

## Report of the Community Roundtable on HIV, Housing, Aging, Complex Care & Cognitive Issues

Ramada Plaza Toronto - June 22, 2011

December 2011

Report writing by John Miller, John Miller Consulting

#### Acknowledgements:

The Housing Working Group, of the Toronto HIV/AIDS Network, would like to thank the following for their work in the planning, and delivery of this exciting day.

- The Toronto HIV/AIDS Network (THN) for funding the Roundtable, through THN's funding from the AIDS Bureau, Ontario Ministry of Health and Long-Term Care.
- Fife House Foundation and its staff for hosting and undertaking the planning and organizing for the day, particularly Michael Blair for his vision and leadership.
- John Miller, John Miller Consulting, for his wisdom, insight, and skills in planning, facilitating, disseminating all of the information of the day, and writing the Report.
- Michael Morgan, Peer Coordinator, Toronto HIV/AIDS Network for his diligent logistical support to the planning committee, and onsite coordination.
- Roundtable Facilitators: Yvette Perreault, Rick Julien, Joan Anderson, Ruth Cameron, Robin Rhodes, Nick Boyce, and Jenn Major.
- Presenters: Keith Hambly, Fife House Foundation; Karen de Prinse, Casey House; Debra Walko, LOFT Community Services; Beatriz Tabac, Toronto Community Housing; Dr. Sean B. Rourke, Ontario HIV Treatment Network
- All reviewers of the Draft Report particularly Vashti Campbell and Sue Hranilovic, St Michael's Hospital, who are new members of the Housing Working Group.
- Members of the Planning Committee: Kay Roesslein, McEwan Housing and Support Services/LOFT
  Community Services; Marco Villa, Service Coordination Program, McEwan Housing and Support
  Services/LOFT Community Services; Keith Hambly and Michael Blair, Fife House Foundation; Robin
  Rhodes, AIDS Committee of Toronto; Todd Ross, Casey House; Michael Morgan and Joan Anderson,
  Toronto HIV/AIDS Network; Dora Londono, Prisoners and HIV/AIDS Support Action Network; Ruth
  Cameron, Ontario AIDS Network; Charles Shamess, Ontario HIV Treatment Network; Jordan Lewis,
  Canadian Working Group on HIV and Rehabilitation; and Chris Gibson, Seaton House Infirmary
  Program.

Many thanks to all of the participants from the various service sectors, and community members who shared their experiences, wisdom, and worked hard through an intensive process.

Keith Hambly and Kay Roesslein, Co-Chairs, Housing Working Group

#### List of Participants:

- Rick Julien, AIDS Bereavement and Resiliency Program of Ontario (Table Facilitator)
- Yvette Perreault, AIDS Bereavement and Resiliency Program of Ontario (Table Facilitator)
- Jessica Cattaneo, AIDS Committee of Toronto
- Robin Rhodes, AIDS Committee of Toronto (Table Facilitator)
- Bomi Daver, Alliance for South Asian AIDS Prevention
- Shannon Ryan, Black Coalition for AIDS Prevention
- Wendy Cameron, Bridgepoint Health
- Elisse Zack, Canadian Working Group on HIV & Rehabilitation
- Karen de Prinse, Casey House (Presenter)
- Todd Ross, Casey House
- Efrem Rone, Centre for Addiction and Mental Health
- Cindy Stephens, City of Toronto, Long-Term Care Homes & Services
- Doug Guest, Community member
- Kenneth Poon, Community member
- Lynn Hillman, Concurrent Disorders Support Services
- Paul Bruce, COTA Health
- Keith Hambly, Fife House (Presenter)
- Michael Blair, Fife House
- Barbara Taylor, Fife House
- Stephen Westfall, Fred Victor
- Belinda Marchese, Hospice Toronto
- John Miller, John Miller Consulting (Community Roundtable Facilitator)
- Debra Walko, LOFT Community Services (Presenter)
- Kay Roesslein, McEwan Housing & Support Services, LOFT Community Services
- Marco Villa, McEwan Housing & Support Services, LOFT Community Services
- Christine Chow, Mid-Toronto Community Services
- Scott Bowler, Mount Sinai Hospital
- Ruth Cameron, Ontario AIDS Network (Table Facilitator)
- Nick Boyce, Ontario HIV & Substance Use Training Program (Table Facilitator)
- Dr. Sean B. Rourke, Ontario HIV Treatment Network (Presenter)
- Jenn Major, Ontario HIV Treatment Network (Table Facilitator)
- Charles Shamess, Ontario HIV Treatment Network

- Frank McGee, Ontario Ministry of Health and Long-Term Care, AIDS Bureau
- Ron Lirette, Perram House
- Paul Follett, Philip Aziz Centre
- Anne Marie DiCenso, Prisoners with HIV/AIDS Support Action Network
- Dora Londono, Prisoners with HIV/AIDS Support Action Network
- Patricia Maxwell, St. Elizabeth Health Care
- Dr. Ken Balderson, St. Michael's Hospital
- Vashti Campbell, St. Michael's Hospital
- Sue Hranilovic, St. Michael's Hospital, 410 Sherbourne Health Centre
- Dr. Vicky Stergiopolous, St. Michael's Hospital
- Bev Lepischack, Sherbourne Health Centre
- Chris J. Gibson, Seaton House
- Carol Danis, Sistering
- Laura Klie, Sunnybrook Health Sciences Centre
- Laurel Stroz, Toronto Central Community Care Access Centre
- Sandra lafrate, Toronto Central Community Care Access Centre
- Anne Stephens, Toronto Central Community Care Access Centre
- Chris Sulway, Toronto Central Local Health Integration Network
- Beatriz Tabak, Toronto Community Housing (Presenter)
- Paulina Vivanco, Toronto Community Housing
- Murray Jose, Toronto People with AIDS Foundation
- Suzanne Paddock, Toronto People with AIDS Foundation
- Marvelous Muchenje, Women's Health in Women's Hands
- Jane Piccolotto, Woodgreen Community Services
- Joan Anderson, Toronto HIV/AIDS Network (Table Facilitator)
- Michael Morgan, Toronto HIV/AIDS Network (Recorder, Logistical Support)

Organizational Regrets: 2-Spirited People of the 1<sup>st</sup> Nations, Ontario Ministry of Corrections, St. Joseph's Health Centre, The 519 Church Street Community Centre, Toronto General Hospital, Wellesley Central Place/Rekai Centre



#### **Table of Contents**

Execut	tive Summary & Glossary		
I. E	Executive Summary	7	
II. C	Glossary	11	
Background			
I. 1	The Housing Working Group of the Toronto HIV/AIDS Network	13	
II. T	The Challenge	13	
Comm	unity Roundtable Summary	15	
III.	Roundtable Goals, Methodology & Agenda	15	
1.	Goals	15	
2.	Methodology	15	
3.	Roundtable Agenda	15	
IV.	The Service System: Identifying the Problems & Opportunities	16	
4.	Context setting presentation:	16	
5.	Brief scan of service environments	16	
6.	Opportunities for service innovation	19	
٧.	The Service System: Solutions	20	
7.	Presentations - Innovative Service Models	20	
8.	Innovative service models we could work on now	21	
9.	Longer term solutions	24	
VI.	Research and evaluation: Filling the Gaps	25	
10.	. Gaps in research	25	
11.	. Gaps in evaluation	26	
12.	. Filling the research gap	26	
13.	. Opportunities for new funding & support with research	28	
VII.	Comments and impressions from participants	28	
VIII.	Next steps	29	
Conclu	sions	20	

## **List of Appendices**

Appendix I – Community Roundtable Participants

Appendix II – Summary of the 2009-10 'Service Coordination Pilot Project for Homeless People Living with HIV/AIDS'

Appendix III – Issues/ Challenges and Current Response – Roundtable discussion group flipchart notes

Appendix IV - Service Gaps and Opportunities - Roundtable discussion group flipchart notes

Appendix V - Gaps in Research and Evaluation – Roundtable discussion group flipchart notes

**Appendix VI – Summaries of Short-term Models Developed by Roundtable Participants** 

Appendix VII - Grants, Research Support & Knowledge Transfer and Exchange Opportunities (current as of June 2011)

## **Executive Summary**

#### I. Executive Summary

#### **Background**

A Community Roundtable on HIV, Housing, Aging, Complex Care & Cognitive Issues was held on June 22, 2011 at the Ramada Plaza Hotel in Toronto. The Roundtable was organized by the Housing Working Group of the Toronto HIV/AIDS Network (THN) and included fifty-six participants from sectors involved in the response to people living with these challenges.

#### The Challenge

The Community Roundtable was convened because Toronto is experiencing a demographic shift in the population of people living with HIV/AIDS (PHAs), resulting in an aging PHA population and a population of PHAs experiencing the effects of accelerated aging after years of living with HIV. Care needs are increasing and many PHAs who have been stably housed for years are losing their housing or experiencing destabilized housing, and the sectors are not adequately meeting the current needs. Furthermore, there is a demographic bubble of aging PHAs that will increase the demand for services and challenge the sectors to find collaborative solutions. The Community Roundtable was convened to begin to find those solutions, and was modeled on a collaborative community process that led to the very successful Service Coordination Program for Homeless PHAs and the Addiction Supportive Housing Program.

Community Roundtable participants were led through background and context by way of a presentation by Keith Hambly, Co-chair of the Toronto HIV/AIDS Network (see Section IV, 4).

#### Goals

The Community Roundtable goals were to:

- Identify the issues and challenges that aging PHAs, PHAs experiencing accelerated aging and PHAs with cognitive issues are facing.
- Identify the current responses, service models, service innovation and partnerships being delivered by agencies and sectors.
- Identify the gaps in program and service delivery that agencies and sectors see related to the issues and challenges we have identified.
- Develop two or three models of solutions that as a community could be developed now for implementation within an eighteen month period.
- Brainstorm ideas for funding short-term solutions.
- Brainstorm ideas for long-term solutions.
- Identify key research questions for moving forward.
- Galvanize a common commitment to collaborative model development for the future.

## Issues and challenges

The Community Roundtable participants were asked to list the issues and challenges as they relate to aging PHAs, PHAs experiencing accelerated aging, complex care and cognitive issues. Issues and challenges fell into the following categories: mental health challenges, physical health challenges, struggles with changing identities; resource and housing challenges; access and equity challenges; stigma and discrimination; caregiver burnout; and emerging community sector/ PHA response (see Section IV, 5, i).

Inventory of current responses, gaps in service, opportunities for innovation The listing of issues and challenges was followed by a quick inventory of current system responses to the population, which brought out a variety of different collaborative models already in place (see Section IV, 5, ii), but then the group was asked to list gaps in service for this population despite these collaborations.

Service gaps identified fell into the following areas: a) knowledge gap/ gap in training; b) poor service navigation/ advocacy support; c) funding gaps and funding silos; d) poor service integration; e) insufficient housing generally; and f) ineligibility for chronic disease care services (see Section IV, 5, iii for more details on gaps identified).

Opportunities for service innovation to respond to these gaps and build on current responses were then identified: partnership and collaboration models; outreach models; education and training; peer and volunteer support; innovative support models; and housing enhancement - both numbers of beds and new models (see Section IV, 6).

Innovative model development - short term solutions we can work on now Participants then got down to work on finding solutions. Grounded in the work of the morning and two presentations giving examples of innovative service models (Debra Walko from LOFT Community Services and Karen De Prinse from Casey House (see Section V, 7)), they began to identify innovative service models that could be implemented within eighteen months, if given \$300,000 in funding for a pilot (a theoretical exercise). Ten models emerged from the small group work, and when participants were asked to choose the models that most addressed the gaps in services and effectively increased cross-sector collaboration, three emerged.

**Model #1** was called Consultative HIV Aging Mobile Program – CHAMP, and it was a consultative multi-disciplinary mobile team which assists agencies in developing their internal capacities on HIV and aging, aimed at increasing accessibility for PHAs to housing, support, and care services.

**Model #2** was called Hub of Community and Clinical Expertise, and it involved the development of an interdisciplinary clinic model, which would provide comprehensive assessment consultation, development of a plan of clinical care, to be linked to coordination and delivery of service in the community.

