

Toronto HIV/AIDS Network – Housing Working Group

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 Shames, Ontario HIV Treatment Network; Jordan Lewis, Canadian Working Group on HIV and Rehabilitation; and Chris Gibson, Seaton House Infirmery 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 Shames, 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 Iafrate, 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 1st Nations, Ontario Ministry of Corrections, St. Joseph's Health Centre, The 519 Church Street Community Centre, Toronto General Hospital, Wellesley Central Place/Rekai Centre

Toronto HIV/AIDS Network – Housing Working Group

Table of Contents

Executive Summary & Glossary	7
I. Executive Summary.....	7
II. Glossary	11
Background	13
I. The Housing Working Group of the Toronto HIV/AIDS Network	13
II. The Challenge	13
Community 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
V. 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
Conclusions	30

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 Health)
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 funding¹.

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

¹ 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 impact².

The demographic bubble of aging PHAs in the Toronto region shows the largest group is aged 40-54³, 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.

² *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.*

³ *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

1. 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 intake⁴. 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-as-usual 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.

5. 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)

⁴ 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 footnote⁵:

- 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

⁵ 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

7. 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)

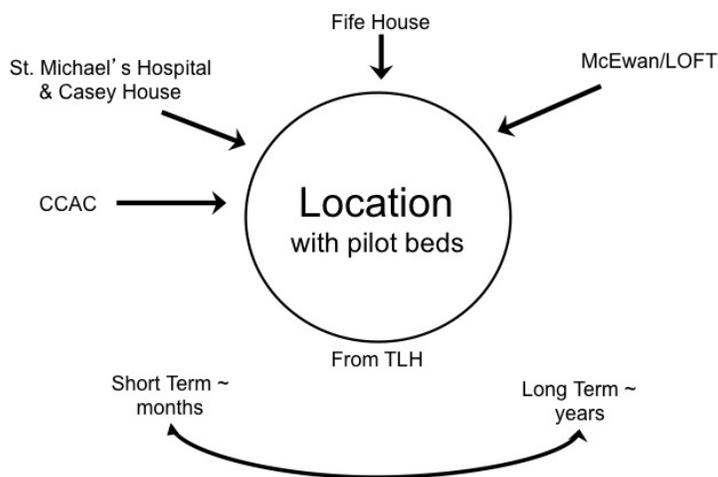
MODEL #3: Transitional Housing Aging/Complex Care

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.