging initiatives.

Accountability: Implementation Monitoring and Reporting

The report recommends the development of a simple accountability framework to monitor the implementation and outcomes of this plan. This framework, with a focus on the service system overall rather than on individual organizations, would collect minimal information needed to help track:

- Progress on the implementation of the plan (i.e., what has happened in relation to the recommendations and Working Group activities); and
- Improvements that have been made for people living with HIV/AIDS (i.e., system outcomes). This aspect of the monitoring could be based on the TCPI "Vision: features of a future HIV/AIDS system", as well as on gaps and issues identified above.

The Next Steps

The next steps in this process include:

- presentation of the plan by the TCPI Co-Champions to the AIDS Bureau, MOHLTC;
- development of a dissemination plan and tools for communicating the results of the TCPI planning process;
- development of an implementation plan that outlines the staging of each recommended priority over the next three to five years; and
- development of a work plan (focusing on major milestones) to guide the implementation process.

INTRODUCTION

1. INTRODUCTION

This report outlines a strategic plan for HIV/AIDS services in Toronto over the next three—five years. The plan was developed by the Toronto HIV/AIDS Community Planning Initiative (TCPI), a group of service provider organizations that included those specializing in HIV/AIDS, as well as a range of broader health and social service organizations that offer HIV-specific programs or other programs relevant to people living with HIV/AIDS (PHAs).

1.1 Purpose

The Toronto HIV/AIDS Community Planning Initiative (TCPI) planning process was developed in response to guidelines issued by the AIDS Bureau, Ministry of Health and Long-Term Care (MOHLTC). This process required all communities in Ontario to develop a plan for HIV/AIDS and related services in their communities. The Ministry guidelines stemmed from recommendations of the Ontario Advisory Committee on HIV/AIDS (OACHA) and identified the following key objectives for local HIV/AIDS planning:

“To develop a community HIV/AIDS strategy that responds to local needs and reflects provincial goals and directions.

To improve access to and co-ordination of services for people living with HIV and populations at risk.²

To provide more integrated, comprehensive, effective, efficient care and support services.³

The planning time frame in most communities was 12 months, but because of Toronto's size and complexity, the local process took just under two years, from the Spring of 2005 until March 2007.

TCPI's efforts have focused on Toronto's HIV/AIDS services overall and not on individual organizations. It concentrates on system-level issues that can best be addressed through coordinated and collaborative community responses. The plan is not intended to replace the strategic or operational plans of individual organizations or programs, but rather, to inform these plans.

This plan is an initial step in ongoing planning and coordination in Toronto. The 10-point set of priorities recognizes that, in order to address diverse HIV/AIDS-related needs and service gaps, Toronto requires a broad-based, ongoing HIV/AIDS planning and coordination function.

2 The AIDS Bureau, Ministry of Health and Long-Term Care guidelines refer to populations, communities and people at risk. References throughout this document to “at risk” means at risk of, or vulnerable to HIV infection.

3 “Improving Services for People with HIV and Communities at Risk: Guidelines for Community Planning”, AIDS Bureau, Community Health Unit, Ministry of Health and Long-Term Care, May 2004.

1.2 Context

Toronto is the largest city in Canada, the fifth largest in North America and one of the most diverse in the world. With a geographic area of over 600 square kilometres and a population of 2.6 million (projected to rise to 2.8 million by 2016 and to 3 million by 2031),⁴ it has the greatest number of HIV+ people in Ontario, at 14,540 and 62% of HIV+ people in the province live in Toronto.⁵

Serving Toronto is a complex array of close to 2,000 health and human service organizations. Among these are approximately 30 organizations specifically dedicated to HIV/AIDS treatment, support and prevention, as well as many HIV/AIDS-related programs in other broader health and social service settings (see section 5 for more information).

These organizations, like others in Ontario, are operating in a context of health system transformation. Of particular relevance is the Local Health Integration Networks (LHINs) transformation that includes restructuring of the province's health planning, funding and service regions to 14. With responsibility for two-thirds of the Ministry's \$35 billion budget (2005/2006), LHINs will fund and hold accountable public and private hospitals, community care access centres, community support services (e.g., personal assistance, homemaking, friendly visiting), community mental health and addiction agencies, community health centres and long-term care homes.

While AIDS Bureau (MOHLTC) funding is currently not planned for inclusion in the LHINs, some TCPI agencies' primary funding will be transferred (e.g., housing, long-term care agencies). One of the first tasks of each LHIN has been to develop an initial three-year Integrated Health Service Plan (IHSP). These strategic plans are guided by provincial direction and involved consultations with community, providers and experts. The Integrated Health Service Plan is the starting point for future activity and is to be updated each year. The Toronto Central LHIN's first Integrated Health Service Plan was released in November 2006. It identified nine areas of focus, four are population-related and five are described as “integration areas of focus.” (See footnote for details)⁶

4 Sources: Statistics Canada estimates, 2005, and projections of Ontario Ministry of Finance.

5 “Epidemiologic Characteristics of HIV Infection and AIDS in Toronto, 1981—2003,” Robert S. Remis, Maraki Fikre Merid, Ontario HIV Epidemiologic Monitoring Unit, Department of Public Health Sciences, University of Toronto, [PowerPoint presentation June 2005].

6 The four areas of population focus consist of: mental health and addictions; seniors; rehabilitation; and provincial Ministry priorities (e.g., wait times, chronic disease management). The five integration areas of focus are: health human resources; education and research; e-health; energy and the environment; and back office integration (<http://www.torontocentrallhin.on.ca>)

A related initiative of relevance to HIV/AIDS is the creation of Family Health Teams (FHTs). These teams are expected to improve access to primary health care. One of the key issues (discussed later in this report) is the need for improved responsiveness of general health services to people living with HIV/AIDS.

As well as these broad health system transformation initiatives, a number of strategies and working groups related to HIV/AIDS provide context for Toronto's planning process. In addition to the 2002 provincial HIV/AIDS strategy "A Proposed HIV/AIDS Strategy for Ontario to 2008", prepared by OACHA, relevant examples include:

- Strategy to Address Issues Related to HIV Faced by People in Ontario from Countries Where HIV Is Endemic;
- Ontario Aboriginal HIV/AIDS Strategy;
- Women and HIV/AIDS Strategy for Ontario (under development);
- Ontario Gay Men's HIV Prevention Strategy; and
- a provincial Hepatitis C Strategy.

1.3 The TCPI Plan

Toronto possesses a deep and dynamic history of HIV/AIDS activism. Some individuals involved early in the AIDS movement are still connected as service users, volunteers, staff and board members. Many have multiple roles. Some currently involved in service delivery were mentored by early activists. Other staff and volunteers bring backgrounds in social justice work for specific communities.

The rich history and complex fabric of HIV/AIDS work in Toronto is underscored with values related to equity, social change and community action. The plan for Toronto builds on this history, addresses the present and looks to the future.

The plan recognizes that while important progress has been made in many relevant spheres, HIV/AIDS continues to be a significant and increasingly complex issue for Toronto. Not only does this city have the highest HIV and AIDS rates in the province [1 out of 140 people in Toronto is HIV+ (see footnote 5)], HIV prevalence⁷ has increased by 27% over the past five years. These statistics, combined with changing needs related to both demographics and the increasingly chronic nature of the disease, reinforce the importance of finding planned ways to use community re-

sources to greatest benefit.

This plan is an initial step in ongoing planning and coordination in Toronto. The 10-point set of priorities recognizes that to address diverse HIV/AIDS-related needs and service gaps, Toronto requires a broad-based, ongoing HIV/AIDS community planning and coordination function.

The remainder of the report is structured as follows:

- Section 2 provides an overview of the planning structure and process.
- Section 3 presents the values developed and approved by the large TCPI group to guide the process.
- Section 4 presents highlights of relevant planning data (e.g., epidemiological data, social context).
- Section 5 presents themes from the consultations conducted as part of the planning process.
- Section 6 contains the plan for Toronto, composed of three elements:
 - a vision of key features of a future HIV/AIDS system in Toronto;
 - a 10-point set of priorities; and
 - recommendations related to accountability for plan implementation.
- Section 7 outlines key follow-up steps to begin implementing the plan.

A series of appendices contains: a glossary of terms; list of participating organizations and programs; and the TCPI conflict resolution guidelines.

⁷ "Prevalence" refers to the current number of people living with an illness in a given year.

THE PLANNING STRUCTURE AND PROCESS

2. THE PLANNING STRUCTURE & PROCESS

Toronto's planning process was divided into two phases, each approximately one year in length.

Phase One included organizations and programs that receive ongoing funding from the AIDS Bureau (MOHLTC) and focused on developing foundational pieces (e.g., values, vision) for the process, as well as data collection and analysis. During Phase Two, representatives from HIV clinics and a broader set of organizations relevant to the needs of people living with and at risk of HIV/AIDS were invited to participate, and the focus shifted to plan development (see Appendices A and B, for a Glossary of terms and a List of participating organizations and programs).

