Resilience, Self-Efficacy, and Peer Support:

Canadian Webinar Series on Implementing the WHO Guidelines on Sexual and Reproductive Health and Rights for Women Living with HIV

Date: Friday, March 9th, 2018

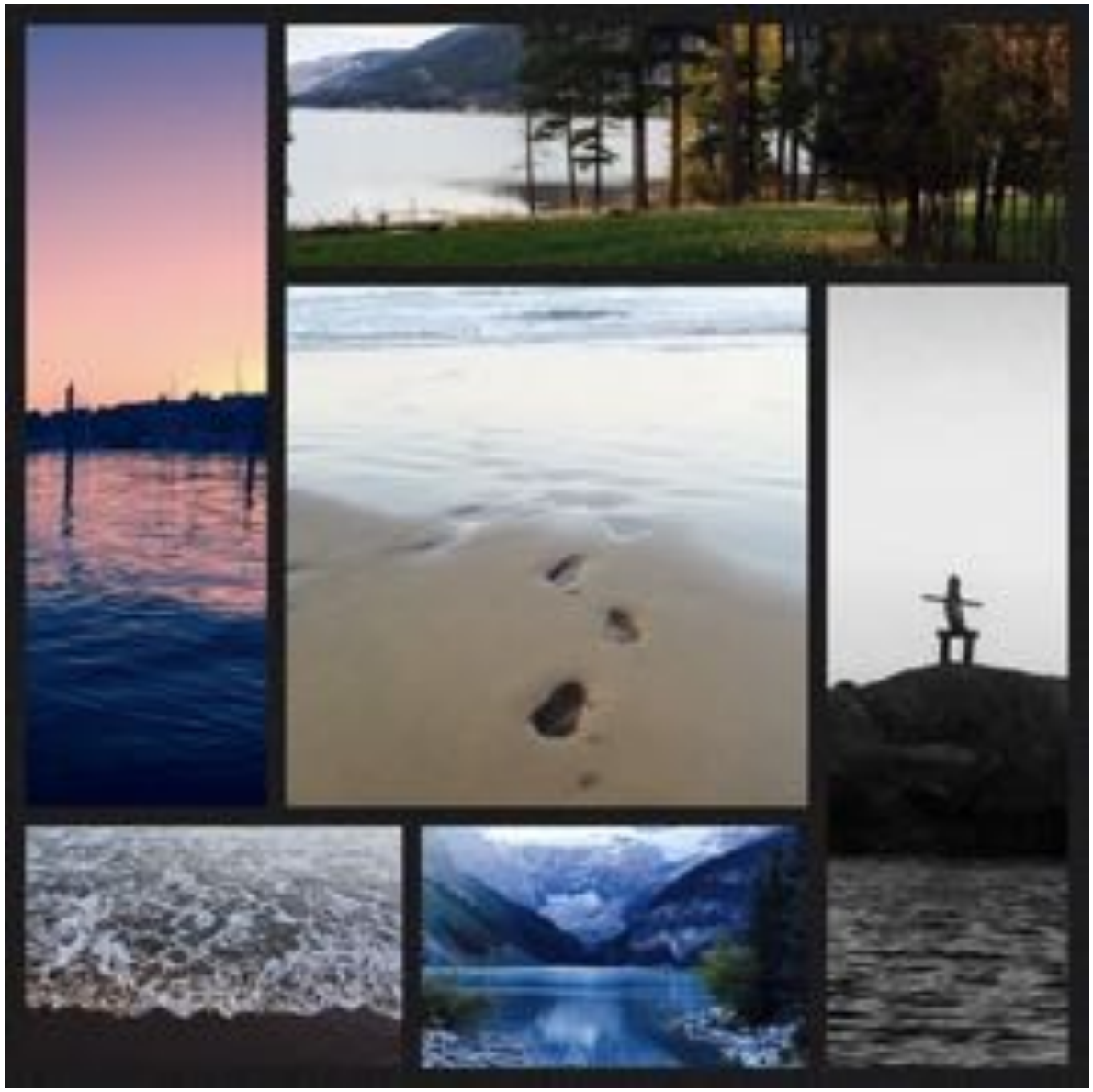
Time: 9:00-10:30 PST, 12:00 -13:30 EST, and 18:00 - 19:30PM in Geneva.