**Model #3**, called Transitional Housing Aging/Complex Care, involved the development of a transitional and complex care housing model for high support needs of aging PHAs and those with advanced cognition issues, whose needs are now not being met in the current high support housing models (see Section V, 8 and Appendix VI).

Although three models emerged as the most workable and responsive to the gaps and service identified earlier in the day, the Working Group will be looking at all of these models to take from them the best elements and develop the most effective project.

## Longer term solutions

After developing innovative short-term models, the group turned to a discussion of longer-term solutions. To lead into the discussion, Beatriz Tabak of Toronto Community Housing (TCH) gave a presentation on TCH's response to an extremely large senior population with increasingly complex needs in multiple sites (See Section V, 9). The key to TCH's strategy lies in collaborative approaches with community partners, and this led to a brainstorming of what elements would be required in a long-term response.

## Research and evaluation: filling the gaps

Although not primarily focused on research, the Community Roundtable identified gaps in research and evaluation and identified potential opportunities for funding.

Gaps in research included a) research into aging and accelerated aging in PHAs; b) research into current knowledge base of health care sector; and c) research into housing and support models (see Section VI, 10).

Gaps in evaluation included evaluation of models for this specific population and needs assessment for the population (see Section VI, 11).

Dr. Sean B. Rourke of the Ontario HIV Treatment Network (OHTN) gave a presentation outlining related emerging research, and gave ideas for relevant research areas (see Section VI, 12). Participants gave input into the key research questions moving forward (see Section VI, 12). Dr. Rourke, Jenn Major, also of the OHTN, and Ruth Cameron of the Ontario AIDS Network informed the group of current research and knowledge transfer funding opportunities (see Section VI, 13).

#### **Next Steps**

At the end of the day, participants gave their impressions of the outcomes, expressing energy and enthusiasm for working together, and for the models developed.

The Housing Working Group Roundtable planning sub-committee committed to circulating this report and to holding a follow-up meeting with participants, the purpose of which would be to bring forward proposed action items based on the Roundtable and further developed by the Working Group for input and development.

#### **Conclusions**

The Roundtable ended with a sense of excitement, optimism, and with consensus on key points:

- Participants are committed to evaluating the proposed models of service delivery, and choosing the best key elements to support the identified gaps in the current provision of service and care.
- There is energy to move forward on a needs assessment and/or to access and analyze existing
  evidence in Toronto which will further support the development of a workable model of
  service delivery and coordination.
- The current clinical models may not be producing the best results in terms of health and wellness outcomes for this population, as we are seeing in our various sectors of practice; a new model of care is needed to support this changing demographic.

- There is a demonstrated need for an interdisciplinary and cross-sector case management response.
- There is a need to enhance collaboration and integration of training and education across sectors.
- There is a desire and need for all agencies involved to examine the ways that stigma exists as a barrier for clients when they access or do not access current services.
- There is an openness to examine the opportunities to adapt, enhance or change existing models of service to engender improved service collaboration and integration.
- Participants are committed to enhance collaboration and integration with the goal of promoting cross-sector training and education to improve existing services.

#### II. Glossary

This glossary does not include all agencies or programs that appear in the report, only those where short forms have been used, even if their long form has been stated elsewhere in report.

ACT AIDS Committee of Toronto

ACT Assertive Community Treatment

ADL Activities of Daily Living

ALC Alternate Level of Care

CAMH Centre for Addiction and Mental Health

CASH Coordinated Access to Supportive Housing (LOFT Community Services)

CBPHC Community Based Primary Health Care Tem Grants

CCAC Community Care Access Centre

CDSS Concurrent Disorder Support Services (hosted at Fred Victor)

CIHR Canadian Institutes for Health Research

CNAP 55+ Community Navigation and Access Program

COTA COTA Health

ER Emergency Room

IADL Instrumental Activities of Daily Living

ICES Institute for Clinical Evaluative Services

ICM Intensive Case Management

KTE Knowledge Transfer Exchange

LTC Long Term Care

OCASE Ontario Community-Based AIDS Services and Evaluation (OCASE) database project

OCS OHTN Cohort Study

OHTN Ontario HIV Treatment Network

PHA(s) Person or People Living with HIV/AIDS

PWA Toronto People with AIDS Foundation

REACH CIHR Centre for REACH in HIV/AIDS (Research Evidence in Action for Community Heath)

SCP Service Coordination Project for Homeless People Living with HIV/AIDS

TASC Team Assessment and Support Care Clinic (St. Michael's Hospital)

TCH Toronto Community Housing

THN Toronto HIV/AIDS Network

TLC Transitional Housing

## Background

#### I. The Housing Working Group of the Toronto HIV/AIDS Network

The Toronto HIV/AIDS Network (THN) mission is to facilitate HIV/AIDS planning, collaboration and innovation to improve access to programs and services for people from diverse communities living with, affected by and at risk of HIV/AIDS.

THN's Housing Working Group exists to improve access to a range of affordable and appropriate housing for people living with HIV/AIDS (PHAs). They meet regularly to:

- · Identify emerging issues and gaps in services
- Explore and support the development of innovative service models
- Exchange related program and community-based research information

In 2008 the Working Group convened a cross-sector response to help address the issues of homeless people living with HIV/AIDS (PHAs), many of whom experience concurrent mental health and substance use issues. Many community agencies came together in the Service Coordination Pilot Project for Homeless PHAs. The evaluation results showed vast improvements in terms of reducing emergency room visits and in-patient hospital stays, achieved by short-term intensive case management, health stabilization in the community involving the use of dedicated beds for respite and housing. This successful collaboration has led to an ongoing program with new funding<sup>1</sup>.

This service system collaboration worked so well that the Housing Working Group decided to tackle a new and emerging challenge facing PHAs.

#### II. The Challenge

Toronto is experiencing a demographic shift in its PHA population. PHAs are aging, and are also experiencing what is called accelerated aging - the more rapid onset of symptoms of aging caused either by the long-term effects of living with HIV or the long-term effects of taking medication to combat it.

With an aging population and with accelerated aging comes complex care and co-morbidities. Many of these PHAs have been stably housed for years and are now seeing significant changes in their health and their support needs. Housing "Toronto's HIV/AIDS experts and activists are growing increasingly alarmed by "a hidden epidemic"— (HIV) infected people who have lived decades longer than anyone imagined and are being hit with a host of aging illnesses in their 30s, 40s and 50s. They include dementia, cardiovascular and liver disease, cancers, diabetes, osteoporosis, emphysema and kidney problems."

Toronto Star Feb 27, 2011

Report of the Community Roundtable on HIV, Housing, Aging, Complex Care & Cognitive Issues

For more information on this project, see Appendix II

and support providers are seeing instances where these changes in health and support needs have resulted in risk for and loss of housing. Meanwhile, current housing and service models are struggling to meet the complex health needs of people with HIV who are aging or experiencing accelerated aging, and who have cognitive issues. Neither the existing higher support housing models nor the long term care sector currently have the capacity to adequately or appropriately serve these aging PHAs. To make matters more challenging, some experiencing accelerated aging are also experiencing cognitive disorders.

Cognitive disorders have been identified as a growing problem for PHAs in Toronto and elsewhere. These disorders are a problem for PHAs who are entering middle or old age, but also for those who are experiencing what is now commonly referred to as 'accelerated aging', i.e. the *early* onset of the effects of aging produced either by the long-term effects of either HIV itself or the drugs taken to manage its impact<sup>2</sup>.

The demographic bubble of aging PHAs in the Toronto region shows the largest group is aged 40-54<sup>3</sup>, indicating that the needs of this cohort as it ages in the next ten years will only put more pressure on an already stretched system.

In the spring of 2011, The Housing Working Group of THN decided to convene a Community Roundtable to build consensus with existing community partners, bring other sectors to the table, and begin to brainstorm solutions.

Many sectors are involved in serving this population: AIDS service organizations, long-term care/hospice, mental health and addictions/harm reduction, housing, hospitals, community health, and funders. It was clear that a coordinated response to the problem will be required if the community is to meet the needs, and that the combined expertise could lead to improved service delivery.

In the spring of 2011, the Housing Working Group engaged a consultant and began planning for a Community Roundtable as a first step to addressing the problem. A list of about sixty key sector and community representatives was identified. An ambitious agenda was developed that would have participants move from problem and gap identification to short and long-term solutions for further consideration by the Working Group in the fall of 2011.

The Community Roundtable was held on June 22, 2011 at the Ramada Plaza Hotel in Toronto.

<sup>&</sup>lt;sup>2</sup> The causes of accelerated aging in PHAs are still not well understood by scientists. Research is being conducted to determine if it is caused by the long-term impact on the body of the virus itself, on the long-term toxicity of highly active antiretroviral therapy, or a combination of both factors.

OCHART – Ontario Community HIV/AIDS Reporting Tool data representing PHAs who accessed services. OCHART data is collected by all provincially and federally funded HIV/AIDS community services in Ontario and housed at the Ontario HIV Treatment Network.

## Community Roundtable Summary

#### III. Roundtable Goals, Methodology & Agenda

#### Goals

The goals of the Community Roundtable were to:

- Identify the issues and challenges that aging PHAs, PHAs experiencing accelerated aging and PHAs with cognitive issues are facing.
- Identify the current responses, service models, service innovation and partnerships being delivered by agencies and sectors.
- Identify the gaps in program and service delivery that agencies and sectors see related to the issues and challenges we have identified.
- Develop two or three models of service innovation that, as a community, could be developed for implementation within an eighteen month period.
- Brainstorm ideas for funding short-term solutions.
- Brainstorm ideas for long-term solutions.
- Identify key research questions for moving forward.
- Galvanize a common commitment to collaborative model development for the future.

#### 2. Methodology

Participants were organized into seven tables, each with a facilitator to guide discussions. The table composition was carefully considered by the Working Group so as to have a mix of people from different sectors, and where possible, a community member.

#### 3. Roundtable Agenda

The Agenda was organized into the following topics:

- 1. Context setting and Background Presentations
- 2. Brief Scan of Service Environments
- 3. Examples of Innovative Service Responses: Inspiration for coming up with short-term and longer-term solutions
- 4. Short-term solutions we can work on now
- 5. Longer-term solutions
- 6. Filling the research gap
- 7. Next Steps

#### IV. The Service System: Identifying the Problems & Opportunities

#### 4. Context setting presentation:

The Housing Working Group of THN has been a model in terms of service innovation and cross-sector collaboration. The Housing Working Group's primary focus and success has been in the identification of gaps in service for the most marginalized PHAs, and its ability to bring key stakeholders to the table to come up with innovative service delivery solutions. For example, the Service Coordination Project for Homeless PHAs.

Keith Hambly, as Co-chair of the Toronto HIV/AIDS Network, gave a presentation to set context and explain how the Service Coordination Project for Homeless PHAs was developed through a similar process to what we are doing here today. There is clear evidence of that Project's successful outcomes. For instance, in the first year there was a 50% reduction in ER visits involving all clients from the year prior to intake into the Project's services. Over the first year there was an 80% reduction in inpatient hospital stays involving all clients from the year prior to intake<sup>4</sup>. Over the first year, 16 of 28 clients used a total of 718 days respite or health stabilization stays in beds dedicated to the Project, and those 718 days of respite care and health stabilization in community is directly linked to the reduction of inpatient hospital days in the prior year.

Central to this partnership's success was the willingness for each agency to challenge their service-asusual models, the creation of dedicated service times or units (respite, health stabilization and housing), and an honouring of each other's strengths.

The Service Coordination Project and its collaborative and consultative process was the model for the development of this Roundtable.

#### Brief scan of service environments

#### i. Issues & challenges for this population

The Roundtable participants were asked to list the issues and challenges as they relate to aging PHAs, PHAs experiencing accelerated aging, complex care and cognitive issues. Responses can be summarized and grouped as follows:

**Mental health challenges** (depression; isolation; anger; long-term and multiple loss; drug interactions; cognition)

<sup>&</sup>lt;sup>4</sup> Based on Project Evaluation data collection done at baseline (intake into services) of pre and post-intake hospital usage data was gathered with primary hospital partner St. Michael's Hospital with client consent.