2.1 Structure

TCPI planning was carried out under the following structure:

- Two Co-Champions, appointed by the AIDS Bureau (MOHLTC), served as overall chairs for the process. These Co-Champions were both from AIDS service organizations - Art Zoccole, Executive Director, 2-Spirited People of the 1st Nations and Ruthann Tucker, Executive Director of Fife House Foundation. These individuals also served as Co-Chairs of the TCPI Steering Committee.
- A Steering Committee, which met on 14 occasions, guided the process. Members of the Committee were not there to represent individual or organizational interests, but to bring their experience and knowledge to the process. Efforts were made to ensure that the Committee included membership from: people living with and at risk of HIV/AIDS; service providers along the continuum of services, from disease prevention and health promotion to palliative care; and service providers funded by the AIDS Bureau (MOHLTC). At all stages of the process, individuals living with HIV/AIDS were active on the Committee. Over the course of the process, those who served on the Steering Committee included: Art Zoccole (2 Spirited People of the 1st Nations), Barbara Macpherson (Toronto Public Health), Cathy Szabo (Etobicoke York Community Care Access Centre), Catherine Adams (Casey House), Don Chiro (Casey House), Eduardo Garay (Centre for Spanish Speaking Peoples), Juanita Smith (Black Coalition for AIDS Prevention), Lori Lucier (AIDS Committee of Toronto), Murray Jose (Toronto People With AIDS Foundation), Ron Lirette (community member), Rosemary Erskine (African Community Health Services), Ruthann Tucker (Fife House) and, Stephanie Karapita (Casey House).

- A large group of HIV/AIDS organizations and programs participated in the process through interviews, questionnaires, focus groups and/or large group meetings (of which there were four). As noted earlier, Phase One TCPI participation focused on organizations and programs that receive non-project based funding from the AIDS Bureau. In Phase Two, representatives from HIV clinics and organizations from related sectors (e.g., income support, legal aid, housing, Community Care Access Centres, mental health, other Community Health Centres, etc) were invited to participate.
- A planning team provided support to the Co-Champions, Steering Committee and large group meetings. The three-member team gathered and analyzed information, planned and coordinated meetings, and drafted materials for the process, including the project report.

2.2 AIDS Bureau (MOHLTC) Support to the Planning Process

To support local planning processes, the AIDS Bureau, Ministry of Health and Long-Term Care (MOHLTC) provided:

- planning guidelines;
- epidemiological information through the University of Toronto's Ontario HIV Epidemiologic Monitoring Unit in the Department of Public Health Sciences;
- funding support for the planning team;
- contact information for planners in other communities; and
- an evaluation process that was developed, administered and compiled by the Community-Linked Evaluation AIDS Resource (CLEAR) Unit at McMaster University.

2.3 Process Highlights

The following were key elements of the planning process:

Development of foundational underpinnings — The initial stages of the work focused on establishing key foundational pieces for the process, including:

- values that should guide the process (presented in section 3);
- vision: desired features of a future HIV/AIDS system in Toronto (presented in section 6, as the first component of the TCPI plan);
- a project Steering Committee and its Terms of Reference;
- conflict resolution guidelines for the process (see Appendix C).

Meetings of the TCPI Large Group — Four large group meetings were held over the course of the project. On each occasion, participants received information about TCPI's progress and were asked for feedback and contributions on topics that would become key elements of either the plan or the planning process, including the:

- foundational underpinnings outlined above;
- data collection plan and identification of questionnaire languages that would be most relevant to the clients;
- ideas about realizable outcomes for the planning process; and,
- strategies for addressing issues identified through the data collection.

Large group participants were also encouraged to suggest who should be included in both phases of the Initiative. A significant outcome of the large group meetings was the development of Working Groups to begin to address the Recommendations.

Information Collection: process — While the project was not intended to be a comprehensive needs assessment, information about system strengths and limitations was collected. Information sources included service users (people living with HIV/AIDS, affected people and people at risk of HIV/AIDS), service providers and existing epidemiological and demographic data and related reports. Original information collected through interviews and questionnaires was qualitative and anecdotal. The information collected was for community planning purposes and not intended to be a formal research study.

Data collection took place over a 10-month period, from November 2005 to August 2006, and consisted of the following:

- On-line and hard copy questionnaires were completed by service users and potential service users. Hard copy questionnaires were available in six languages (French, English, Simplified Chinese, Traditional Chinese, Spanish and Portuguese). These languages were selected based on the most commonly spoken client languages of TCPI member organizations and within the confines of the project budget. Phase One organizations and some of those that joined in Phase Two (e.g., HIV/AIDS clinics) helped distribute the hard copy questionnaires.

- Eleven focus groups were held involving people who use services of Phase One organizations and programs. Participants were primarily HIV+ people, although some were partners or family members of a person living with HIV/AIDS, and others were considered at risk of HIV/AIDS. Participating agencies promoted the groups and recruited members. In one of the focus groups, participants completed questionnaires rather than having a group discussion. To encourage and facilitate involvement, participants were offered an honorarium, TTC tickets and a child care allowance. Groups were scheduled at a variety of times and locations. Some groups were hosted by TCPI member organizations, while others were held at more generic locations. Food was provided at all focus groups.

To explore the greatest diversity of needs, seven of the focus groups were organized to hear from specific communities (women, people from specific ethno-cultural communities and injection drug users). The other four were open to clients from all TCPI member organizations.

- Three focus groups were held with front-line service workers (staff and volunteers).
- An on-line questionnaire was provided to front-line staff and volunteers.
- A focus group was held with representatives of organizations that joined the process in Phase Two.
- Interviews were conducted with Executive Management (generally a senior management representative and a Board representative) of Phase One organizations.
- Agency questionnaires were completed by Phase One participants about the services they provide.
- Four meetings of the large TCPI group were held (June 2005, December 2005, May 2006 and January 2007).

Overall participation levels were as follows:

People living with, affected by or at risk for HIV/AIDS:

79 focus group participants

89 questionnaires.

Service providers:

27 focus group participants

23 individual staff questionnaires

28 interviews with Executive Management representatives (the number of people involved in each interview ranged from one to five individuals, with the majority involving one or two)

23 agency service questionnaires

The information collection process was challenging and labour intensive, but its effectiveness was greatly enhanced by the active participation of TCPI organizations. In spite of their limited resources, many made extra efforts to ensure service users' voices were heard. They organized focus groups, reviewed and revised questionnaire translations, and encouraged and supported individuals living with HIV/AIDS to complete questionnaires and participate in focus groups.

Process Limitations

It is important to acknowledge the limitations of the information collection process:

- While efforts were made to hear from a wide range of people, those who participated were connected to services. The process relied on front-line workers' views about the needs of people at risk of HIV/AIDS who were not connected.
- Not all TCPI agencies completed the survey concerning their service offerings and some questionnaires were incomplete. Efforts had been made to create a simple survey drawing upon data currently reported to the Ministry of Health and Long-Term Care. In the end,

the real value of this survey lay in the views expressed about current HIV/AIDS services and suggestions for the future.

- Developing the scope for Phase Two was challenging, particularly balancing the need to involve relevant organizations and sectors while keeping the process manageable in size. The Steering Committee focused on inviting into the process organizations or sectors identified by Phase One organizations as those used most frequently by their clients and others seen as critical to the future delivery of services in Toronto (e.g., Community Care Access Centres (CCACs)). As the process evolved, additional organizations continued to join.

GUIDING VALUES

3. GUIDING VALUES

The following values were developed by the TCPI large group to guide the planning process. Many of these values are reflected in the features of a future system, also developed by the group and presented as the first part of the TCPI plan (see section 6.1).

Introduction — The purpose of the Toronto Community Planning Initiative (TCPI) is to develop a strategic plan for HIV/AIDS services in Toronto. While forward looking, the plan and the planning process will both acknowledge and build on the unique strengths and history of the participating organizations. In addition, the process will be grounded in the following values:

Greater Involvement of People Living With and Affected by HIV/AIDS (GIPA principle)— In particular, TCPI recognizes the necessity of developing meaningful opportunities for people living with and affected by HIV/AIDS to be involved in all aspects of the planning process.

Driven by documented and expressed needs — The plan will focus on addressing the needs of people living with and affected by HIV/AIDS. Needs will be defined through epidemiological data as well as through qualitative information provided by individuals and participating organizations.

Inclusion — TCPI will strive to create an open and engaging process, actively making space for the voices of participating organizations and programs.

Respect and integrity — Recognizing that participants bring a wide range of needs, expectations and experiences, TCPI will strive to be flexible, non-judgemental and collaborative, fostering the courage necessary to work through differences and see the creative potential of diversity.

A social justice and anti-oppression approach — The process will reflect an understanding of the broad determinants of health,⁸ the intersection of oppressions and the power differences that may exist between communities, organizations and individuals. This approach is also in keeping with the guidelines of the AIDS Bureau, MOHLTC.

Accountability — The TCPI process will be characterized by:

- realistic and attainable goals;
- transparency;
- shared responsibility of the member organizations to each other, to their communities and to the process itself;
- commitment of participating organizations to remain throughout the process and to demonstrate their support;
- the development of outcomes that meet the requirements of the AIDS Bureau, Ontario Ministry of Health and Long-Term Care.

⁸ As defined by Health Canada. Key determinants identified by Health Canada are: Income and Social Status; Social Support Networks; Education and Literacy; Employment/Working Conditions; Social Environments; Physical Environments; Personal Health Practices and Coping Skills; Healthy Child Development; Biology and Genetic Endowment; Health Services; Gender; and Culture (see <http://www.phac-aspc.gc.ca/ph-sp/phdd/determinants/index.html>).

Highlights of Epidemiological Data and Social Context

4. HIGHLIGHTS OF EPIDEMIOLOGICAL DATA AND SOCIAL CONTEXT

This section presents highlights of relevant Toronto HIV/AIDS epidemiological data provided by the Ontario HIV Epidemiologic Monitoring Unit, Department of Public Health Sciences, University of Toronto. It also highlights other key features of Toronto's social context that should be considered in planning for the future.