Link:
https://attendee.gotowebinar.com/register/1453739478222693377

Webinar series hosted in collaboration with:

WHO HRP, CHIWOS, Canadian Positive People's Network, Oak Tree Clinic, Women's Health in Women's Hands, Canadian Aboriginal AIDS Network and the IBP Initiative

Welcome



We honour and remember the 55 CHIWOS participants from across Canada who have passed away and are no longer with us but will always remain in our hearts.

In memory of
Marisol Desbiens
CHIWOS PRA and valued colleague

Feb 23, 2018

Acknowledgements

We would like to thank…

-All the women living with HIV who participate in CHIWOS;

-The national team of Peer Research Associates, Co-investigators and Collaborators;

-The Steering Committee, Community Advisory Boards, and Aboriginal Advisory Board;

-The BC Centre for Excellence in HIV/AIDS for data support and analysis;

-Our affiliated studies: CANOC, REACH, OSC;

-All of our partnering organizations who support study recruitment and operations;

-Our funders: CIHR Institute of Gender and Health, the CIHR Canadian HIV Trials Network (CTN 262), the OHTN, and the Academic Health Science Centres Alternative Funding Plans Innovation Fund.

Thank you to all of our community and clinical partners!

B.C.: Oak Tree Clinic at BC Women's Hospital, AIDS Vancouver Island, BC Centre for Excellence in HIV/AIDS, Cool Aid Community Health Centre, Downtown Community Health Clinic, Keys Housing and Health Solutions (Positive Haven), Living Positive Resource Centre,, Positive Living Fraser Valley, Positive Women's Network (closed), Positive Living North, and Vancouver Island Persons with AIDS Society.

ON: 2-Spirited People of the 1st Nations; 519 Community Centre; ACCKWA; Africans in Partnership Against AIDS (APAA); AIDS Committee of Durham Region; AIDS Committee of Guelph and Wellington County; AIDS Committee of Simcoe County; AIDS Network Hamilton; Alliance for South Asian AIDS Prevention; Black Coalition for AIDS Prevention; Bruce House; Casey House; Centre Francophone; Elevate NOW; Fife House; Hemophilia Ontario; HIV/AIDS Regional Services (HARS); Maggie's: Toronto Sex Worker's Action Project; Peel HIV Network; Positive Living Niagara; Positive Pregnancy Program: P3; Prisoners with AIDS Support Action Network; Réseau Access Network; Toronto PWA Foundation; Women's Health in Women's Hands; Children's Hospital of Eastern Ontario; Kingston Hotel Dieu Hospital; Health Sciences North, Sudbury Regional Hospital, HAVEN Program; Lakeridge Health; Maple Leaf Medical Clinic; McMaster Family Practice; Ottawa General Hospital; Riverside Family Health Team; SIS Clinic, Hamilton Health Sciences; St. Joseph's Healthcare London; St. Michael's Hospital; Sunnybrook Health Sciences Centre; Toronto East General Hospital; Toronto General Hospital; William Osler Health System; Windsor Regional Hospital, HIV Care Program.

QC: ACCM; L'ARCHE de l'Estrie; ASTT(e)Q; BLITS; BRAS-Outaouais; CACTUS; CASM; Centre des R.O.S.E.E.S; Centre Sida Amitié; Corporation Félix Hubert d'Hérelle; COCQ-SIDA; GAP-VIES; M.A.I.N.S-Bas St-Laurent; Maison Plein Coeur; Maison Dominic; Maison du Parc; Maison Re-Né; MIELS-Québec; Le MIENS Chicoutimi; Portail VIH/sida du Québec; Sidaction Mauricie; Sida-Vie Laval; Stella, l'amie de Maimie; UHRESS-Notre-Dame du CHUM.