**Physical health challenges** (drug interactions; cyclical wellness/illness; aging-related health issues; early onset of HIV-related health issues in PHAs; complex co-morbidities relating to HIV)

**Struggles with changing identities** (growing older; loss of livelihood and identification with job or career; physical changes; sexuality; and changes to/loss of social networks)

**Resource and housing challenges** (poverty in general; limitations of disability income; lack of sufficient, safe, affordable housing with appropriate supports; need for a wider continuum of housing options; food security)

Access and equity challenges (systems already at capacity; geriatric services excluding younger people experiencing accelerated aging; need for cross-sector, inter-disciplinary training about geriatrics on the one hand and HIV on the other; timeliness of service response; resistance from some sectors; funding deficit; collaboration challenges; stakeholders unaware of one another; language barriers)

**Stigma and discrimination** (related to aging; HIV; homelessness; sexual identity/orientation; substance use; mental health; race and culture; related to how the layering of internalized HIV-related stigma, *combined with* the stigma that may be experienced within HIV services and in the broader health sector, can create barriers to access to service)

Caregiver burnout (partners; friends; families and volunteers; staff)

**Emerging community sector/PHA response** (PHAs and service providers, until very recently, have not been organized around this issue.)

#### ii. Current system responses to this population

Roundtable participants were asked to list the current system responses to housing, support and care for this population, thinking in particular about service models, innovations, partnerships and/or referral agreements. Participants were asked to think of HIV-specific responses but other applicable responses were also solicited. Participants were also asked to frame their responses in the context of the issues facing aging PHAs, PHAs experiencing accelerated aging, complex care and

cognitive issues. Responses fell into the following categories, and specific programs are mentioned in the footnote<sup>5</sup>:

- Programs that provide transitional housing
- Food security programs
- Addictions supportive housing intensive case management models
- Programs that serve the Lesbian/Gay/Bi/Trans populations
- Long-term care specialized units
- Intensive case management team model
- Eviction prevention models
- Concurrent Disorder Support Services model
- Community nursing
- CASH model Coordinated Access to Supportive Housing, centralized intake for all mental health supportive housing in the City of Toronto
- Community Navigation and Access Program (CNAP) a network of over 30 not-for-profit organizations, working together to serve seniors in communities across Toronto
- Hospice care
- Virtual ward models
- Critical time intervention models

#### iii. Gaps in service for this population

Roundtable participants were asked to identify gaps in service to this population, and opportunities for innovation. Responses can be summarized and grouped as follows:

**Knowledge gap/gap in training** - About one another's services, about HIV, about gerontology, about accelerated aging

**Poor service navigation/advocacy support** - People who for a long time have been stable in their housing and medical needs are suddenly in the system and many of them lack knowledge of the service, medical and housing systems and how to access it

**Poor service integration -** HIV+ clients not integrated into complex care settings, rehab or senior services

Fife at PWA; LOFT's Service Coordination Program; CAMH Rainbow Services, and John Gibson partnership; Food security: Food for Life partnership; CNAP 55+ program (but isn't HIV specific); Casey House complex care and resident care; LOFT housing for seniors; U of T cognitive module checklist; 490 Sherbourne Seniors Program and HIV+ support group as a resource; Winnipeg Community Health Centre; Providence dementia program

**Insufficient housing generally** - Lack of appropriate and affordable housing with adequate supports, lack of a continuum of housing options, from transitional housing to long-term housing with high supports

**Ineligibility for chronic disease care services** - HIV is not defined as a chronic disease eligible for enhanced ongoing nursing, home-care and occupational therapy in the community, etc.

#### Funding gaps and funding silos

#### 6. Opportunities for service innovation

Roundtable participants were asked to brainstorm opportunities for service innovation. Responses can be summarized and grouped as follows:

**Partnership and collaboration models** - Integrating all sectors; hybrid interdisciplinary service coordination project and TASC clinic; CCAC partnerships with clinical HIV providers

Outreach models - Targeted home support for this vulnerable, at-risk population

**Education & training** - Broad, interagency knowledge transfer; training for lay caregivers; building community champions

**Peer & volunteer support** - PHAs in peer-based volunteer roles including treatment support; spiritual care; adapting the buddy systems and care-teams of the 80s and 90s

**Innovative support models** - Service navigation; Assertive Community Treatment Team; 24-hour support units; piggy-backing on existing services; opportunity to look at coordinated intake for all HIV-related services; a need to integrate prevention and health promotion models into service delivery

**Housing enhancement** - Need to increase the number of high support beds; the need to envision a new model of housing support to adapt to changing and higher support needs of an aging PHA population.

#### V. The Service System: Solutions

#### Presentations - Innovative Service Models

As the group moved to solutions in the afternoon, they heard two presentations of innovative service responses to help frame the discussion.

#### Presentation #1: Debra Walko, LOFT

The first presentation was by Debra Walko, Director of Seniors' Services for LOFT Community Services. Ms. Walko gave an overview of two partnerships they have developed:

- 1) The Crosslinks Seniors Housing and Support Services, which is in partnership with Humber River Regional Hospital, Downsview Services for Seniors, Central CCAC, Saint Elizabeth Health Care and Toronto Community Housing. The program offers supportive housing to seniors living with mental health and addictions. The program includes a component where 'reintegration units' offer a short-term transitional housing option with enhanced support for up to three months, so that patients from Humber River Regional Hospital can reintegrate into the community.
- 2) The Stepping Stones Project of John Gibson House, which provides transitional housing personal support and intensive case management support for 36 seniors coming from Alternate Level of Care beds in the Centre for Addictions and Mental Health and other Toronto hospitals. This program is a partnership of LOFT and CAMH.

Ms. Walko indicated that these programs demonstrate that:

- "High risk" seniors can remain in the community with the appropriate support
- The length of stay for ALC patients is decreased or ALC stays are avoided altogether
- There is improved access to supportive services through system navigation and psychosocial support
- They improve coordination among various community support agencies who deliver services to this high-risk senior population
- They increase stability in housing as well as other social determinants of health
- They keep seniors at home in the community while embracing their individuality

#### Presentation #2: Karen de Prinse - Casey House

The second presentation was by Karen de Prinse, Chief Nursing Executive and Director of Clinical Programs at Casey House. Ms. de Prinse presented Casey House's model of working and

educating 'beyond our 4 walls'. She outlined a number of collaborative educational initiatives provided to partner organizations and their staff, often in collaboration with some of those partners (e.g. ACT, Fife House, Fudger House).

Their experience demonstrated:

- How these collaborations go beyond education to psychiatric consultations, community case consultations, etc.
- There were challenges, for instance, the lack of dedicated organizational coordinator; timeliness/responsiveness; capacity to support participation; moving beyond the ASO community; front line engagement; availability of funds; triage/short term focus; system/ sector navigation; and bridging the service gaps
- There were rewards, for instance stakeholder engagement and appreciation; knowledge exchange, skill acquisition and development; building relationships within and across sectors and enhanced client outcomes

#### 8. Innovative service models we could work on now

Building on the work done in the morning, each table of participants was given a task. They were asked to come up with one or two ideas for an innovative service model.

Question: If you had up to \$300K in the next fiscal year to pilot an innovative service model around these issues, what would that look like?

The caveat was that the models should:

- a) Address issues and challenges, gaps in service that were identified in the morning sessions
- b) Be cross-sector collaborative partnerships
- c) Be ready to be operationalized within eighteen months
- d) Be simple enough to explain in a two-minute report-back

After developing the models, each table presented them, and then participants were given four stickers and asked to cast their votes for the models they felt were most responsive to the issues.

The full list of models can be found in Appendix VI. Although three of them emerged as the most workable and responded to the gaps and service identified earlier in the day, the Working Group will be looking at all of these models to take from them the best elements and develop the most effective project.

#### These models are:

#### MODEL #1: Consultative HIV Aging Mobile Program - CHAMP

**Summary**: This is a consultative, multi-disciplinary mobile team which assists agencies in developing their internal capacities on HIV and aging, aimed at increased accessibility for PHAs to housing, support and care services.

#### Elements of this model could include:

- A team would provide consultation primarily to seniors' services and to agencies supporting people who are aging and living with HIV
- The team would be multi-disciplinary in scope and would include PHA peers
- The expertise would be on HIV related psycho-social/medical issues
- Services would include education, outreach, through on-site agency visits and telephone support
- A focus of the model would be in assisting agencies with their internal capacity building
- Might include helping an agency develop champions from within that agency
- The model would facilitate enhanced interconnectedness across community agencies

#### MODEL #2: Hub of Community and Clinical Expertise

**Summary:** The development of an interdisciplinary clinic model, which would provide comprehensive assessment consultation, development of a plan of clinical care, to be linked to coordination and delivery of services in the community.

#### Elements of this model include:

- This is an expansion of the Treatment Access Supportive Care (TASC) pilot (St. Michael's Hospital) that learnt from the Service Coordination Pilot Project
- Team Hub there would be 6-10 places the team will go
- Core team would include: Nursing, Case Manager, Pharmacist, Social Worker
- Tasks: 1. identify at what agency 2. clarify issues 3. link with specialized services
- In-kind partners plus some positions up to 300K to be determined (case management/care positions)
- Services: Assessment, Rehab, Case Management, Health Promotion, Clinical, Mental Health, Consulting, Addictions, Nurses, Vocational, Peer support, Peer navigation
- Objectives: To expand existing services, To coordinate with existing services
- Links to, draws on:
  - Service Coordination Program (LOFT) Housing
  - ACT (Assertive Community Treatment) Teams

- ER Diversion will help with costs
- COTA (mental health supports) link back to ER diversion, case management resources
- St. Michael's
- HIV virtual ward, 1-6 weeks home care (providing clinical care services in the home)

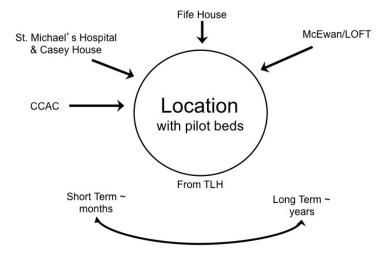
#### **MODEL #3: Transitional Housing Aging/Complex Care**

**Summary:** The development of a transitional and complex care housing model for high support needs of aging PHAs and those with advanced cognition issues, whose needs are currently not being met in the current high support housing models.

#### Elements of this model could include:

- Inclusion criteria: HIV, aging (accelerated), rising complexity, needs not able to be met elsewhere, mild to advanced cognitive issues
- Delivery: short term to long term supportive housing, 24/7 clinical support (physio, nursing, rehab, pharmacy, Nurse Practitioner, Mental Health), Personal support (ADL and IADL), Housing support (food, cleaning, laundry), Case Management including transition planning (community, palliative, LTC), Recreational and Wellness programs, Continuum protocols from ER and Acute Care (St. Michael's) to contribute to system pressures
- A diagram expressed the model as follows:

## Transitional Housing - Aging/Complex Care



#### 9. Longer-term solutions

This session was kicked off by a presentation from Beatriz Tabak, Project Manager, Senior's Strategy, Toronto Community Housing, then followed by a brainstorming session with participants.

#### Presentation: Beatriz Tabak, Toronto Community Housing (TCH)

Ms. Tabak gave a presentation outlining the challenges faced by the aging population in TCH's buildings, and demonstrating how TCH has developed a response built on partnerships to compensate for finite staffing resources within the buildings.

The profile of the volume of seniors in TCH is cause for reflection: There are 26,000 seniors living in TCH, speaking 26 languages. Of these, 6,500 are over 80 years old. 18,500 seniors live alone. There are 68 seniors only buildings.

In 2008, the TCH board approved a plan to serve them. Pillar 1: Buildings would ensure access to adequate housing. Pillar 2: Health & Well Being would promote physical and mental health, participation and engagement. Pillar 3: Community Engagement would enable connection, engagement and partnerships within the community. Pillar 4: Culture of Change and Continuous Learning would make aging an organizational priority.