4.1 Epidemiological Highlights

According to the most recently available sources, there are 14,540 people living with HIV in Toronto (Remis 2005), accounting for 62% of all HIV infections in Ontario. Toronto has both the highest HIV rates and highest AIDS rates in Ontario. Gay, bisexual and other men who have sex with men (MSM) continue to represent the greatest number of individuals living with HIV/AIDS in Toronto. The growing incidence of HIV infection among women — and particularly among women from countries where HIV is endemic (the Caribbean and Africa) — is a particular concern as it relates to prevention work and service provision to women and children. Infections among injection drug-using populations have remained stable with respect to prevalence and low HIV incidence.⁹ (Note that *incidence* refers to the frequency of development of a new illness in a population in a certain period of time, normally one year; and prevalence refers to the current number of people living with an illness in a given year.)

Data presented by the Ontario HIV Epidemiologic Monitoring Unit at the first TCPI large group meeting emphasized “serious concern about sustained HIV transmission among men who have sex with men (MSM), people from countries where HIV is endemic and heterosexual groups”. It further noted that “the HIV epidemic in Toronto is considered to be unstable and increasing.”

- Over the past five years, HIV prevalence in the city has increased by 27%.
- Men who have sex with men continue to represent the largest group of people infected with HIV in Toronto. Among this population, HIV diagnosis has increased by 44% since 2000.

9 “Epidemiologic Characteristics of HIV Infection and AIDS in Toronto, 1981—2003,” Robert S. Remis and Maraki Fikre Merid, Ontario HIV Epidemiologic Monitoring Unit, Department of Public Health Sciences, University of Toronto, [PowerPoint presentation June 2005].

- People from countries where HIV is endemic now represent the second most important and growing group of people with HIV, representing 13% of infected persons. Between 1998 and 2003, the prevalence among this group of people increased by approximately 86%.
- Over the 5 year period between 1998 and 2003, the prevalence of HIV among people identifying as heterosexuals increased by approximately 69%.
- While HIV prevalence is stable and low among people who identify as intravenous drug users (IDU), concern over potential growth in this population remains.¹⁰

4.2 Social Context

At first glance, Toronto is one of the best resourced cities in the world for HIV/AIDS health care and services. Home to research, clinical and community programs, Toronto appears to be doing well. In the context of inequities in the global HIV/AIDS pandemic, that is accurate.

However, a closer look reveals many of these same services and resources are not easily accessed by some of the people who need them most. HIV continues to be a health and social concern largely associated with experiences of marginalization and exclusion. When considered in terms of the social determinants of health,¹¹ the complexity of Toronto's population growth gives rise to a number of service development issues:

A growing population: diverse communities, diverse needs

The City of Toronto is Canada's largest, with a current population of more than 2.6 million people and projected to increase to 3 million over the next 15 years. Furthermore, the Greater Toronto Area (GTA) is home to more than 5.4 million people, many of whom use HIV-related health services and resources located in the City of Toronto, as do residents from other parts of the province.

Toronto is Canada's most *ethno-culturally diverse* city. The 2001 Canadian census indicates that more than 40% of Toronto's population belong to a “visible minority” group¹², including 259,710 Chinese, 253,920 South Asian and 204,075 Black residents.¹³ With respect to future planning,

10 Ibid.

11 Key determinants identified by Health Canada are: Income and Social Status; Social Support Networks; Education and Literacy; Employment/Working Conditions; Social Environments ; Physical Environments; Personal Health Practices and Coping Skills; Healthy Child Development; Biology and Genetic Endowment; Health Services; Gender; and Culture. (See <http://www.phac-aspc.gc.ca/ph-sp/phdd/determinants/index.html>.)

12 Community Highlights for Toronto”, Statistics Canada, 2001.

13 “Population by selected ethnic origins, Toronto”, Statistics Canada, 2001.

it is anticipated that by 2017, visible minorities will account for more than half of Toronto's citizens. The visible minority population of Toronto will range between 2.8 to 3.9 million in 2017. Of these visible minorities in Toronto, more than 1.0 million will be South Asian and more than 745,000 will be Chinese.¹⁴

Two recent surveys, conducted among African and Caribbean communities (regions where HIV/AIDS is endemic) in Toronto found that factors such as racism, homelessness, transience, poverty, underemployment, settlement and status concerns presented barriers to HIV/AIDS program access. Other identified barriers included: fear and stigma; denial as a coping mechanism; social isolation; lack of social support; job loss; fear of deportation; discrimination; power relations; and cultural attitudes and sensitivities about HIV/AIDS transmission, homosexuality, status of women, and sex/sexuality. The surveys also found a lack of culturally competent and accessible services because of location of services, language barriers, and concerns that health care may not be free depending on immigration status. Five East African communities in Toronto identified as critical issues: stigma, the isolation of HIV+ individuals, and cultural and linguistic barriers to treatment.¹⁵

According to the federal government, Canada has the highest per capita *immigration* rate in the world. More than 100,000 new immigrants settle in the Greater Toronto Area every year, accounting for 43% of all new immigrants to Canada.¹⁶ In 2004, the United Nations Development Programme (UNDP) ranked Toronto second in its list of world cities with the largest percentage of foreign-born population (after Miami, which has a largely Latino immigrant population). Landed immigrants in Canada have a 37% unemployment rate indicating a significant potential for health vulnerability, including to HIV infection.¹⁷

City of Toronto census data (2001) indicates there is an *Aboriginal population* of 11,370, making Toronto's Aboriginal community larger than most reserve communities in Ontario. Epidemiological data from the Public Health Agency of Canada indicates that an increasing percentage of people living with HIV/AIDS

are people from Aboriginal communities. "Before 1993, 1.2% of reported AIDS cases were among Aboriginal peoples. This increased to 13.4% in 2003. In 1998, 18.8% of positive HIV test reports were among Aboriginal peoples. This increased to 25.3% in 2003. Furthermore, in contrast to non-Aboriginal populations, females make up a comparatively larger part of Aboriginal HIV and AIDS cases."¹⁸

Toronto is home to *Canada's largest visible lesbian, gay, bisexual, transgender and 2-spirit (LGBT) communities* with its appeal as a comparatively safer haven for people who experience violence or exclusion in their home communities. Of significant concern is the vulnerability of immigrant and visible minority individuals who may be LGBT or engaged in same-sex sexual activity. Toronto is also a particular magnet for LGBT youth, who face risks upon arrival.¹⁹ With the high prevalence rate among men who have sex with men, the possibility for increases in HIV infection remains a serious concern.

An aging population

Statistics Canada estimates show that the proportion of Canada's population accounted for by seniors has doubled over the past 60 years (i.e., 7.2% to 13.2% of the population).²⁰ By comparison, "*the proportion of individuals aged 20 to 64 increased from 56.3% to 62.8%.*" Further, the report notes a substantial decline in the number of children and young people, which is projected to continue for the next 50 years.

By 2056, it is projected that those aged 0—19 could account for less than 20% of the population and seniors could account for more than one out of every four individuals.

The implications of Canada's aging population are significant and have been widely noted in the media, academia and elsewhere. Primary among these implications are the expected increased demands on health and social services — along with increased funding pressures — and the need to consider new models of prevention, care and resourcing.

14 "Canada's visible minority population in 2017", Statistics Canada, 2005.

15 As reported in "HIV/AIDS Epi Updates", Centre for Infectious Disease Prevention and Control, December 2005.

16 "Canada's Immigration Program", Library of Parliament, Revised October 2004.

17 "Immigrants' labour force rates, by immigration category, 2001," Statistics Canada, 2005.

18 HIV/AIDS Epi Notes, "Understanding the HIV/AIDS Epidemic among Aboriginal Peoples in Canada: The Community at a Glance," Public Health Agency of Canada.

19 "Assessing HIV Vulnerability among Lesbian, Gay, Bisexual, Transgender, Transsexual (LGBT) and 2-Spirited Youth Who Migrate to Toronto," Travers, Leaver and McLelland, Canadian HIV/AIDS Research Conference, 2002.

20 "Canada's population by age and sex," Statistics Canada, The Daily, Thursday, October 26, 2006

Increase in homelessness and poverty

Toronto also has a considerably larger homeless population than many cities of similar size, a group of people particularly vulnerable to HIV infection. In 2003, 31,985 individuals stayed at least once in a Toronto homeless shelter.²¹

Toronto's poverty rate continues to increase, as does the income gulf between rich and poor. According to City of Toronto data, the poverty rate among Toronto's families has risen substantially over the last two decades, with nearly one in every five families in 2001 living in poverty. Today, Toronto's 'poor' families are much more concentrated in neighbourhoods where there are a high proportion of families living in poverty compared to twenty years ago. In 1981, just 17.8% of 'poor' families lived in such neighbourhoods, compared with 43.2% in 2001.

This trend toward concentration has resulted in a dramatic rise in the number of higher poverty neighbourhoods in the City of Toronto over the last two decades. The number has approximately doubled every ten years, from 30 in 1981 to 120 in 2001. This is especially acute in the inner suburbs (i.e., in the former municipalities of Scarborough, North York, Etobicoke, York and East York), whose combined total of higher poverty neighbourhoods rose from 15 in 1981 to 92 in 2001.

There has also been a profound shift in the resident profile of higher poverty neighbourhoods. Today poor visible minority and immigrant families make up far larger percentages of the total poor family population in these neighbourhoods than twenty years ago.

21 "Housing and Homelessness Report Card", City of Toronto, 2003.

community needs and
service capacity

5. COMMUNITY NEEDS AND SERVICE CAPACITY: CONSULTATION THEMES

Toronto has 18 AIDS Service Organizations (ASOs), 9 anonymous HIV testing sites and 4 outpatient hospital-based HIV/AIDS clinics, as well as HIV/AIDS support and prevention programs in a range of community agencies and health centres. The ASOs range in size from relatively large to very small. Some focus on serving specific communities and populations; others have broader mandates. Services range from prevention to end-of-life care, and include education and awareness initiatives, a variety of treatment services, supportive housing, concrete and practical assistance, and emotional supports. Services are also offered in a range of settings, from somewhat formal to street-based. As the population becomes more diverse, the number of small organizations serving specific communities has grown to ensure culturally appropriate services. Because many services are funded on a time-limited basis, it can be extremely difficult to develop a comprehensive picture of services at any one time. Almost all organizations are involved in partnerships with other organizations (including other HIV/AIDS services, other organizations serving the same community and population, and organizations in other sectors).

From the TCPI consultations, several themes arose related to community service needs and the capacity to meet those needs. These themes provide the basis for the strategic priorities identified in Section 6. The themes are summarized under the following topics:

- strengths of current HIV/AIDS and related services;
- limitations and challenges; and
- growing and emerging needs that should be considered in planning for the future.

5.1 Strengths of Current HIV/AIDS and Related Services

As noted, an important assumption underlying the TCPI process was that it should both recognize and build on strengths of the current HIV/AIDS and related service systems. These strengths were identified in discussions with people living with HIV and service providers. Key strengths, described more fully below, include:

- diversity of HIV/AIDS Service Organizations, programs and settings;
- strong community-based response;
- services that make a difference;
- harm reduction programs based in communities settings where other services are available;
- many informal inter-organizational partnerships and working relationships;
- human resource strengths;
- support to the sector through networks, funding, policy and research.

Diversity of HIV/AIDS Service Organizations, Programs and Settings

“Different organizations have different strengths. If we continue to have the diversity of ASOs, that’s a positive future that offers people choice.”

“We must have a diversity of responses. People of colour and Aboriginal people have been stigmatized in the world and by many health and human services. Even if people have only one incident of exclusion, the sting of that stays with people long after.”

“Ontario is the only Province that has services designed for deaf people with and at risk of HIV.”

While many service users and providers identified strengths of individual agencies, the diversity of Toronto’s HIV/AIDS service systems was, by far, the most frequently identified strength. Service users, front-line workers, management and board members all identified this as a critical base for future system planning. Service users were emphatic about not wanting a “*super AIDS organization*.” Benefits attributed to this diverse range of provider organizations and service settings included:

- it helps to ensure the availability of services that are appropriate and responsive to individual communities and groups;

- it provides real choices for individuals wanting service (related to safety, comfort, connection, accessibility, and confidentiality and anonymity); and
- once connected, it is possible for some people to obtain a relatively comprehensive range of community services

Strong Community-Based Response

“Our services are rooted in the community. PHAs (people living with HIV/AIDS) and people at risk have a say in their service.”

“GIPA (greater involvement of people living with and affected by HIV/AIDS) — not every organization does it perfectly, but there’s a consciousness about making it part of the process.”

Toronto is also seen to have a strong community-based response, rooted in the needs of the communities served and responsive to the context of a person’s life. Service users, many of whom had experienced highly negative interactions with broader health and social service systems, talked about being respected as a person with potential, rather than being treated as a disease. Connection to community is also evidenced by the governance models of many organizations, as well as the historical relationship between services and political action.

Services That Make a Difference

“After years... my health suddenly went down hill fast. I had no idea how to negotiate the ins and outs of going on disability. The staff were remarkable in helping me file all of the many documents. I have no idea how I would have done had I not taken their advice. Everything that they said would happen did happen.”

“You come depressed, you leave happy — the staff here really try to make a connection with you. They give you a tomorrow.”

“Getting massage and alternative health care have been really good. Practical assistance — food, meals, help with forms.”

“Financial assistance has been occasionally of considerable practical importance, but it is also psychologically helpful. Personal counselling has been invaluable in maintaining some balance, especially around work related issues...”

“All of the information that I have been given was extremely helpful. I shall always be extremely grateful for all of that help, especially when I was so sick and had to complete all of this stuff very quickly.”

Service users provided many concrete examples of the positive differences they attribute to HIV/AIDS services in both community and clinical settings. Examples included giving concrete and practical assistance (e.g., help filling out forms, food, etc), establishing connections with other people living with HIV/AIDS, and support in coping with the psycho-social impacts of HIV. Some talked about the importance to them of establishing a connection with an individual worker.

Harm Reduction Programs Based In Communities Settings Where Other Services Are Available

“It’s important to house these programs where they’re not isolated. It promotes broader understanding of harm reduction and increases access to other services for clients.”

A number of people noted that harm reduction programs offered in community settings, such as Community Health Centres (CHCs) are important for a number of reasons:

- The anonymity offered by a multi-service setting.
- The potential to educate workers in that setting about HIV and drug use and the needs of people who are intravenous drug users.
- The possibility that people might obtain other health and dental services offered in the organization, which they might not otherwise be able to access.

Many Informal Inter-Organizational Partnerships and Working Relationships

There are many informal partnerships among ASOs and some between ASOs and other organizations serving the same community. These partnerships range from informal working relationships between individual workers who see a need for joint services, to more formal inter-agency arrangements for shared space, administrative services and other infrastructure. These partnerships and relationships offer more choice for service users and more comprehensive services, based on strengths of the partnering organizations. They have led to the development of new services and, sometimes, to more culturally responsive services (e.g., an ethno-cultural service provider working at a broad-based agency can provide choice related to confidentiality). Many partnered initiatives are time-limited because funding is so often project-based.

Given the growing diversity of Toronto’s population and the increasing complexity of needs, the following kinds of

partnerships are seen to be of increasing relevance:

- those between population/community-specific AIDS organizations and other AIDS organizations;
- those between population/community-specific AIDS organizations and non-AIDS organizations serving the same population/community;
- those between individual population/community-specific ASOs; and
- those between all ASOs and organizations from other service sectors.

Human Resource Strengths

While significant staff retention issues exist in the community HIV/AIDS sector, longevity of some staff, Board members and other volunteers has helped preserve valuable sector memory. In addition, staff and volunteer involvement in the HIV/AIDS movement has contributed to service relevance and a shared sense of commitment.

Supports to the Sector through Networks, Funding, Policy and Research

A number of individuals noted that despite challenges associated with resource levels, resource distribution and human resource compensation, HIV/AIDS organizations and programs do benefit from some important shared initiatives. For example, the Ontario AIDS Network, the Canadian AIDS Society, and the Ontario Ministry of Health and Long-Term Care all provide access to networks and learning opportunities. The Ontario AIDS Bereavement Project and the Ontario Organizational Development Program are examples of support to the sector.

In addition, many people acknowledged the importance of ongoing funding from the AIDS Bureau of the Ontario Ministry of Health and Long-Term Care, as well as the AIDS Bureau's efforts to connect policy to what is going on in communities.

Finally, the ongoing interest and commitment to research was also seen as a strength.

5.2 Limitations and Challenges

Limitations and challenges relate both to HIV/AIDS-specific services and to broader health and social services relevant to people living with, affected by or at risk of HIV infection. Many of the limitations and challenges identified indicate the need for the service system to address social determinants of health, including racism, homophobia and

barriers to housing, income, employment and education. Other issues indicate lack of service system responsiveness to changes in HIV treatment and the impacts of these changes.

As well, many of the issues relate to overall systems-level challenges, notably the significant need for increased inter-sectoral and inter-organizational communication, relationship-building, education and collaboration. For some, this included a desire for more collaboration and joint training between ASO Boards so that throughout organizations "inter-organizational and inter-sectoral cooperation becomes the standard way of operating."

Specific themes concerning limitations and challenges included:

- lack of access to up-to-date information about HIV/AIDS services;
- need for a system of services where access can be gained at any entry point;
- need for appropriate, safe and affordable housing and shelter;
- lack of responsiveness by broader (non-HIV-specific) health and social services;
- barriers to HIV/AIDS services;
- access to affordable, effective medications;
- the need to enhance income and employment-related supports;
- ambivalence about harm reduction;
- need for coordinated, targeted and innovative prevention education strategies;
- substantial service gaps remain.

Lack of Access to Up-to-Date Information About HIV/AIDS Services

"Unless you know about what's available, it's very hard to find out."

"I hit a lot of walls when I was trying to get information as a spouse."

Both service users and staff described difficulties when trying to obtain up-to-date and comprehensive information about HIV services in Toronto and about new service development:

- Service users noted that it can take tremendous persistence to get into the AIDS service system because of difficulties obtaining information about

available services. Lack of a shared, coordinated, current and easily accessible service information system can result in people being shut out of services or facing significant barriers to access.

- Service providers also reported difficulties with staying up-to-date on current services. These difficulties are compounded by the high turnover in agency staff and the fact that many services are time-limited because of project-based funding. Some providers also identified the need for a more coordinated access approach (i.e., in which any service can become the point of entry to the range of HIV/AIDS services).

Access to current and accessible information about HIV services was seen as critical priority for the TCPI plan.

Need for a System of Services Where Access Can Be Gained at Any Entry Point

“We need to become a network of services rather than just a bunch of services.”

“No one has the whole picture.... I thought someone would, but it is too complex.”

A number of groups expressed the importance of creating a system of HIV/AIDS services that plan and work together. It was suggested that such a system would involve HIV/AIDS services in both community and clinical settings, as well as in organizations and services from other relevant sectors. With the goals of (1) improving access to available services; and (2) making the most of existing resources, identified features of a system include:

- a basic, or consistent, level of service that anyone could expect from any service provider organization/program;
- access to all services through any entry point (e.g., an individual would be able to learn about all services regardless of the first contact organization);
- effective referral relationships;
- ongoing and up-to-date information sharing;
- coordinated system-level planning; and
- sharing of knowledge, research, skills and resources.