Ms. Tabak highlighted in particular efforts since 2009 to go after funding for supportive housing and new services for seniors, as well as to refine their integrated team work (between their own front line staff and support agencies). In addition, their focus has been to examine the scope of on-site partnerships, i.e. to assess, expand, prepare and market services, and to expand the face-to-face relationships with tenants.

#### Brainstorming in large group

Long-term solutions for this population:

- Sustainable
- Culturally competent and gender sensitive
- Holistic services, not just HIV specific, and based at the local level
- More 24-hour supportive housing for PHAs facing aging/accelerated aging
- Integrated, flexible models, to respond to needs emerging over 5-10 years
- Partnerships need to be formalized
- One-stop 'shop', close proximity radius models
- Plan for care givers so they don't get sick

- Service delivery doesn't just remain among formal partnerships we need to recognize that in any solutions
- Immigration patterns are changing. Agencies and sectors need to recognize this and be responsive to what the communities are saying and use a community development model that capitalizes on skills and capacities within these communities
- Must meet high needs, but also include health prevention strategies and crisis prevention for those at risk of becoming high need
- Develop models that build on strengths of communities and families
- Must provide a wide range of supports to communities and families
- Must build models across the service and housing continuums, and any new funding needs to include the HIV sector
- Must partner with institutions and organizations with a focus on seniors and aging
- We should build a network/portal for resource sharing across the country

#### VI. Research and evaluation: Filling the gaps

Although the primary objective of the Community Roundtable was not focused on research, the planning Committee felt it would be a missed opportunity if the stakeholders who had come together didn't identify research gaps and opportunities, and also gaps in evaluation. It should be noted that, by design and primarily because of time constraints, the question of how to address the evaluation gap was not dealt with in any detail and is therefore not dealt with in this report.

#### 10. Gaps in research

Roundtable participants were asked to identify the main research gaps for serving this population. Although participants were asked to restrict their responses to research as it related to housing, aging, accelerated aging, complex care and cognitive issues, many of the research gaps were more general research questions related to this population.

Responses that related to the topic of the Roundtable discussion can be summarized and grouped as follows (other research questions, and details of the various topics can be found in Appendix V):

**Research into aging and accelerated aging in PHAs** - Questions relating to physiological/ clinical and psycho-social impacts; long-term impacts of antiretroviral therapy; stigma in housing settings

**Research into current knowledge base of health care sector** – on the issues of aging and HIV, accelerated aging, complex care and cognition

**Research into housing and support models** - Literature reviews, both in this sector and in related sectors; impact research on residents

#### 11. Gaps in evaluation

The gaps in evaluation can be grouped and summarized as follows:

Evaluation of models for this population specifically – Efficiency, health outcomes, and costs

**Needs assessments for the population** - There was consensus in the room around three issues:

1) There should be a needs assessment about the needs of aging PHAs; 2) While there is evidence about the needs of the population, the evidence base should be expanded about the gaps in service and the need for a response; and 3) We need to make the links to larger studies and needs assessments in development nationally about aging and cognition.

#### 12. Filling the research gap

#### Presentation by Dr. Sean B. Rourke

Dr. Sean Rourke of the Ontario HIV Treatment Network gave a presentation outlining some of the emerging neuropsychological research in the field that relates to the population in question. The studies he touched on were:

- Heaton et al, HIV-associated neurocognitive disorders persist in the era of potent antiretroviral therapy CHARTER Study, *Neurology 2010, 75, 2087-2096*
- Wright et al, Cardiovascular risk factors associated with lower baseline cognitive performance in HIV-positive persons, *Neurology 2010, 17, 864-873*
- Foley et al, Neurocognitive Functioning in HIV-1 Infection: Effects on cerebrovascular risk factors and age, *The Clinical Neuropsychologist*, 23, 265-285, 2010
- Vivthanaporn et al, Neurologic disease burden in treated HIV/AIDS predicts survival a population-based study, Neurology 2010, 75, 1150-1158

He then highlighted the Canadian Institute of Health Research's HIV Co-morbidity Initiative, stating that its objectives are to:

Build a national, collaborative, cross-disciplinary research response to address the challenges
of co-morbidities for people living with HIV/AIDS in Canada

 Support excellent and innovative projects at various stages of the research and knowledge translation continuum

Dr. Rourke then outlined ideas for relevant research areas. These were:

- 1. HIV and aging
  - Burden of disease
  - Disease progression
  - Interventions
  - Community-based primary health care
- 2. HIV, mental health and neurological conditions
  - Burden of disease
  - Disease progression
  - Interventions
  - Community based primary health care

Finally, Dr. Rourke outlined some research opportunities (see Appendix VII).

#### Discussion

Participants were asked what the key research questions are moving forward:

- What are the impacts of specific services for clients in supportive housing?
- What is the impact of cognitive issues on PHAs?
- What is the prevalence of cognitive issues, do we need a needs assessment?
- What are the long-term effects of ARVs (anti-retrovirals) with co-morbidity treatments?
- How do we define cognitive issues and accelerated aging?
- Best practice advice on managing cognitive decline from a client perspective
- What is the effect on the sustainability of housing (and/or access to) due to cognitive issues?
- Effective prevention interventions related to cognition?
- What are the research needs of the community?
- A validated tool that can measure mild cognitive deficits with 10 questions or less
- Where do people go to decline/die?
- What does it mean for long-term survivors to be facing death/decline?
- Emphasis on services to look at what are the models of service that are going to meet the behaviours/problems that people are expressing what is going to be the most practical and/or community-based (care team) models?

- Look at aging what are the differences when looking through the diversity lens?
- Look at research initiatives in the disability community and/or at the national level that are broader but relevant to HIV

#### 13. Opportunities for new funding & support with research

Ruth Cameron of the Ontario AIDS Network, and Dr. Sean Rourke and Jenn Major of the Ontario HIV Treatment Network outlined a) new research funding opportunities in which Roundtable participants might be interested, and b) support for research initiatives.

The following grants were discussed (please see the Appendix VII for details of the grants, current as of June 2011):

- CIHR CBPHC (community-based primary healthcare) Team Grants
- OHTN Community-Based Research (CBR) Capacity Building Fund
- CIHR Catalyst Grant: HIV/AIDS
- CIHR Dissemination Events
- CIHR Knowledge Synthesis Grant
- CIHR Community-based Research Operating Grants
- CIHR Partnerships for Health System Improvement Initiative
- CIHR Planning Grants

Also, the following Research Support and Knowledge Transfer and Exchange Opportunities were discussed (see also Appendix VII for details of the support activities available, current as of June 2011):

- OHTN Rapid Responses Service
- OHTN OCASE System
- OHTN Cohort Study and links with ICES
- OHTN Evidence-based Practice Unit
- CIHR Centre for REACH in HIV/AIDS

#### VII. Comments and impressions from participants

Five people were asked ahead of time to provide comments at the end of the day that gave their impressions of what had been accomplished. Their comments can be summarized as follows:

**Kenneth Poon** - A very good day. Good to hear various organizations talk about aging/housing. A lot of talk about important buzzwords: collaboration, integration. Doesn't consider himself a long-term survivor – he's just living. Encourages dialogue with the 'aging population' to determine what their needs are...don't speak for them.

**Chris Sulway** - What a broad topic. This is a very necessary dialogue and this is what the Local Health Integration Networks hope to have happen. A broad cross-section of service providers coming together to innovate service models and provision...and how to do more with what we have.

**Sue Hranilovic** - Felt invigorated and excited and will become part of the Housing Working Group. Today has been so practical. The timeline and limited budgets are feasible...hybrids. To merge into one room is vital and clear action items as a result are exciting.

**Kay Roesslein** - Is in a position of reflecting on the early days of HIV. It was about reaction then, now we're grappling with the complexity and the many faces of the disease. She's proud to be part of the community in this room ready to act.

**Murray Jose** - An echo of what Chris Sulway said—this is exactly what we need to be doing; furthermore we know it works. Bringing people together is critical to build the collaborations and the accountability. The impact is exponential. The learning that has happened in the room and the building pieces that were dialogued on today. Also pleased with the very strength based approach that has underlined today's Roundtable. Peer engagement freely put forward as viable elements of the action plans.

#### VIII. Next steps

Participants were informed of the intended next steps following the Roundtable, which in addition to producing this report included:

- The Housing Working Group Roundtable Planning Committee meeting, vetting the draft report, and discussing next steps;
- Circulating the report to all Housing Working Group and Roundtable participants and making it available more widely;
- The opportunity for participants in the Roundtable to join the Housing Working Group of the Toronto HIV/AIDS Network (a few people have already joined)
- The Housing Working Group Roundtable Planning Committee committed to circulating this report
  and to holding a follow up meeting with participants, the purpose of which would be to bring
  forward proposed action items based on the Roundtable and further developed by the Working
  Group for input and development.

#### **Conclusions**

The Roundtable ended with excitement and optimism. The participants expressed a high level of energy to generate models of service delivery that capture the creativity and commitment of the group. Although a lot of work remains to be done to develop a practical model that could be more clearly articulated and moved forward, there was consensus on the following:

#### **Strengths**

- Participants are committed to evaluating the proposed models of service delivery, and choosing the best key elements to support the identified gaps in the current provision of service and care.
- There is energy to move forward on a needs assessment and/or to access and analyze existing evidence in Toronto which will further support the development of a workable model of service delivery and coordination.

#### Gaps

- The current clinical models may not be producing the best results in terms of health and wellness outcomes for this population, as we are seeing in our various sectors of practice; a new model of care is needed to support this changing demographic.
- There is a demonstrated need for an interdisciplinary and cross-sector case management response.
- There is a need to enhance collaboration and integration of training and education across sectors.

#### Opportunities

- There is a desire and need for all agencies involved to examine the ways that stigma exists as a barrier for clients when they access or do not access current services.
- There is an openness to examine the opportunities to adapt, enhance or change existing models of service to engender improved service collaboration and integration.
- Participants are committed to enhance collaboration and integration with the goal of promoting cross-sector training and education to improve existing services.

Goals of the group are to identify and fill gaps in service and care for PHAs with early/age-related illness. This endeavour is consistent with the THN Housing Working Group's previous work. Additionally, the group continues to address broader social/government priorities including generating models of service provision for an aging population thus ensuring seamless transitions across services, enhancing continuity of care, and promoting stable, secure, supportive housing for people living with complex health conditions.

#### Appendix I - Community Roundtable Participants

Community Roundtable Facilitator/ Consultant: John Miller <sup>2</sup> (John Miller Consulting) Recorder/ logistical support: Michael Morgan <sup>1,2</sup> (Toronto HIV/AIDS Network)

Recordery logistical support: Michael Morgan (Toronto Hiv/AlDS Network)				
Table 1	Table 2	Table 3	Table 4	
<ul> <li>Yvette Perreault (AIDS Bereavement and Resiliency Program of Ontario) – table facilitator</li> <li>Wendy Cameron (Bridgepoint Health)</li> <li>Vashti Campbell (St Michael's Hospital)</li> <li>Karen de Prinse (Casey House)</li> <li>Keith Hambly <sup>1,2</sup> (Fife House)</li> <li>Sandra lafrate (Toronto Central Community Care Access Centre)</li> <li>Marvelous Muchenje (Women's Health in Women's Hands)</li> <li>Beatriz Tabak (Toronto Community Housing)</li> </ul>	<ul> <li>Rick Julien (AIDS Bereavement and Resiliency Program of Ontario) – table facilitator</li> <li>Jessica Cattaneo (AIDS Committee of Toronto)</li> <li>Bomi Daver (Alliance for South Asian AIDS Prevention)</li> <li>Paul Follett (Philip Aziz Centre)</li> <li>Bev Lepischack (Sherbourne Health Centre)</li> <li>Frank McGee (Ontario Ministry of Health and Long-Term Care, AIDS Bureau)</li> <li>Kay Roesslein <sup>1,2</sup> (LOFT Community Services, McEwan Housing &amp; Support Services)</li> <li>Todd Ross <sup>1,2</sup> (Casey House)</li> <li>Paulina Vivanco (Toronto Community Housing)</li> </ul>	<ul> <li>Joan Anderson <sup>1,2</sup> (Toronto HIV/AIDS Network) – table facilitator</li> <li>Paul Bruce (COTA Health)</li> <li>Sue Hranilovic (St. Michael's Hospital, 410 Sherbourne Health Centre)</li> <li>Murray Jose (Toronto People with AIDS Foundation)</li> <li>Dora Londono <sup>1,2</sup> (Prisoners with HIV/AIDS Support Action Network)</li> <li>Elisse Zack (Canadian Working Group on HIV &amp; Rehabilitation)</li> </ul>	<ul> <li>Ruth Cameron <sup>1,2</sup> (Ontario AIDS Network) – table facilitator</li> <li>Dr. Ken Balderson (St Michael's Hospital)</li> <li>Scott Bowler (Mt Sinai Hospital)</li> <li>Anne Marie DiCenso (Prisoners with HIV/AIDS Support Action Network)</li> <li>Patricia Maxwell (St Elizabeth Health Care)</li> <li>Jane Piccolotto (Woodgreen Community Services)</li> <li>Stephen Westfall (Fred Victor)</li> </ul>	
<ul> <li>Robin Rhodes <sup>1,2</sup> (AIDS Committee of Toronto)         <ul> <li>table facilitator</li> </ul> </li> <li>Michael Blair <sup>1,2</sup> (Fife House)</li> </ul>	Nick Boyce (Ontario HIV & Substance Use Training Program) – table facilitator     Barbara Taylor (Fife House)	Jenn Major (Ontario HIV Treatment Network) – table facilitator     Christine Chow (Mid-Toronto Community Services)		
Doug Guest (community member)     Ron Lirette (Perram House)     Suzanne Paddock <sup>1</sup> (Toronto People with AIDS Foundation)     Cindy Stephens (City of Toronto, Long-Term Care Homes & Services)     Laurel Stroz (Toronto Central Community Care Access Centre)     Chris Sulway (Toronto Central Local Health Integration Network)	Chris J. Gibson <sup>1,2</sup> (Seaton House) Laura Klie (Sunnybrook Health Sciences Centre) Shannon Ryan (Black Coalition for AIDS Prevention) Anne Stephens (Toronto Central Community Care Access Centre) Dr. Vicky Stergiopolous (St. Michael's Hospital) Debra Walko (LOFT Community Services)	<ul> <li>Lynn Hillman (Concurrent Disorders Support Services)</li> <li>Belinda Marchese (Hospice Toronto)</li> <li>Kenneth Poon (community member)</li> <li>Efrem Rone (Centre for Addiction and Mental Health)</li> <li>Charles Shamess <sup>2</sup> (Ontario HIV Treatment Network)</li> <li>Marco Villa <sup>1,2</sup> (LOFT Community Services, McEwan Housing &amp; Support Services)</li> <li>Carol Danis (Sistering)</li> </ul>		

<sup>&</sup>lt;sup>1</sup> - THN Housing Working Group member <sup>2</sup> - Roundtable planning committee member

## Appendix II – Summary of the 2009-10 'Service Coordination Pilot Project for Homeless People Living with HIV/AIDS'

In 2008, the Housing Working Group of the Toronto HIV/AIDS Network made it a priority to improve access to a range of affordable and appropriate housing for people living with HIV/AIDS (PHAs) with these objectives:

- 1) Identify emerging issues and gaps in services
- 2) Explore and support the development of innovative service models
- 3) Exchange related program and community-based research information

The work of the Housing Working Group led to a cross sector response with twelve partner agencies developing a Pilot Project, "The Service Coordination Pilot Project for Homeless People Living with HIV/AIDS". From 2009-2010, a short-term intensive case management model focused upon service coordination, health stabilization, primary care reconnection, and housing. The results were highly successful:

- 70 % of all clients served had concurrent mental health and substance use issues.
- 70 % of all clients engaged in intensive case management services were successfully housed.
- In the first year there was a 50 % reduction in ER visits involving all clients from the year prior to intake into services.
- Over the first year there was an 80% reduction in inpatient hospital stays involving all clients from the year prior to intake.
- Over the first year, 16 of 28 clients utilized a total of 718 days respite or health stabilization stays in dedicated beds to the Project

The outcomes, and evidence from the' Service Coordination Project' supported the funding proposal for a new 'Addictions Supportive Housing Program' (also a partnership between Loft/McEwan and Fife House), which has 32 units of rent supplement housing for homeless PHAs with substance use issues, with a high level of case management support attached.

## Appendix III – Issues/ Challenges and Current Response – Roundtable discussion group flipchart notes

#### Table 1 – Issues/Challenges and Current Response

table 1 issues/ chancinges and current response	
Issues/Challenges	Current Responses
<ul> <li>Highly isolated – depressed</li> </ul>	<ul> <li>Better services for HIV+ population than for others</li> </ul>
<ul> <li>Difficulty accessing services in a timely manner</li> </ul>	Vs. perspective other sectors have greater integrated
<ul> <li>Chronic diseases beside HIV – drug reactions</li> </ul>	responses (ie. Mental health)
<ul> <li>Finding supportive community members (peers)</li> </ul>	<ul> <li>Housing = priority if you are going to die within 2 years –</li> </ul>
<ul> <li>Service provider capacity – professional expertise requires</li> </ul>	but what if housing would prevent you from dying?
broad, deep expertise	WHIWH – as service model example – prevention
<ul> <li>Inter-professional capacity not strong – too many</li> </ul>	HIV clinic – hospital mental health
referrals/overwhelmed	Casey House complex care and resident care/ Fudger House
<ul> <li>Non-identifying PHAs – being identified after becoming</li> </ul>	– working on day program
really sick	Survive to Thrive – ABRPO
<ul> <li>Lack of indentified PHA of HIV designated buildings</li> </ul>	<ul> <li>Service Coordination Project – asset, but funding gap and</li> </ul>
<ul> <li>Stretched to provide support to complex needs of PHAs</li> </ul>	capacity
current housing	<ul> <li>Other models – coordinated access to care for the</li> </ul>
<ul> <li>Senior's care already at capacity in long term housing – how</li> </ul>	homeless (St. Mikes)
can LTC house early aging PHAs?	Concurrent Disorder Support Services model (Fred Victor) –
<ul> <li>Not everyone can age at home</li> </ul>	functions well and provides timely service
<ul> <li>Long term facilities are not eager to take 30yr old PHA</li> </ul>	Fudger House – LGBTQ initiative/safe space in long term
<ul> <li>Staff are not trained to handle early aging</li> </ul>	care facility – training for staff
<ul> <li>Stigma – still exists in some service providers</li> </ul>	Wellesley Central, Fife , Woodgreen project – housing
	construction – evolving service model

Issues/Challenges	Current Responses
Systemic stigma – not used to servicing PHAs	Black CAP long term group
<ul> <li>Hospitals don't want long term – cost of meds</li> </ul>	<ul> <li>Addictions Supportive Housing – as a model</li> </ul>
Care is costly – meds and monthly services	<ul> <li>Eviction prevention – models that housing funders are</li> </ul>
Stigma – people fear going into facilities	using
<ul> <li>Access to specialists – not available, not timely, timely assessment of cognition</li> </ul>	
<ul> <li>Service providers don't have cross-specialty training</li> </ul>	
No one has aged with HIV before	
<ul> <li>Care provider burden – marginalization, homelessness, drug/alcohol use</li> </ul>	
<ul> <li>Capacity – knowledge and case load</li> </ul>	
Consent capacity and decision making	
Recognizing HIV related dementia	
<ul> <li>PHAs aging younger – can't access senior services – too young</li> </ul>	
<ul> <li>When clients don't fit the model – too little flexibility in system – doors are closed</li> </ul>	
Burden on staff and community supports	
Not sustainable	
Cultural issues – finding out HIV+ status as part of refugee	
process	
Housing not stable – precariously housed     Try ding restrictions	
Funding restrictions	
Health fluctuates so quickly	
Ongoing monitoring	

Issues/Challenges	Current Responses
Climate of no money - targeted money from funders	
<ul> <li>Aging – long term trauma and losses</li> </ul>	
<ul> <li>Peer support groups can be seen as preventative – NA coordinated</li> </ul>	
<ul> <li>Focus on losses inherent for PHAs in these complex situations/counseling/peer support</li> </ul>	
<ul> <li>Financial situations – trapped in limitations of disability income and can't work</li> </ul>	
<ul> <li>Identity – how can people resume more meaningful engagement in their communities – volunteers/facilitator roles</li> </ul>	
Neighbourhood support – lacking	
<ul> <li>Lack of geriatric knowledge across the board particularly with HIV</li> </ul>	
HIV historically serviced in the HIV sector – need to link	
<ul> <li>Internalized stigma within HIV sector – race, religion, drug use, orientation, mental health, age</li> </ul>	

#### Table 2 – Issues/Challenges and Current Responses

Issues/Challenges	Current Responses
<ul> <li>'Fired' by agencies – discharged due to unmanageable behaviour</li> <li>Feelings of underserved/feel locked out</li> <li>Challenges of collaboration of services</li> <li>Geographical challenges to reach services/system</li> <li>How do current services integrate HIV services, or is it seen as separate or extra?</li> <li>Street health services need to be connected to HIV</li> <li>TCH not able to respond to changing housing needs – complexity and accessibility – wait lists are far to long</li> <li>Accessible re: aging, disability, location of housing</li> <li>Don't' fit mandate of long term care – example age requirements – seniors only programming</li> <li>Where to refer that is appropriate?</li> <li>Focus on recovery needs to be maintained</li> <li>Safety issues: people don't feel safe/workers don't feel safe</li> </ul>	<ul> <li>Online services (ACT/OHTN)</li> <li>Narrative groups at Mt. Sinai</li> <li>All current ASO services</li> <li>Other health providers: Alzheimers/Acquired Brain Injury</li> <li>Challenges of current responses: resource burn out (or at 200% capacity), long wait lists, accessing rehab services, limited respite resources, response is crisis driven rather than preventative, awareness of available services, training LTC re: aging, availability of safe, affordable housing, lack of innovative creative alternative.</li> </ul>

### Table 3 – Issues/Challenges and Current Responses

Appropriate care re: dementia, mental health	Primary care tool for doctors (Dr. Arbess) – reminders for physical tests – cognitive module check list (UofT)
<ul> <li>Which categories of care – who can provide the best care</li> <li>Complex – addiction, illness, housing – what's first</li> <li>Services are silo-ed</li> <li>PHAs in housing – their issues are becoming more complex – need services brought in –strain on staff and services</li> <li>Challenge to keep housing – and to get enough on-site service</li> <li>2 populations – aging, complex care</li> <li>LTC facilities for HIV, LGBT, prison background</li> <li>Non HIV settings – lack knowledge about HIV and accelerated aging</li> <li>Can affect the young</li> <li>Age criteria</li> <li>PHA fears, stigma to being indentified and deal with diagnosis</li> <li>Inappropriate – 40s with 80s in facilities</li> <li>Homophobia – back in the closet</li> <li>Cognitive impairment – other disability groups</li> <li>Concurrent disorders – substance use, mental health</li> <li>Health promotion – later – not catching cognitive issues</li> <li>Hep C and HIV</li> <li>No LGBT positive options</li> </ul>	Challenge catching subtle changes – next steps SCP multiple partners – intensive case management – central coordination – great but limits to capacity Aging sector – age friendly communities – housing to learn from 490 Sherbourne – seniors an HIV+ groups helps normalize HIV and share health issues Resources – rehab opportunities, ex physio – teach mind exercises, health care, CWGHR – module for Doctors re: aging, HIV and rehab with component on aging CHIME study – PHAs involved in training of students Food for Life partnership program – short term transition – food delivery Satellite partnerships ex. Fife at PWA – meet people where they are – need more ex. Clinical PWA at SHC service navigation role in clinic settings Integrating rehab into service settings O.T, Physio Winnipeg CHC – a model to look at 410 Sherbourne task clinic interdisciplinary – 4x 4 weeks in a row – social COTA – geriatric, psychiatric – neuro assessment (differentiate depression, dementia, vascular