Need for Appropriate, Safe and Affordable Housing and Shelter

“If we can't address quality of life issues, we can't address HIV issues and housing is key to quality of life. They (governments) don't seem to understand how important good housing is to your health.”

“We need HIV-specific housing with harm reduction services.”

“Right now, there is no supportive housing for HIV+ families. Our clients live in the worst housing”

“We need affordable housing (not necessarily supportive housing) and we need more supportive housing for individuals dealing concurrently with HIV/AIDS and untreated addictions”

By far the most frequently identified service gap was housing. The need for permanent, affordable housing and information about housing was identified by people living with HIV/AIDS, people at risk of HIV/AIDS and service providers. Many women spoke of the need for family housing (including supportive housing) and the relationship between housing and the health and well-being of themselves and their children. Barriers to housing for drug users was also seen to be a significant issue, including access to housing for people who have recently been in prison.

A number of individuals were very concerned about their experiences when attempting to secure rent-geared-to-income housing. Some referred to encounters in which they were told that they would be “fast tracked” if they could provide proof that they would die within two years. Others have been waiting more than 10 years for housing. Many described their treatment as rude and dismissive.

Concerns were also expressed about private landlords. Some people described situations in which an HIV+ individual felt compelled to disclose their HIV status, with the result that the landlord would not rent to them.

A number of individuals raised concerns about shelters and private rooming houses and boarding homes. Key concerns included:

- Stigma, disclosure and safety — Experiences in some shelters, where people who are HIV+ have been isolated in a separate section. In addition to the stigma that results, this raises concerns about safety once a person’s status has been openly disclosed.
- Access to HIV medication — Two concerns were raised here: 1). HIV medication has been stolen, resulting in some regular shelter users not taking their medication at all and 2). Some people not being able to take their injection HIV medication because of shelter policies about needles.
- Difficulties for people who are ill with an HIV-related health problem — Several individuals talked about people with HIV who are unwell and live in shelters. They noted that they have no place to go and talked about the need for infirmary services.
- Few rental options — People noted the unwillingness of some rooming house and boarding home proprietors to rent to someone who is HIV+ (when this is either disclosed by the applicant or inferred by the landlord).

Several of the people living with HIV/AIDS focus group participants stressed the need for a range of housing models — transitional and permanent — as well as supports to help people retain housing (both linked to person and to housing unit). Such supports would include different funding and payment models that recognize the difficulties that individuals can face in retaining non-subsidized housing.

Lack of Responsiveness by Broader (Non-HIV-Specific) Health and Social Services

“These are the people we’re supposed to trust for health care services (e.g., emergency health services) and they’re scared of us...What can we do? Training needs to be improved because professionals treat us with mistrust because of their fears of HIV/AIDS. We need training for everyone — doctors, dentists, staff, volunteers — on sensitivity, discrimination and respect... with a capital R.”

“Trans clients, especially those who are substance users and have been in conflict with the law, face huge issues accessing services, including housing, drop-ins, doctor’s offices, hospitals.”

“Health care professionals such as surgeons and dentists are reluctant to care for HIV+ individuals.”

“I was so alone when I was first diagnosed. Nobody should feel like that. Shame on the doctor for giving you such drastic news that’s going to affect your life and sending you off with nothing... you might even be suicidal.”

Concerns about broader health and social services,²² including hospitals and long-term care facilities, were raised by both service users and service providers. Many people reported experiences they associated with a lack of staff understanding of HIV/AIDS, and policies that are not up-to-date with advances in the clinical treatment of HIV/AIDS. They identified a need for education, training and advocacy that would address stigma and discrimination and increase the broader system’s capacity to respond appropriately to people living with HIV/AIDS.

It was suggested that priority be placed on providing education about medical issues, understanding HIV as a disability, disclosure and how to support individuals when they are informed they have a positive diagnosis. Types of organizations and services for education would include: hospital emergency departments, long-term care facilities, primary health care providers, dental services, income support and employment assistance, immigration services and mental health and addictions services.

²² The term “broader health care” does not include HIV/AIDS clinics in hospitals.

Barriers to HIV/AIDS Services

"I'm Native, not White; most places don't know how to deal with Natives."

"My main concern was around stigma with entering certain places for services. Some agencies are known for a variety of services other than HIV care but others are very specific so everyone knows why you're there when you walk in the door. As long as stigma and discrimination exist, this will be a barrier."

"Some staff ask too many questions upfront which can be culturally invasive. Staff need to take time with people and not just hand them a flyer and send them out the door."

"Staff need appropriate skills to work with people who use drugs. All agencies should have to take the 519's workshop and Harm Reduction training if they are funded by the MOHLTC. There is a need for training on how to deal with chaotic behaviours and lack of life skills, rather than focusing on drug use."

"The downtown core is the location for many agencies. Travel costs and difficulties place unreasonable demands on people in poor health."

"Services should be offered in different areas of the city and maybe there should be more workers to visit places like shelters, drop-ins and supportive housing units."

All groups identified access barriers that people can face as they try to use ASO services. These barriers are grouped below under three broad categories: practical considerations; agency capacity constraints; and barriers related to culture and access.

Barriers related to **practical considerations** were identified:

- Hours of service can be a barrier because many services are provided primarily during daytime hours on weekdays. (As one focus group participant said, *"It turns out that HIV/AIDS is a Monday to Friday disease because from Monday to Friday you can get all of the help that you need."*) Access would be easier for some people if service was available during more evening and weekend hours.
- Geographic location of service is challenging because the majority of services are located in the downtown core. It was suggested that larger agencies should consider providing services in key non-downtown locations where people are at risk/vulnerable, either through satellite offices or at the facilities of local community services. Others note that while it is difficult to get downtown, they

value the anonymity and confidentiality they associate with obtaining services outside of their geographic community. Others talked about a model that involves providing services in closer proximity to people but in locations where the nature of a visit could not be easily deduced (e.g., women's centres, Community Health Centres).

- Costs of transportation can be a problem because most HIV/AIDS services are concentrated in downtown Toronto. Some agencies provide for costs of transportation, but not necessarily in situations that involve crossing geographic boundaries (e.g., travelling from Peel to Toronto).

Barriers identified related to **agency capacity constraints** included:

- Wait times to get services — A number of individuals talked about having to wait for support groups and buddying. Several PHA focus group participants and questionnaire respondents stressed the value of retreats and other opportunities for peer support and connection, and felt that there should be more of these opportunities.
- Limited resource levels of smaller (generally population/community-specific) ASOs — Such limitations result in some people not being able to obtain a full range of services. Examples include limited information and counselling for people who speak languages other than English and limited services for people who are in conflict with the law, particularly people who have recently been in prison. Resource limitations of community harm reduction programs also limit their capacity to respond to ever increasing needs. Both staffing and supplies (e.g., needles, condoms) were seen to be constrained. Limited resources of harm reduction programs that serve large geographic areas with growing but widely dispersed populations is also a problem.

Barriers related to **culture and access** encompasses issues such as:

- "Pride and Privacy" — Many people talked of fears and concerns about disclosure of HIV status, particularly within an organization where someone might meet other members of one's cultural community. The challenge here is addressing this concern while still ensuring the availability of services that are culturally responsive and appropriate.
- Discrimination - Experiences of discrimination, racism and homophobia with broader health and social services and some ASOs.

- Immigration status - Some people do not want to apply for immigration status because they are HIV+ and thus do not acquire health cards.
- Limited cultural competencies and language capacities (including access to sign language interpreters for deaf people) of service provider organizations — Many people identified the need for ongoing training of ASO staff to increase their cultural competence and language capacity.

Access to Affordable, Effective Medications

“The only way you can access drugs is to go on ODSP — but I can’t afford to.”

“Trillium doesn’t cover lots of medication and the deductible is very high.”

“It’s harder and harder to get on clinical trials.”

“Many people living with HIV are capable of working, but the cost of drugs is just not financially viable. Government should adjust the Trillium Program for people who want to return to the workforce.”

Issues identified here mostly concerned the Trillium Drug Plan. Some people living with HIV/AIDS were concerned that this drug plan:

- may not provide for the most up-to-date or effective medications;
- does not include beneficial complementary therapies; and
- limits the potential for an individual to work when he or she is healthy because it does not recognize that the illness can be episodic. Concerns were raised that people who might be able to work between episodes could not do so because they would risk losing their drug coverage.

The Need to Enhance Income and Employment-Related Supports

“90% of our clients live in poverty.”

“The continuance of the Special Diet status has not only been extremely helpful to me, but I also cannot now imagine trying to live without it. Even with this ‘extra’ money, the cost of food, especially things like meat and cheese, would never be affordable without that extra coming in. The biggest costs have been rent and the monthly prescription bills. There would be no way at all that anyone who was not a CEO could afford all of that on their own.”

“Employment! I was just starting meds when I was not able to work three days in a row and got let go for that! They stated on my T4 let go due to health concerns! I felt very discriminated against!”

“Some organizations use us for years as volunteers and then they hire someone from outside.”

Poverty is both a risk factor and a consequence of HIV. Many of our focus group participants noted that the cost of HIV treatment means that people still have to stop working and rely on income support programs to qualify for HIV drug coverage. They also talked about people who have been out of the work force for long periods. As a result of clinical advances, they could work again with appropriate preparatory support²³ and flexible job arrangements that acknowledge the episodic nature of the disease and the impacts of treatments. The challenges associated with going back to work, including finding flexible and supportive work environments, were noted. Some people thought there should be greater access to jobs in HIV/AIDS organizations and programs by people who are HIV+. Others talked about their interest in more volunteer opportunities in these organizations and programs, both to give more meaning to their lives by “contributing to society” and, where honoraria are provided, to supplement limited incomes.

Ambivalence about Harm Reduction

“We need to support and grow harm reduction programs in our organizations, not just “try them out.”

“Drug users are at the bottom of the heap.”

The need to continue to provide education about harm reduction and its value was identified as important. Some people felt that harm reduction programs face challenges, not only by the communities where they are situated, but

²³ Examples of preparatory support include job search, resume development, interview preparation and skills development.

also by the very organizations of which they are a part. In some cases, board, policy or management support of harm reduction is not consistently understood throughout an organization or easy to implement. Some organizations resist adopting harm reduction approaches (including simply putting out condoms). It was also noted that many programs are stressed by limited resources. This is felt particularly by programs that serve large geographic communities with populations broadly dispersed outside of the downtown core. With limited program resources, partnerships with other organizations become critical to enable service delivery across large catchment areas.

Need for Coordinated, Targeted and Innovative Prevention Education Strategies

“There is a real need for even more linguistically and culturally appropriate education materials, prevention education and support for multicultural populations — programs focused on prevention with women at risk through heterosexual contact, especially those who are marginalized by language, newcomer status, low income, gender inequalities.”

“There will continue to be more need for work with straight and queer youth who are misinformed about the transmission and treatment of HIV due to a lack of education and homophobic views.”

“What about more wellness-based approaches for working with people who have seroconverted but who do not yet have an AIDS diagnosis (i.e., how to prevent/delay the progression of the disease)?”

“We need prevention services created with input from affected communities and delivered in collaboration with other projects like safer crack kit distribution to reach homeless/street-involved populations. More outreach through the distribution of clean needles and a safe drug use space.”

Many people identified the need to reinforce the importance of prevention education and to find creative and integrated (e.g., with support and treatment) prevention education approaches. Public education campaigns to address apathy and inaccurate information, including widespread misperceptions about risk (e.g., “HIV is not a heterosexual issue” and “HIV is curable, so why worry?”), were seen to be critical. In addition, creative strategies tailored to specific populations (e.g., immigrant women) were emphasized. Sexual health education (in schools and other settings) for school-aged youth, including deaf

youth, was also stressed.

Several individuals identified the need for more local research to support the development of prevention models for marginalized women who may be at high risk of HIV. A number of individuals also referred to the need to strengthen the relationships between existing prevention education networks and working groups.

Substantial Service Gaps Remain

“There are no services that currently meet my need to engage in informed dialogue with other long-term survivors. Discussions (are needed) about policies and their impact, i.e. disclosure, treatment access and development, networking, etc.”

“Ethno-cultural communities make up more than 50% of the population, yet the majority of funding is not available to these very large communities.”

“There are no services for spouses. I’d like a group where I don’t have to explain why my life is stressful.”

“In prison there are no prevention services.”

While some people pointed out that capacity of service is often a more significant issue than gaps in service, many service gaps were identified. Each of these service gaps represents an important area of need, and many reflect the lack of available services for the most marginalized groups.

Although the TCPI plan will not address service gaps directly, it does attempt to provide a strategic framework where gaps may be closed through ongoing planning, advocacy and other collaborative initiatives.

The following areas were frequently identified in response to questions about service gaps:

- Services for people who are long-term HIV/AIDS survivors, including wellness services, counselling supports, venues for exchanging information and views
- Services for women, including culturally appropriate substance use treatment services for Aboriginal women; housing; concrete supports such as food, clothing, child care and affordable medications; treatment services that are easily accessible for women whose children are also HIV+
- Culturally appropriate services for Aboriginal people living with HIV/AIDS, including palliative and long-term care facilities and substance use treatment services

- Insufficient ethno-specific services and services for people who have recently immigrated to Canada, including counselling for people who speak languages other than English; legal services, including affordable immigration legal services and services for people without drug cards
- Services for people who are in conflict with the law, particularly those who have recently left prison including housing, case management to promote continuity of service, community support programs that help to re-orient people to the community; accompaniment and other supports to address life skills issues. Lack of services for people within prison was also noted
- Services designed specifically for members of Trans communities, specifically gay/queer FTM (transsexual men), including those in conflict with the law and those who are substance users
- More services tailored to the needs of individuals who are HIV+, drug users, and homeless, under-housed or street-involved. Specific examples included:
 - improved access to health care for street involved and homeless youth, within a harm reduction perspective;
 - hospice/palliative care services specifically for HIV+ drug users;
 - 24-hour needle exchange services;
 - resources and programs to meet the needs of marginalized crack users;
 - more outreach services by ASOs to HIV+ homeless or under-housed people (many are reluctant to access on-site ASO services), including more service provision in nightclubs, raves and warehouses events
- More services for people with dual and concurrent diagnoses, such as individuals with HIV and mental health problems and individuals with developmental delays
- More supports for affected people such as partners, family and friends including access to information and support groups
- In addition, the need was identified for **research** that is strongly linked to community and involves knowledge transfer and exchange.

5.3 Growing and Emerging Needs

The following themes emerged in discussions about growing and emerging needs.

Population Demographics: Diversity and Aging

Changing population demographics — in particular, the increasingly multicultural nature of Toronto and needs of new immigrants - were recognized as the most fundamental factor that must be considered in planning for the future. Essential responses to this situation include: increasing the capacity and resources of ethno-specific services and the cultural competency of all services; combined with creating additional partnerships between HIV/AIDS organizations and programs and with allied sectors (such as immigration lawyers who are able to offer services in multiple languages).

Issues were identified related to population aging. These included the need to ensure that services consider the particular needs of people living with HIV/AIDS who are aging.

“Poverty, gender and cultural background will always be barriers. Now, we are also seeing AGE as a barrier. There’s no programming designed to assist seniors and older people living with HIV/AIDS.”

“Issues arise out of treatment (liver or kidney damage) — this gets worse as people age”

The need to provide Prevention Education targeted for people who are older was also named as an issue.

Need for Supports to Living Well Longer — Whole Person Wellness Approach

As has been noted throughout this report, many people stressed the importance of developing approaches that recognize the chronic nature of HIV and develop a framework, services and policy advocacy that address this reality by focusing on the whole person’s wellness. In addition to chronic disease management strategies, this would include policy work related to drug coverage, housing, income and employment.

Increasing Poverty

As noted earlier, poverty is an increasing reality in Toronto, where the gap between rich and poor is widening (well documented in the United Way report: “Poverty by Postal Code: The Geography of Neighbourhood Poverty”)(April

2004). Poverty is increasingly concentrated in specific geographic neighbourhoods and among immigrant and visible minority populations. Many participants in the TCPI process emphasized that the plan should recognize that poverty is both a determinant and an outcome of HIV. Furthermore, as noted by the Canadian AIDS Society, people living with HIV/AIDS experiencing poverty are at greater risk of having their disease progress quickly.²⁴

Children Growing Up with HIV/AIDS

Many issues were raised that relate to children growing up with HIV/AIDS — issues that are often situated in contexts of poverty, violence, single-parenting, narrowly defined gender roles, homelessness or near homelessness:

- the importance of supports, as well as individual and systemic advocacy for children who are growing up HIV+, particularly in light of fears that their HIV status might inadvertently be disclosed (e.g., resulting in lack of acceptance at school);
- the need for education about healthy sexuality for people growing up HIV+;
- strategies for addressing the impacts on children who are caring for HIV+ parents (such as emotional burden and associated school or social difficulties); and
- service delivery models to help support HIV+ mothers address their own health needs when they see the needs of their HIV+ child as a much higher priority.

Impacts of Long-Term Use of Medication

The potential side effects (e.g., cancer, heart disease and neurological issues) of the long-term use of highly active antiretroviral therapy have several implications for care and support. (Note: The Canadian AIDS Treatment Information Exchange [CATIE] provides up-to-date information on this issue).²⁵

HIV and Drug Use

In addition to concerns about how drugs such as crystal meth (methamphetamine hydrochloride) and crack cocaine impact on risk behaviours, some people noted the challenges they face in keeping up with the rapid changes in street drugs, how they are being used and the implications for HIV prevention strategies.

Co-infections

“Co-infection is not being effectively addressed by most organizations. We are beginning to build alliances to work on this.”

Concerns were raised about the impact of co-infections (i.e., HIV along with another infection) and the consequent treatment considerations. Particular reference was made to Hepatitis C, although syphilis and tuberculosis were also noted.

24 Canadian AIDS Society, Position Paper: Poverty and HIV/AIDS (September 2004)

25 Canadian AIDS Treatment Information Exchange (CATIE) Treatment Update 153, Vol. 17, Issue 7, December 2005 <http://www.catie.ca>

The plan

6. THE PLAN

The plan consists of these main elements:

- a vision outlining desired key features of a future HIV/AIDS service system;
- 10 recommended priorities to guide future development; and
- recommended monitoring and accountability strategies related to plan implementation.

This plan is intended to enhance the capacity of HIV/AIDS and related services to respond in a coordinated manner to changing, complex and diverse needs of people living with, affected by and at risk of HIV/AIDS. While it does not attempt to outline ways to address all service gaps, it offers a framework through which these issues can be addressed. In keeping with the values described earlier, and in light of the following vision, the plan assumes an overall approach that integrates an anti-oppression and anti-racism perspective and recognizes social determinants of health. It also assumes that inter-organizational coordination is a preferred way of operating.

section 6

6.1 Vision: Key Features of a Future HIV/AIDS System

A vision of desired features of a future HIV/AIDS service system for Toronto was developed by the large TCPI group. It is recognized that not all of these features will be realized over the next three to five years, but they are set out as goals toward which the community will strive.