Issues/Challenges	Current Responses
<ul> <li>MSM, homeless, stigmatized – not a cohesive group to get care</li> <li>When people don't fit into a category – hard to find services</li> <li>Care giver fatigue – partners, family, staff</li> <li>Return to work – then issues – multi-tasking, cognitive capacity – need accommodation</li> <li>Cognitive issue – impact on treatment adherence</li> <li>Undiagnosed mental health</li> <li>Lack of ongoing psychiatric support</li> <li>PHAs caring fro parents, siblings and own issues</li> <li>Cognitive issues can be connected to depression but impairment and depression also go together and HIV meds</li> <li>Children born with HIV – aging across the lifespan</li> <li>General lack of training for health care practitioners on mental health and cognitive issues</li> </ul>	<ul> <li>SHC infirmary – homeless – includes HIV immediate follow-up on health issues</li> <li>Arthritic – access to free physio – connect with PHAs with them</li> <li>Skill building – PHAs communicating with doctors and front line workers</li> </ul>

### Table 4 – Issues/Challenges and Current Responses

Issues/Challenges	Current Responses
<ul> <li>Knowledge of issues</li> <li>Agencies not serving population</li> <li>Stakeholders unaware of each other</li> <li>Lack of coordination across sectors/system issue</li> <li>Co- morbidities</li> <li>Lack of geriatricians</li> <li>HIV psychiatrists don't know about psycho-geriatrics and vice versa</li> <li>Is not a mode of communication across sectors</li> <li>For PHAs with a history of homelessness or incarceration – behaviour is misunderstood and misdiagnosed</li> <li>If diagnosed with HIV related cognitive deficit, what then?</li> <li>Interactions between street drugs and ARVs</li> <li>HIV stigma discrimination on referral to group community supports</li> <li>Recognition of supports as valid</li> <li>Acknowledging lack of supports</li> <li>Clients may be totally isolated socially – lost network due to epidemic</li> <li>Supports may be in crisis – street involved etc.</li> <li>Lack of funding for all of this</li> <li>Where does this fit in with LHIN priorities</li> <li>Homophobia</li> <li>Ageism</li> </ul>	<ul> <li>Supportive housing models need funding for intensive case management and more spaces</li> <li>The population of aging PHAs is very diverse – some need LTC, some need to age in place, some need different levels of supportive housing</li> <li>Need finer demographics and stats of the population</li> <li>Need to evaluate existing supports to work with client</li> <li>Service Coordination Project – good model</li> <li>CASH model – CNAP model – good</li> <li>Eden model homes?</li> <li>Barriers zero tolerance implemented vs. harm reduction how to serve all rather than restrict access</li> <li>Ewart-Angus homes run by Sprint for seniors with mild dementia</li> <li>Geriatric consultants to consult with LTC</li> <li>HIV clinicians should consult with LTC and the community across the board</li> <li>Need a single navigator role</li> <li>Shared care model – case conferencing</li> <li>Shared living models to promote independence and functionality</li> <li>Define person centered or client centered care – very different across sectors</li> </ul>

Issues/Challenges	Current Responses
Life enrichment geared to seniors	
<ul> <li>Housing models need supports that are client centered</li> </ul>	

### Table 5 – Issues/Challenges and Current Responses

Issues/Challenges	Current Responses
<ul> <li>Aging – lack of formal/informal supports; masks other health conditions (mimics)</li> <li>Think to narrowly (fragmented) – individual sectors/programs instead of networks/collaboration/coordination</li> <li>Depression/concurrent disorders</li> <li>Poverty</li> <li>Unknown issues - *new older population with HIV</li> <li>Lack of services for older PHAs</li> <li>Language barriers</li> <li>Difficulty articulating needs</li> <li>Reluctance to disclose - *stigma</li> <li>Lack of Health/System navigation</li> <li>Grief, loss, limited support knowledge for impact</li> <li>Sr. organizations not equipped to deal with population –</li> </ul>	<ul> <li>Current Responses</li> <li>McEwan House etc.</li> <li>Addiction supportive housing – int. case management</li> <li>LTC – specialized units (eg. Alzheimers)</li> <li>50-60 spaces for Mental Health and Addiction with 24/7 support</li> <li>ICM teams – but long wait lists/qual.</li> <li>Approximately 200 spaces</li> <li>Casey House</li> <li>Good Shepherd</li> <li>Community hospices – Hospice Toronto and Philip Aziz Center</li> <li>Alternate level of care – private – PSWs, Group Homes, Lic/not reg.</li> <li>Providence – dementia – 24/7 program</li> <li>Social support programs – PHAs, Caregivers (Mt. Sinai,</li> </ul>
knowledge gap – perception of PHAs that not supported/welcome by such programs	<ul><li>Dementia)</li><li>Palliative Care (Chronic/Complex) programs</li></ul>
<ul> <li>Lack of housing with or without appropriate level of support</li> </ul>	<ul> <li>Resource matching referral (not HIV specific)</li> <li>CNAP – 55+ (comm navigation access program) – not HIV</li> </ul>

Issues/Challenges	Current Responses
Additional skills/supports not provided – denied due to	Specific
eligibility criteria	
<ul> <li>Lack of family/caregiver understanding, education and support</li> </ul>	
<ul> <li>Funding rules – 55+ for 'aging'</li> </ul>	
<ul> <li>Tenancy reg's – inadequate support – eviction/convince</li> </ul>	
need ++ care	
Transitional support too short	
<ul> <li>HIV may be low on the list of health concern – may</li> </ul>	
therefore not be disclosed at all – other networks are then	
not accessed	

### Table 6 – Issues/Challenges and Current Responses

Issues/Challenges	Current Responses
<ul> <li>Funding availability</li> <li>Non- identifiable HIV housing – specific cultural groups</li> <li>Do we need to segregate? Similar complex care to other populations</li> <li>Accelerated aging – not meeting age criteria for geriatric services</li> <li>HIV (LGBTQ) stigma in general Long Term Care staff and clients</li> <li>Knowledge and understanding in broader social services (eg. Importance of meds.)</li> <li>Increased need for personal support, case management and peer support</li> <li>LTD not supporting cognitive issues</li> <li>Assessments and knowledge of people administering them</li> <li>Lack of engagement with family physicians</li> <li>Medical needs easier to meet than cognitive</li> <li>Number of beds are just not there</li> <li>Core competencies for intensive case management – who is responsible? – standardized training</li> <li>Durable discharge/planning CTI</li> <li>Fragmentation of services – how do we know/share information?</li> <li>Transition points</li> </ul>	<ul> <li>Current Responses</li> <li>Coordinated access points</li> <li>Critical time intervention models</li> <li>Intensive case management teams with appropriate ratios</li> <li>Virtual ward models</li> </ul>

Issues/Challenges	Current Responses
<ul> <li>Can coordinate all of the services – but where is the roof</li> </ul>	
over head?	
<ul> <li>Lack of system navigation and integrated records</li> </ul>	

### Table 7 – Issues/Challenges and Current Responses

Issues	Challenges
<ul> <li>Younger population with co-morbidities</li> <li>Lack of community support</li> <li>Long wait lists for LTC –due to ODSP</li> <li>Food security</li> <li>Improved intensive case management models</li> <li>Isolation</li> <li>Long term survivors – finance – medical/dental benefits</li> <li>Bereavement – loss – post ARV</li> <li>Depression</li> <li>Complex care – palliative HIV and aging</li> <li>Stigma – access to clinical care, access to appropriate care</li> </ul>	<ul> <li>Current Responses</li> <li>Inst. have not been approached to develop/work with/support 55+ HIV+ individuals</li> <li>Multi-agency approach – Hospital; Housing; ASOs; Substance Use; Mental Health</li> <li>Expansive respite beds</li> <li>Addictions supportive housing model (8 clients : 1 worker = high support)</li> <li>Expanded case management within teams</li> <li>Wellness programming – expanding service, holistic service</li> </ul>
	· · · · · · · · · · · · · · · · · · ·

#### Challenges

- Lack of knowledge
- Complex support around dementia
- Dental care
- Volunteers aging lack of knowledge education
- Income security challenges
- Lack of education in senior population about
- HIV
- Meaningful engagement of community
- More focus required on aging with HIV
- Lack of palliative care beds long term palliation
- Lack of transitional clinical beds
- Not used to working with HIV within the 40-50 year old age bracket
- Stalling models in housing (support) does not necessarily meet needs
- Complex care
- Lack of education
- Family fears
- Not meeting holistic care needs
- Too few house visits

- Tele-assurance peer support
- Education for Long term care homes
- Lack of appropriate diagnosis for cognitive issues
- Education knowledge knowledge transfer
- More complex, higher need clientele individuals in the community
- ASOs need to evolve their programs and services to meet the needs of PHAs
- Partnerships with mental health and others
- Specialized unit in Long Term Care for PHAs
- Younger persons unit
- Increased psycho-geriatric programming in LTC
- ACT workshop presentation by CCAC to promote knowledge and awareness for PHAs aging – homecare – LTC care – housing – resources
- Medication management ASO response for med checks
- ACT team expansion for marginalized populations
- Address systemic issues for LTC
- Personal Support Worker/homemaking agency targeting PHA population
- Housing models for seniors 55+ with HIV
- CCAC/CH partnership expansion of model

# Appendix IV - Service Gaps and Opportunities – Roundtable discussion group flipchart notes

Table 1 – Service Gaps and Opportunities

Service Gaps	Service Opportunities
<ul> <li>Physician/Gerentology etc – capacity in the professional sector to deal with HIV</li> <li>Continuing services</li> <li>Monitoring after a referral</li> <li>A client can decide to cut services</li> <li>Privacy – agencies can't share information about a shared client – major barrier</li> <li>Know what issues are hampered by legislation, agency limitations, money</li> <li>Integrated, continuity of care "didn't know y'all existed"</li> <li>Lack of innovative programs – room to create</li> <li>Clients haven't made transition to complex care identity</li> <li>Navigating the system – overloaded system</li> <li>Day programs??</li> <li>Ability to manage someone at home with complex needs is almost impossible</li> </ul>	<ul> <li>Circle of care – health care agencies but usually not community groups</li> <li>Duty to report 'abuse'- any legislation requires proper training and support for community based workers – damages relationships and trust</li> <li>Disability models of service – access to beds, different levels of support, services come to the table of service providers</li> <li>Money sharing vs. organizational ownership</li> <li>PHAs in peer based/volunteer role – re services for seniors programming</li> <li>Focus on social part of health – not only on physical needs</li> <li>Education – broad interagency – systematic knowledge transfer</li> <li>Can be tried in 67 seniors housing</li> <li>Engagement of individuals to disclose – then support them</li> </ul>
LTC – HIV care is too complex	in their housing once they've done so

Service Gaps	Service Opportunities
<ul> <li>Hospital sector not willing to give up money – reorganization of dollars is needed</li> <li>Fluidity and innovation on part of funders/system</li> <li>Wait time – immediacy of services</li> <li>Service access diversity in community</li> <li>Stigma – comprehensive services across the sector</li> <li>Care givers are not HIV proficient – families also need help</li> <li>Lack of system advocacy for therapists – broader than psychiatry – therapy vs, counselors</li> <li>Disciplinary services – CCAC case management mandate – Fife = very specific case management</li> <li>Complex care – Bridgepoint not seeing HIV+ folk</li> <li>Don't meet the criteria = don't receive care</li> </ul>	<ul> <li>Access – how can we provide greater access to supports in a coordinated way – demonstrated effectiveness</li> <li>Education – seniors' services – drop age related needs</li> <li>Services balanced according to needs not age</li> <li>Opportunities for money other than through government sources – private sector</li> </ul>