The future Toronto HIV/AIDS service system, made up of HIV/AIDS organizations and programs and allied service providers, will be characterized by the following features:

Client-directed services — Services will be client-directed and non-judgemental, offering choices that respond to the needs of people who are living with HIV/AIDS, including those who are asymptomatic, as well as the needs of people affected by or at risk of and vulnerable to HIV/AIDS.

Needs driven — All elements of the system (planning, service delivery, advocacy and funding) will be based on the needs of people living with or at risk of HIV/AIDS, inclusive of the social determinants of health, identified through the

experiences of service users and service providers, research on best practices and outcome-focused evaluation.

Comprehensive and responsive — A comprehensive spectrum of services and supports will be available from prevention through to end-of-life care. Services will be available in a range of settings and through a variety of service providers.

Accessible — People living with HIV/AIDS or at risk of HIV/AIDS will be able to learn about and obtain appropriate and needed services in a consumer-friendly, barrier-free,²⁶ timely manner, regardless of their first point of contact. Services will be accessible to people across the City of Toronto.

Culturally competent and grounded in an anti-racist, anti-oppression framework — Service provider organizations will continuously work toward enhancing the cultural competency of their organizations to increase access, responsiveness and accountability to Toronto's diverse communities. Service provision, advocacy and system planning will acknowledge the intersection of oppressions and the power differences that exist among communities, organizations and individuals.

Coordinated and collaborative — Coordination and collaboration will be a matter of regular practice, both between HIV/AIDS services and with allied service providers.

A focus on ongoing system quality improvement — Valuing ongoing research, monitoring and evaluation will facilitate a system that is able to:

- respond to and influence emerging trends and research;
- demonstrate service and system outcomes;
- identify gaps and needs and who should address them;
- share knowledge, information and evidence with funders;
- facilitate the development of common data sets (e.g., related to outcome reporting) and data management;
- track progress toward goals;
- build capacity of individuals and organizations; and
- incorporate and enhance best practices.

Efficient and effective — In the future, the service sys-

²⁶ It is recognized that there may be multiple barriers to service access facing different communities and individuals.

tem will be resourced to maximize benefits and avoid unnecessary duplication.²⁷

6.2 Recommended Priorities

Based on the information collected and the work done by the TCPI large group at its December 2005, May 2006 and January 2007 meetings, the following is a set of ten recommended priorities for realizing positive changes in Toronto over the next three to five years. As noted earlier, the plan does not attempt to address all service gaps identified; it provides a framework through which issues and gaps that would benefit from coordination and collaboration can be addressed.

1 Establish an ongoing HIV/AIDS planning and coordination committee. This plan is the first step towards the creation of an ongoing HIV/AIDS-related planning and coordination process aimed at fostering a collaborative system of HIV/AIDS and services. Effective, efficient and sustainable implementation of the plan will be challenging in a city as large and complex as Toronto. To build on current momentum, it is recommended that a committee be established to:

- i oversee the implementation of the remainder of these recommendations;
- ii encourage continued coordination, planning and information sharing among HIV/AIDS and related organizations and programs; and
- iii report to the AIDS Bureau (MOHLTC), participating organizations (and, through them, to their members) and other relevant stakeholders.

Through this ongoing coordinated planning and implementation function, service needs and gaps identified in this document and other sources can be addressed on a system-wide basis.

2 Develop an accessible, coordinated HIV/AIDS service information system. It is recommended that the TCPI Information and Access Working Group

- i build on existing tools to develop a centralized information²⁸ system that would coordinate and provide

27 Toronto HIV/AIDS Community Planning Initiative Vision: Features of a Future HIV/AIDS Service System, Revised Version, May 2006.

28 Information would include an up-to-date and realistic description of services offered, how to obtain them, service criteria, hours and location of service and how to connect. Additional information for service providers should also include any plans for new service. Inclusion of information about relevant current community-based research initiatives would also be beneficial and could contribute to knowledge transfer. On-line access as well as easy-to-use hard copy formats (e.g., an up-to-date calendar of services and events) and multiple languages will be important. Strategies to optimize access for people who are not able to connect electronically or

access to up-to-date information about HIV/AIDS and related services in Toronto;

- ii ensure the availability of this information for people who need services and for service providers; and
- iii facilitate information access electronically, in hard copy and multiple languages, and with the support of service providers in a range of service delivery settings.

3 Promote integrated, innovative and targeted HIV/AIDS Prevention Education strategies. Recognizing the need to sustain and further develop prevention education work, it is recommended that a Prevention Working Group be established to:

- i support harm reduction programs by advocating their important role in HIV prevention and their need for sustained and adequate resources;
- ii make concerted efforts to involve health and social service organizations that serve particularly marginalized populations in HIV/AIDS prevention education planning, service development and advocacy initiatives (e.g., organizations serving people who face issues with homelessness, street-involvement, mental health, substance use, cultural dislocation, and their intersections); and
- iii facilitate communication, coordination and collaboration between groups and networks working on targeted provincial prevention education initiatives and their local implementation.

4 Improve the responsiveness of health and social services to people living with HIV/AIDS. A five-fold approach is recommended for improving the responsiveness of broader health and social services to the needs of people living with HIV/AIDS. It is recommended that the ongoing planning and coordination committee and its Training and Education Working Group facilitate and support:

- i inter-sectoral relationship building and partnership development between HIV/AIDS organizations/programs and broader health and social service organizations;
- ii training organizations in the broader health and social service sectors about HIV/AIDS (e.g., hospitals, primary health care, emergency health, long-term care, housing, immigration, income support, shelter, mental health and addictions services);
- iii training HIV/AIDS organizations and programs by or use hard copy information will be an important consideration.

ganizations in the broader health and social service sectors (e.g., related to services, access processes and other system pressures);

- iv coordinated advocacy by HIV/AIDS organizations/programs and partners in other sectors about the need for changes to policies and practices affecting people living with HIV/AIDS and people at risk of HIV/AIDS; and
- v investigation and development of more coordinated approaches to service delivery, such as “shared care/case management” models that involve greater coordination by different service provider organizations.

5 Enhance the capacity of HIV/AIDS-specific programs and services to serve more diverse communities across Toronto. As has been noted throughout this document, Toronto must be able to develop appropriate responses to address the needs of an increasingly diverse population. It is recommended that the ongoing planning and coordination committee promote a three-pronged approach, as follows:

- i advocacy initiatives to increase the funding levels of population-specific ASOs and programs;
- ii training staff and volunteers of HIV/AIDS organizations and programs to increase their cultural competency, using an anti-racist anti-oppression framework.²⁹ Training should be accompanied by follow-up support resources to sustain training benefits;
- iii actively pursuing partnerships to respond to concrete needs; approaches include:
 - staff of a population-specific HIV/AIDS organizations and programs offering services at the location of more general HIV/AIDS organizations, and vice versa;
 - inter-agency and inter-sectoral partnerships that address practical barriers related to location of service and transportation costs (e.g., ASOs providing services in the space of other organizations that serve non-downtown neighbourhoods);
 - expanding or altering hours of services; and
 - offering services in more “neutral” settings to address concerns about privacy and inadvertent disclosure of HIV status.

6 Improve access to a range of affordable and appropriate housing for people living with HIV/AIDS. It is recommended that the TCPI Housing Working Group:

- i develop relationships with other community groups (e.g., mental health agencies) involved in housing issues, including those developing innovative housing access models;
- ii focus on policy advocacy initiatives related to housing supply and access. The first steps in this policy work will be to carry out some basic information-gathering that can be used to “make the case” for improved housing for people living with HIV/AIDS and people at risk of HIV/AIDS; and
- iii develop a Users' Guide to Affordable Housing using peer involvement.

Note that the group should include shelters and long-term care facilities in its definition of housing.

7 Advocate to address income and employment-related needs. It is recommended that the ongoing planning and coordination committee, along with the Education and Training Working Group, pursue a four-fold response to income and employment-related issues:

- i continue participation in provincial and federal level advocacy initiatives on matters related to income and employment;
- ii reinforce the importance of employment programs in HIV/AIDS organizations and programs because they are tailored to the needs of people living with HIV/AIDS;
- iii educate general employment programs about the needs of people living with HIV/AIDS, with respect to securing and retaining employment (e.g., the importance of flexibility and supports); and
- iv build strategic alliances with key collaborators (e.g., unions, employers) in this process.

8 Develop a coordinated training strategy targeted at HIV/AIDS organizations and programs. In addition to taking the lead on the training components of recommendations 4, 5 and 7 above, it is recommended that the Education and Training Working Group develop and coordinate a two-fold training strategy specifically targeted at HIV/AIDS organizations and programs to:

- i meet self-identified training needs of people living with HIV/AIDS;

²⁹ In this case, “cultural” is meant broadly to include ethnicity and culture, deaf culture, gay, lesbians, trans, queer and 2-spirited cultures, and drug culture.

ii support consistent levels of service across HIV/AIDS organizations and programs in Toronto.

9 Promote infrastructure partnerships and address human resource retention issues. Many shared infrastructure pilot projects are currently underway in Toronto's HIV/AIDS organizations and programs. It is recommended that the Infrastructure Working Group:

- i document, monitor and disseminate lessons learned from existing infrastructure initiatives and pilot projects;
- ii promote further-reaching initiatives that build on current infrastructure projects; and
- iii develop a staff and volunteer retention strategy for the HIV/AIDS sector.