### Table 2 – Service Gaps and Opportunities

Service Gaps	Service Opportunities
<ul> <li>Multiple needs met comprehensively</li> <li>Appropriate long term care in housing</li> <li>Rehab for younger PHAs</li> <li>Match senior and HIV services</li> <li>HIV education for non-ASO service providers</li> <li>Occupational therapies for HIV</li> <li>Affordable service for mild cognitive impairment</li> <li>Affordable safe housing</li> <li>Health stabilization services – respite and infirmary care</li> <li>Not a broad understanding of 'what is rapid aging'</li> <li>Stats re: gay men, sexual identity</li> </ul>	<ul> <li>Develop treatment support strategies – med adherence</li> <li>Peer facilitated treatment support workers</li> <li>Integrate bench mark figures for cognition and case management</li> <li>Collaboration and partnership to coordinate comprehensive: housing, senior services, mental health, addiction, food, transit, case management and medical case management</li> <li>Recreational therapies</li> <li>Spiritual care</li> <li>Dedicated housing</li> <li>Support to remain in current housing</li> <li>Acquired Brain Injury/Alzheimers and HIV</li> <li>Cultural supports</li> <li>Chaos therapy – complex adaptive response focused systems</li> <li>Re-vamp the buddy system</li> <li>Day health programs</li> <li>Sexual health programs</li> <li>Cay men health and recreation programs</li> <li>Identify individual and community strengths</li> </ul>

### Table 3 – Service Gaps and Opportunities

Service Gaps	Service Opportunities
Supportive housing with support services	In-house support services teams
Poor communication with primary care and inter-sectoral	Hybrid interdisciplinary SCP + TASC clinic
Support to stay housed	Targeted mobile home support for this
Lack of supportive housing	population(cognitive, episodic)
<ul> <li>Lack of housing for younger people</li> </ul>	Single room occupancy for families with mobile support
Respite care for fluctuating health status	Training and Education for facilities
<ul> <li>Care teams' knowledge not being adapted or used</li> </ul>	Mixed housing with peer support onsite
<ul> <li>Lack of services for people with mild symptoms</li> </ul>	Peer programs to break isolation
<ul> <li>Earlier diagnosis of what services are needed</li> </ul>	Integrate harm reduction
Social Isolation	Partner with Bed/Breakfast (example) link with program
Supportive Housing	support from services
<ul> <li>Lack of awareness and training</li> </ul>	Training for caregiver
	Revise and adapt for chronic and episodic new training
	Identify what components personal relationships and pros
	<ul> <li>Promote, 'normalize', reduce stigma</li> </ul>
	Confidentiality but needs help attached
	Network of those willing to partner to develop quicker
	solutions. Sectors: community housing, addictions,
	hospitals, rent geared to income, elders program STOP,
	dedicated units and collaborate with service to PHAs
	Network Think Tank
	Peer support connecting day by day (US model)
	Technology – example text for ARV
	Mental Health mobile intensive visiting support HIV

Service Gaps	Service Opportunities
	specific of collaborate
	<ul> <li>Assertive Community Treatment Team (ACTT)</li> </ul>
	<ul> <li>Dedicated affordable supportive housing with</li> </ul>
	interdisciplinary team with clinical primary care element
	<ul> <li>Increase capacity to meet needs of street involved;</li> </ul>
	outreach to precariously housed or those on the street
	<ul> <li>ACTT model, shared case model, alternate primary care</li> </ul>
	<ul> <li>Adaptive mentorship models (PASAN)</li> </ul>
	<ul> <li>Virtual World (St. Michael's)</li> </ul>
	Build capacity in the community champions
	<ul> <li>Linking homeless people at shelters, services to housing</li> </ul>
	and support services

### Table 4 – Service Gaps and Opportunities

Service Gaps	Service Opportunities
<ul> <li>Need a variety of models and services for PHAs to serve different needs – diversity of needs</li> <li>Need integration and stand alone models in neighborhoods</li> <li>Crisis response leads to lack of planning</li> <li>Don't know how to care for some of these clients – for HIV cognition and aging</li> <li>Is not a norm re: aging as a starting point in society</li> <li>Aging is not valued</li> <li>For clients, need to contextualize</li> </ul>	<ul> <li>Expansion of current system navigator roles and areas of expertise</li> <li>Advocacy re: issue</li> <li>To find out how to communicate among sectors</li> </ul>

Service Gaps	Service Opportunities
<ul> <li>Traditional access points to services do not work for most marginalized clients; need tailored, intensive, flexible models of support</li> </ul>	

### Table 5 – Service Gaps and Opportunities

Service Gaps	Service Opportunities
<ul> <li>Transitional Housing</li> <li>Affordable/stable housing for complex care</li> <li>Funding arrangements/jurisdiction – difficult to access</li> <li>Comprehensive LT housing for people with behavioral issues</li> <li>Training – LTC – University or 'formal' training not 'complete' – Toronto specifically</li> <li>Caregiver support</li> <li>Geographic service barriers</li> <li>Lack of services for older PHAs</li> </ul>	<ul> <li>More transitional/suitable housing</li> <li>Comprehensive LT housing for (behavioral)</li> <li>24 hour support units</li> <li>Funding</li> <li>Link/integrate networks in different sectors – concurrent disorders support network</li> <li>Gateway – formal/semi-formal – access to semi-formal services</li> <li>Continuity of knowledge to it is sustainable</li> <li>Buddy programs for aging PHAs – volunteer supports</li> <li>Dr. Peter Centre model (BC)</li> <li>Community support programs</li> <li>Peer support, creative models for caregivers – better dissemination of knowledge and resources</li> <li>Piggyback on existing programs – CNAP</li> <li>Practical outcome based programs – meal preparation etc.</li> <li>Holistic evaluation at intake – long term tracking of care – enhance continuity</li> </ul>

#### Table 6 – Service Gaps and Opportunities

Expand existing RM + R resource matching and referrals (CCAC)

Making services available where people are rather than moving people to services

Cluster care through CCAC – consistency of care and personal

Centralized housing service – expanded beyond marginalized/at risk

Physiological vs. Chronological age (eg. Geriatric services).

HIV specific services

Service Coordination project

Some people working with several CMs – portable records – look at palliative care

#### Table 7 – Service Gaps and Opportunities

Service Gaps	Service Opportunities
Supportive housing	ASO – day programs for aging population
Long Term palliative beds	National homeless strategy
Training for providers	<ul> <li>Cluster care model – high density areas and service</li> </ul>
F support	delivery
<ul> <li>Expansion of ACT – dental care, med management</li> </ul>	Supportive Housing
<ul> <li>Level supportive housing – cognition – clinical support</li> </ul>	Education – community workshops
<ul> <li>Silo of CS and Health and LTC – limitations of regulations –</li> </ul>	CCAC to partner with clinical HIV providers – expand
barriers to HIV	current programs
<ul> <li>Aging services in general – outside of HIV</li> </ul>	Centralized intake to facilitate appropriate services and no
<ul> <li>Wait list for basic LTC beds – currently 3 years</li> </ul>	falling through the gaps
<ul> <li>Need money from higher than basic service</li> </ul>	<ul> <li>Training modules into LTC from current HIV service</li> </ul>
Education for professionals	providers
<ul> <li>Hard to forward plan – need for support – POA,</li> </ul>	Service navigation to help with transition

Service Gaps	Service Opportunities
retirement, money etc.	<ul> <li>Partner with Forensics and Police</li> </ul>
<ul> <li>Stigma and barriers to using ASOs</li> </ul>	<ul> <li>Break down silos to create 'system'</li> </ul>
<ul> <li>Common database that collects information</li> </ul>	Mobile services unit
<ul> <li>Different sectors use different systems</li> </ul>	Transitional beds
<ul> <li>Access to affordable rehab services</li> </ul>	<ul> <li>Learn from chronic disease models – not task specific</li> </ul>
	intervention – more holistic needed

# Appendix V - Gaps in Research and Evaluation – Roundtable discussion group flipchart notes

#### Table 1 – Gaps in Research and Evaluation

- Long term outcomes of service coordination project/CATCH/ASH and Streets to Homes
- Trans HIV and Aging research needed
- How to influence policy change at a government level with the research we do have
- Gaps in standardized information coming from data research from projects out there are we talking about sure things?

#### Table 2 – Gaps in Research and Evaluation

Research	Evaluation
<ul> <li>Impact of new comers receiving HIV diagnosis</li> <li>Intersection of immigration and/or law/health needs</li> <li>Cultural specific impacts</li> <li>Accelerated aging specifics and effect of HIV – cognitive deficits</li> <li>What prevents accelerated aging</li> <li>Side effects of meds</li> <li>Impact of complexity of homelessness vs. only HIV</li> <li>Social determinants of health as key piece</li> <li>Long term impact of A.R.T. and different populations – symptomology</li> </ul>	<ul> <li>Broadest connections of services and access and how to improve complimentary/comprehensive service provision</li> <li>Intensive case management programs impact and outcomes over long term health</li> <li>Impact on health for younger PHAs who receive rehab services and outcomes for long term survivors</li> <li>Quality of service outside of ASO sector</li> <li>Complexities for PHA children</li> <li>Cost/saving for proper care</li> <li>Of strength based approaches</li> </ul>

Research	Evaluation
Complexity of treatments for trans people	
<ul> <li>Impact of older newly diagnosed</li> </ul>	
<ul> <li>Laws impact on seeking care</li> </ul>	
Impact of aging on different	
populations/cultures/genders	
<ul> <li>Impact of holistic treatment programs: physical, mental,</li> </ul>	
emotional and spiritual	
<ul> <li>Impact of stigmas and cross-sectionality</li> </ul>	
<ul> <li>Impact on stigmas and treatment</li> </ul>	

### Table 3 – Gaps in Research and Evaluation

Research	Evaluation
<ul> <li>Impact of stigma – OAN – Australian study on stigma in process</li> <li>Clinical impact of accelerated aging</li> <li>Knowledge of Cognitive Impairment</li> <li>What we can learn from other illnesses</li> <li>Prevalence – Long term studies</li> <li>OHTN Cohort study – changes and episodes process</li> <li>What do health care pros know now</li> <li>Needs assessment</li> <li>How are people housed now</li> <li>Cognitive tool to capture low grade</li> <li>Impact on services, housing</li> </ul>	<ul> <li>How are services doing now in response</li> <li>Linking to other services</li> </ul>

Research	Evaluation
Pro-active rehab keeping people well	
<ul> <li>Review other models – what is transferable, what is</li> </ul>	
unique	
<ul> <li>Cultural ways of looking at aging – integrating diversity</li> </ul>	

### Table 4 – Gaps in Research and Evaluation

Gaps	Opportunities
<ul> <li>Data gaps</li> <li>Incidence trends, finer epi-data</li> <li>Impact of role loss on PHAs</li> <li>Social research on aging experiences</li> <li>Environmental scan of the group in Toronto</li> <li>Research on what is an HIV related aging and cognition disorder and what is not</li> <li>What other programs and services are used outside of the sector</li> <li>What research has been done in this sector</li> <li>Needs assessment</li> <li>Impact evaluation</li> <li>Service evaluation to make business case for changes</li> </ul>	Stand alone centers for care are an opportunity for implementing and evaluating best practices

Table 5 – Gaps in Research and Evaluation

Research	Evaluation	
<ul> <li>Dementia in young people</li> <li>Implications of practical living for 'sliding scale' of dementia – level of care</li> <li>Housing pop in unit (together) vs. community (broader/integrated)</li> <li>What supportive housing services lead to better outcomes</li> <li>Staff skills – needs assessment – aging PHAs in and out of services – diverse populations</li> </ul>	<ul> <li>Ways to measure outcomes of transitional housing</li> <li>More standardized ways to collection of data</li> <li>Valid/reliable/meaningful complexity scoring</li> </ul>	

#### Table 6 – Gaps in Research and Evaluation

- Relationship management management of care teams for each client peer support models
- Evidence that segregated service leas to better outcomes
- Impact on fragmentation stigma
- Literature review environment survey?
- System responses in other jurisdictions and disabilities
- Reality of minimal resource housing types
- How to support people that choose to live on the street can't fit everyone into our models.

Table 7 – Gaps in Research and Evaluation

Research	Evaluation	
Description of Aging Cohort	<ul> <li>Users of services – proactive use pre-crisis</li> </ul>	
<ul> <li>Lived experience of aging – legacy, sexual health etc.</li> <li>Disseminate what is out there</li> </ul>	<ul> <li>Lower money for evaluation – outcomes are money based and lower qualitative</li> </ul>	
<ul><li>Share with other disease based sectors</li><li>Funding models</li></ul>	<ul> <li>Needs assessment – services, clients' demographics, numbers, current capacity</li> </ul>	
<ul> <li>Impact of losses on a community</li> <li>Future needs with income changes</li> <li>HIV aging vs aging</li> </ul>	<ul> <li>THN – community partner with UofT, Wellesley Institute and Hospitals to do research and evaluation</li> </ul>	

# Appendix VI – Summaries of Short-term Models Developed by Roundtable Participants

### This chart summarizes the models presented by Roundtable participants.

Table	# of votes given during "dotmocracy" exercise	Title	Broad Description
1	40	Consultative HIV Aging Mobile Program –CHAMP	<ul> <li>This is a consultative mobile team where aging and HIV consultation services help PHAs access HIV services, to support ongoing, sustainable housing</li> <li>consultation team would consult primarily to seniors' services and agencies dealing with people aging (HIV),</li> <li>The team would multi-disciplinary in variety or expertise, and would include PHA peers,</li> <li>The expertise would be around HIV related social/medical issues,</li> <li>Services include visits/telephone/education,</li> <li>There would be internal capacity building,</li> <li>Might include helping agency develop champions from within that agency,</li> <li>The model would facilitate enhanced interconnectedness across community agencies</li> </ul>

Table	# of votes given during "dotmocracy" exercise	Title	Broad Description
1	No votes, (however, in participant dialogue, this linked to the system navigator component of Table 3's model: "Hub of Community and clinical expertise"	System Navigator Model	<ul> <li>two navigators to provide consultation and expertise</li> <li>not direct service other than referral and resourcing expertise</li> <li>to help individuals navigate the system,</li> <li>support = workers,</li> <li>similar to SNAP (Seniors Navigator Access Program)</li> </ul>
2	14	Aging in Place	Peer Support Team  Buddy Program Case Management  Focus on Prevention, Planning in Recovery  Evaluation component for both

Table	# of votes given during "dotmocracy" exercise	Title	Broad Description
2	13	Fudger House Hub with 6 beds	Fudger House Hub with 6 beds  Peer Supports  Fudger Frager Recreational Therapy Peer Supports
3	36	Hub of Community and clinical expertise - expansion of the TASC pilot – learn from Service Coordination Pilot Project	<ul> <li>In-kind partners plus some positions up to 300K to be determined (case management/care positions)</li> <li>Services: Assessment, Rehab, Case Management, Health Promotion, Clinical, Mental Health, Consulting, Addictions, Nurses, Vocational, Peer support, Peer navigation</li> <li>Objectives: To expand existing services, To coordinate with existing services</li> <li>Links to, draws on:         <ul> <li>Service Coordination Project - Housing</li> <li>ACT (Assertive Community Treatment) Teams</li> <li>ER Diversion will help with costs</li> </ul> </li> </ul>

Table	# of votes given during "dotmocracy" exercise	Title	Broad Description	
			<ul> <li>COTA (mental health supports) – link back to ER diversion, case management resources</li> <li>St. Mike's</li> <li>HIV virtual ward, 1st 6 weeks home care</li> </ul>	
4	10	Service Coordination Model	<ul> <li>Suspected cognitive decline of a PHA at any service agency</li> <li>Front line staff can contact Service Coordinator</li> <li>\$\$ for Service Coordinator, office staff and space, TP, salary</li> <li>Service coordinator role: no decision on disciplines involved, hub – bridge between resources for assessment, delivery or services in community, advocacy, accompaniment, gap bridging, follow-up care coordination,</li> <li>Situated in community central Toronto,</li> <li>18 months evaluation built in.</li> </ul>	
5	33	Transitional Housing Aging/Complex Care	<ul> <li>Inclusion criteria: HIV, Aging (accelerated), rising complexity, needs not able to be met elsewhere, mild to advanced cognitive issues</li> <li>Delivery: short term to long term supportive housing, 24/7 clinical support (physio, nursing, rehab, pharmacy, Nurse Practitioner, Mental Health), Personal support (ADL and IADL), Housing support (food, cleaning, laundry), Case Management including transition planning (community, palliative, LTC), Recreational and Wellness programs, Continuum protocols from ER and Acute Care (St. Mike's) to contribute to system pressures</li> </ul>	

Table	# of votes given during "dotmocracy" exercise	Title	Broad Description	
			Transitional Housing – Aging/Complex Care  St. Michael's Hospital & Casey House  CCAC  Location with pilot beds  From TLH  Long Term ~ years	

Table	# of votes given during "dotmocracy" exercise	Title	Broad Description
6	19	PHA Knowledge Portal - Knowledge Generation, Translation, Exchange (eg. OHTN Rapid Response)	<ul> <li>Centralized services, programs by regions and sectors</li> <li>Expanding on existing models (eg. ASO411.ca)</li> <li>Wrap around care</li> <li>Not about finding a service provider and moving client on, but linking to help you.</li> </ul> PHA Knowledge Portal ~ Wrap Around Care Housing Addiction Client

Table	# of votes given during "dotmocracy" exercise	Title	Broad Description
7	9	Care in the Community	<ul> <li>Health Navigator, ii 'Buddy' Peer Model, iii Community Helpers</li> <li>Objective: keep people in home of choice, maintain access to services</li> <li>Mobile Model – follows person</li> <li>Asset based</li> <li>System Integration</li> <li>Incorporates formal and informal networks</li> <li>Clinical and Community Care</li> <li>Training and Education: continuous, community identified, freely available, team led</li> <li>Supporting caregivers resiliency</li> </ul>
7	23	Intensive Case Management	<ul> <li>Clinicians – MD, SW, RN, Hospital based etc.         <ul> <li>Peers</li> <li>Community Supports</li> </ul> </li> <li>High needs – at risk or/are homeless</li> <li>HIV, Mental Health, Substance Use (triple diagnosis)</li> <li>Objective: to obtain and maintain the quality of health and housing</li> </ul>

# Appendix VII - Grants, Research Support & Knowledge Transfer and Exchange Opportunities (current as of June 2011)

#### **Grants**

Grant	Deadline	\$	Area
CIHR CBPHC (community-based primary healthcare) Team Grants	unknown	25,000	<ul> <li>These will support inter-disciplinary, cross-jurisdictional teams of researchers to conduct excellent research, to provide superior research training and mentorship, and to engage in knowledge translation activities. The first launch of CBPHC Team Grants will take place in Fall 2011.</li> <li>Successful Teams will receive funding of up to \$500,000 per year for up to five years to address the following research priority areas:         <ol> <li>Better Systems: Chronic Disease Prevention and Management in Community-Based Primary Healthcare; and</li> <li>Access to Appropriate Community-Based Primary Healthcare for Vulnerable Populations</li> </ol> </li> </ul>

Grant	Deadline	\$	Area
OHTN Community-Based Research (CBR) Capacity Building Fund.	October 15	25,000	<ul> <li>Meetings and team building, pilot research</li> <li>There are quarterly calls for applications requesting up to \$25,000. The purpose of the fund is to support community-driven projects that aim to develop capacity of community-based organizations and people living with HIV to conduct CBR, as well as to aid community-based organizations to develop, enhance, or modify programs and services to better address the needs of people living with and at risk of HIV in Ontario.</li> </ul>
CIHR Catalyst Grant: HIV/AIDS	October 17	33,000	Team development pilot research
CIHR Dissemination Events	October 17	25,000	facilitate uptake of research findings related to HIV/AIDS.

Grant	Deadline	\$	Area
CIHR Knowledge Synthesis Grant	October 3	100,000	This research agenda aims to address the challenges of comorbidities for people living with HIV/AIDS in Canada with an emphasis on 1) issues of aging with HIV (aging process, chronic disease, frailty); and 2) the intersection of HIV with mental health and neurological conditions
CIHR – Community- based Research Operating Grants			<ul> <li>The HIV/AIDS CBR program is intended to support the goals of the Federal Initiative to Address HIV/AIDS in Canada. It was created to facilitate and ensure the direct involvement of communities and people living with HIV/AIDS in research aimed at fighting the disease and its impacts and to promote interaction between researchers and communities as they strive to achieve mutually beneficial goals.</li> <li>The specific objectives of the HIV/AIDS CBR Operating Grant RFA are:         <ul> <li>to promote the creation of new knowledge that is relevant to communities and to the goals of the Federal Initiative;</li> </ul> </li> </ul>

Grant	Deadline	\$	Area
			<ul> <li>to promote the dissemination of new knowledge so that it may positively impact the response of community-based organizations to the HIV/AIDS epidemic;</li> <li>to develop partnerships between researchers and affected communities.</li> </ul>
CIHR – Partnerships for Health System Improvement Initiative			CIHR's Partnerships for Health System Improvement (PHSI) program supports teams of researchers and decision makers interested in conducting applied and policy-relevant health systems and services research that responds to the needs of health care decision makers and strengthens the Canadian health system.
CIHR Planning Grants	October 3	25,000	<ul> <li>provide support to individuals or groups for planning activities, that will contribute to the advancement of research consistent with the mandate of CIHR.</li> </ul>

Grant	Deadline	\$ Area
		<ul> <li>Initial planning and discussion of a research project among potential team members including researchers, knowledge-users and/or partners to assess the viability of the research project and the partnership;</li> <li>Conducting an environmental scan or preliminary synthesis of relevant literature, activities or programs</li> </ul>

### Research Support and Knowledge Transfer & Exchange Opportunities

Research support or KTE opportunity	Details
OHTN Rapid Responses Service	The OHTN supports community-based organizations to obtain the latest and most reliable information about a given topic, through a Rapid Response Service. OHTN staff conduct searches of the scientific literature and contact experts in the appropriate field to locate key information resources, and then develop a summary or fact sheet relating to the requested topic. The guidelines for requesting a Rapid Response are available on the OHTN website.
OHTN OCASE System	The Evidence-based Practice Unit of the Ontario HIV Treatment Network is responsible for maintaining on behalf of the province of Ontario a standardized case management tool to assist AIDS service organizations in documenting the activities of their organization. This is called the Ontario Community-Based AIDS Services and Evaluation Database Project (OCASE). Although primarily for support services (counselling, case management, etc.), it also includes features to document brief services such as education activities.

Research support or	Details	
KTE opportunity		
OHTN Cohort Study and links with ICES	• The OHTN Cohort Study (OCS) is a community-governed, scientifically rigorous research initiative, designed to improve the health and well-being of people living with HIV in Ontario by promoting and supporting scientific, community-based and policy-relevant research. The OCS is a multi-site research study that collects clinical and socio-behavioural data on a cohort of participants living with HIV over time. The mission of the OCS is to develop, support and sustain a unique research database and cohort, governed by people living with HIV in Ontario and used in partnership by scientists, community-based researchers and other stakeholders.	
	http://www.ohtn.on.ca/Pages/Research/OHTN-Cohort-Study.aspx	
OHTN Evidence-based Practice Unit	<ul> <li>The purpose of the Unit is to provide more support for Ontario's community-based agencies in their efforts to evaluate and strengthen their programs and services.</li> </ul>	
CIHR Centre for REACH in HIV/AIDS	<ul> <li>The CIHR Centre for REACH in HIV/AIDS (Research Evidence in Action for Community Heath) is a collaborative, national partnership among:         <ul> <li>leading health researchers in Canada from over 20 academic institutions</li> <li>people living with HIV</li> <li>front-line service providers</li> <li>knowledge translation and exchange (KTE) specialists</li> <li>federal, provincial and regional policy makers</li> </ul> </li> </ul>	

Research support or KTE opportunity	Details
	<ul> <li>Launched in May 2009, the CIHR-funded Centre provides a pan-Canadian forum where partners can come together to develop innovative, interdisciplinary approaches to the prevention, care and treatment of HIV/AIDS. The Centre aims to strengthen policy, programs and practices, and make a measurable difference in the health of people with and affected by HIV.</li> <li>The major objectives of the Centre include:         <ul> <li>fostering interdisciplinary research</li> <li>developing collaborative relationships and networks between researchers and research end-users</li> <li>supporting strategic population health and health services research programs</li> <li>addressing Aboriginal research and KTE needs</li> <li>fostering knowledge exchange</li> <li>establishing a national training network.</li> </ul> </li> </ul>
	See: http://www.ohtn.on.ca/Pages/Research/reach.aspx