10 Coordinate implementation of Toronto's HIV/AIDS plan with Local Health Integration Networks (LHINs), provincial HIV/AIDS strategies and other emerging initiatives. The TCPI Steering Committee should initiate efforts to:

- i create a profile for HIV/AIDS in the LHINs structure (e.g., encouraging health system planning and delivery that addresses barriers faced by people living with HIV/AIDS). At the same time, the importance of preserving the AIDS Bureau (MOHLTC) distinct funding must be emphasized;
- ii support the local implementation of provincial population-specific HIV/AIDS strategies by encouraging dissemination and training about these strategies to TCPI members; and
- iii communicate and collaborate with other strategy, coordination and system restructuring initiatives of relevance to people living with or at risk of HIV/AIDS (e.g., other local or regional plans).

6.3 Accountability: Implementation Monitoring and Reporting

It is recommended that a simple accountability framework be developed to monitor the implementation and outcomes of this plan. This framework, with a focus on the service system overall rather than on individual organizations, would collect minimal information needed to help track:

- progress on the implementation of the plan (i.e., what has happened in relation to the recommendations and Working Group activities); and

- improvements that have been made for people living with HIV/AIDS (i.e., system outcomes). This aspect of the monitoring could be based on the TCPI "Vision: Features of a future HIV/AIDS system", as well as gaps and issues identified in sections 5.2 and 5.3.

Data collection, based on pre-established and clear measures, should be conducted periodically with service providers and service users. Emphasis should be placed on limiting the burden of data collection by focusing on a few key measures.

Responsibility for this monitoring function should lie with the ongoing planning and coordination committee (as outlined in recommended priority 1, with reporting to participating agencies (and through them to their members/service users) and to the AIDS Bureau (MOHLTC).

The next steps

7. THE NEXT STEPS

The next steps in this process include:

- presentation of the plan by the TCPI Co-Champions to the AIDS Bureau, (MOHLTC), and consideration given to seeking funding to support the implementation of major recommendations;
- development of a dissemination plan and tools for communicating the results of the TCPI planning process;
- development of an implementation plan that outlines the implementation staging of each recommended priority over the next three to five years (recognizing that not all recommendations need to be implemented at once or at the same time, and that a staged approach might be most effective); and
- development of a work plan, focusing on major milestones, to guide the implementation process.

To build on current momentum, it is recommended that the current Steering Committee take the initial lead in:

- facilitating the above-noted dissemination, implementation planning and work planning tasks;
- finalizing the ongoing planning committee structure (e.g., terms of reference, processes for identifying gaps in membership/participation, preferred committee composition, working group reporting templates, and other governance-related materials); and
- organizing a process for committee membership and leadership.

APPENDIX A: Glossary of Terms

AIDS Acquired immunodeficiency syndrome.

ASOs AIDS Service Organizations.

CATIE The Canadian AIDS Treatment Information Exchange.

CLEAR Community-Linked Evaluation AIDS Resource, McMaster University Health Sciences.

Co-infection Having two infections at the same time.

Cultural competence “Cultural and linguistic competence is a set of congruent behaviors, attitudes and policies that come together in a system, agency or among professionals that enables effective work in cross-cultural situations. “Culture” refers to integrated patterns of human behavior that include the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious or social groups. “Competence” implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors and needs presented by consumers and their communities”.³⁰

Determinants of health Key determinants identified by Health Canada consist of income and social status; social support networks ; education and literacy; employment/working conditions; social environments ; physical environments; personal health practices and coping skills; healthy child development ; biology and genetic endowment ; health services; gender and culture³¹.

Epidemiology The study of the occurrence, distribution and determining factors associated with health events and diseases in a population³².

FHT Family Health Team

GIPA Greater Involvement of People Living with and Affected by HIV/AIDS.

Harm Reduction See the Canadian Harm Reduction Network at: <http://www.canadianharmreduction.com>

HIV Human immunodeficiency virus.

IDU People who inject drugs, also called injecting drug users.³³

HIV Incidence The number of new HIV infections occurring

30 <http://bhpr.hrsa.gov/diversity/cultcomp.htm> (Cross, T., Bazron, B., Dennis, K., & Isaacs (1989). Towards A Culturally Competent System of Care Volume 1. Washington, DC: Georgetown University Child Development Center, CASSP Technical Assistance Center). Health Resources and Services Administration Bureau of Primary Health Care Office of Women and Minority Health.

31 <http://www.phac-aspc.gc.ca/ph-sp/phdd/determinants/index.html>

32 A guide to HIV/AIDS epidemiological and surveillance terms, Published collaboratively by the Canadian AIDS Society (CAS) and the Centre For Infectious Disease Prevention And Control (CIDPC), Health Canada, 2002; p.20.

33 Ibid., p.3

in a specified period of time in a specified population³⁴.

IHSP Integrated Health Service Plan.

MOHLTC Ministry of Health and Long-Term Care (Ontario)

LGBT lesbian, gay, bisexual and transgender and 2-spirit.

LHINS Local Health Integration Networks.

APPENDIX B: List of Participating Organizations and Programs

Phase One: HIV/AIDS Organizations and Programs (Funded Through The AIDS Bureau, Ministry of Health and Long-Term Care)

1. 2-Spirited People of the 1st Nations (2 Spirits)
2. AIDS Committee of Toronto (ACT)
3. Asian Community AIDS Services (ACAS)
4. Alliance for South Asian AIDS Prevention (ASAAP)
5. African Community Health Services (ACHS)
6. Africans in Partnership Against AIDS (APAA)
7. Barrett House - Good Shepherd Ministries
8. Black Coalition For AIDS Prevention (Black CAP)
9. Casey House Hospice
10. Central Toronto Community Health Centres (CTCHC)
11. Centre for Spanish Speaking Peoples
12. COUNTERfit Harm Reduction Program, a project of the South Riverdale Community Health Centre
13. David Kelley HIV/AIDS Community Counselling Program, Family Service Association of Toronto
14. Deaf Outreach Program, Ontario Association of The Deaf
15. Fife House Foundation
16. Hassle Free Clinic
17. Hemophilia Ontario
18. Lawrence Heights Community Health Centre
19. Maggie's Toronto Prostitutes' Community Service Project
20. McEwan Housing & Support Services, LOFT Community Services
21. Ontario Aboriginal HIV/AIDS Strategy
22. PASAN (Prisoners' HIV/AIDS Support Action Network)
23. Street Outreach Services (S.O.S.), LOFT Community Services
24. St. Stephen's Community House Wellness Promotion Program
25. The Teresa Group
26. The Toronto People With AIDS Foundation
27. Voices of Positive Women
28. Warden Woods Community Centre
29. YOUTHLINK Inner City

34 5 Ibid., p.31

Phase Two: Invited Organizations That Attended One Or More Meetings Or Focus Group

1. Anishnawbe Health Toronto
2. Centre for Addiction and Mental Health (CAMH)
3. Etobicoke-York Community Care Access Centre
4. Fred Victor Centre
5. HALCO HIV & AIDS Legal Clinic (Ontario)
6. Ministry of Community and Social Services
7. Mt. Sinai Hospital, Clinic for HIV-Related Concerns
8. Planned Parenthood Toronto
9. Regent Park Community Health Centre
10. Scarborough Community Care Access Centre
11. Sherbourne Health Centre
12. St. Michael's Hospital, Health Centre at 410 Sherbourne
13. Sunnybrook Health Sciences Centre, Medical Out-patient Clinic
14. The 519 Church Street Community Centre
15. Toronto Central Community Care Access Centre
16. Toronto Community Housing
17. Toronto General Hospital, Immunodeficiency Clinic, Division of Infectious Diseases
18. Toronto Housing Connections
19. Toronto Public Health
20. Women's College Hospital
21. Women's Health in Women's Hands

APPENDIX C: Conflict Resolution Guidelines

Toronto Community Planning Initiative (TCPI) Conflict Resolution Guidelines Final Draft (Oct. 27/05)

The Toronto HIV/AIDS Community Planning Initiative will employ a conflict resolution approach that provides members a fair and neutral process. The Co-Chairs (appointed Community Champions) will respond to conflicts as they arise. Recognizing that each individual has both a personal interest in, and a share of the responsibility for, resolving conflict, members should direct their concerns regarding difficulties between members to the Co-Chairs for support and facilitation when both parties are unable to reach an amiable resolution without Co-Chair intervention.

Principles

1. This policy is intended to address issues arising out of and specifically related to, the community planning process, not pre-existing issues or differences related to the outcomes;
2. Conflicts are inevitable and may produce benefits and positive results if managed effectively and expeditiously. An effective conflict resolution process promotes collaboration as people learn how to work

harmoniously, develop creative solutions to problems, and reach outcomes that mutually benefit those involved. In some cases, a reasonable outcome is for members to agree to disagree;

3. Early recognition of conflict is critical;
4. It is both the right and the responsibility of individuals involved in a conflict situation to attempt to resolve conflict on an informal basis;
5. The Co-Chairs will promote an environment that emphasizes commitment and consistency with respect to conflict resolution so that members are encouraged to seek resolution within the planning process;
6. All parties involved in the resolution process should encourage open communication and cooperative problem solving, with an assumption of positive intent;
7. All parties involved in the resolution process should communicate in a constructive and appropriate manner, addressing behaviours rather than personalities and consequences rather than motives.
8. The process should be based in present events, with a forward-looking solution focus.

Steps

1. Issues should first be brought to the attention of the relevant individual(s), and an attempt at resolution made through informal discussion.
2. If there is no resolution after the initial discussion, a member may submit a complaint in writing to the Co-chairs.
3. The Co-chairs will meet with those involved to resolve the issue within 15 days of receiving the written complaint.
4. In the event that the conflict is not resolved by the Co-Chairs, a request will be made to the Ministry for guidance and assistance.