BRITISH COLUMBIA CENTRE *for* EXCELLENCE *in* HIV/AIDS

Providence HEALTH CARE

CHIWOS

Webinar Objectives

- **Provide an overview** of current research about **resilience among women living with HIV and pathways between resilience and self-efficacy and other health outcomes** in the Canadian context using data from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS);
- **Introduce strategies and programs** developed by women living with HIV and allied researchers, clinicians, and serviced providers to understand the importance of peer support and leadership and capacity building in fostering resilience and self-efficacy, and how best to support peer leaders;
- **Gain insights** from women living with HIV to highlight gaps in research and priority areas for further attention;
- **Develop an action plan** on how to support the sexual and reproductive health and rights of women living with HIV in the Canadian context, including best practices to foster resilience, self-efficacy, peer support, and peer leadership among women living with HIV.

World Health Organization
CHIWOS
BC WOMEN'S HOSPITAL+ HEALTH CENTRE
CRCPN
WOMEN'S HEALTH IN WOMEN'S HANDS COMMUNITY HEALTH CENTRE
human reproduction programme hrp research for impact
IBP Initiative Scaling up what works in family planning/reproductive health

Today's Speakers

Tracey Conway

Kerrigan Johnson

Dr. Manjulaa Narasimhan

Allyson Ion

Carmen Logie

Doris Peltier

Shazia Islam

Kath Webster

World Health Organization

CHIWOS

BC WOMEN'S HOSPITAL+ HEALTH CENTRE

CRCPN+ CRCPN+

WOMEN'S HEALTH IN WOMEN'S HANDS COMMUNITY HEALTH CENTRE

human reproduction programme hrp research for impact

IBP Initiative Scaling up what works in family planning/reproductive health

Housekeeping

1. Asking questions

- During presentations, please submit any questions using the text feature of the application
- We have allotted 20 minutes at the end of the webinar for discuss and Q&A
- If you are joining us on the phone, please send any comments or questions to Project Coordinator Sarah Watt (sawatt@sfu.ca)
- If we do not get to answer or discuss all questions posed during the webinar, the organizing team will collate the questions and send responses to all webinar attendees after the webinar. Questions & answers will also be posted online with the recorded version of the webinar.
- Please type any technical difficulties into the text feature.

2. Webinar recording

- This webinar will be recorded and posted on the IBP Channel and the WHO RHR Youtube Channel. Links will be posted at the end of the webinar.

3. Handouts

- There are handouts that you can download for your own viewing and reference

Overview of the Agenda

Time	Title of Presentation	Presenter	Affiliation
9:15-9:18 PST 10:15-10:18 MST 12:1512:18 EST	Integrating principles of GIPA and MIWA	Tracey Conway	Canadian Positive People Network
9:18-9:23 PST 10:18-10:23 MST 12:18-12:23 EST	Consolidated guidelines on sexual and reproductive health and rights of Women Living with HIV	Dr. Manjulaa Narasimhan	World Health Organization
9:23-9:31 PST 10:23-10:31 MST 12:23-1:31 EST	Framing the Issue: Important of peer support to resilience and self-efficacy	Allyson Ion	McMaster University
9:31-9:39 PST 10:31-10:39 MST 12:31-12:39 EST	Current overview of research: Pathways to resilience	Dr. Carmen Logie	University of Toronto
Implementation 9:40-10:06 PST 10:40-11:06 MST 12:40-1:06 EST	Strengths-based and culturally grounded approaches to Indigenous women's health	Doris Peltier	Visioning Health II
	Building resilience and self-efficacy through peer support	Shazia Islam	Alliance for South Asian AIDS Prevention
	Leadership and capacity building, training for peer support	Kath Webster	Positive Leadership Development Institute
10:06-10:30 PST 11:06-11:30 MST 1:06-2:30 EST	Discussion & Next Steps	Tracey Conway Kerrigan Johnson	

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Social Sciences and Humanities Research Council of Canada

Conseil de recherches en sciences humaines du Canada

Canada

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Conflict of Interest

Today's webinar presenters have no conflicts of interest to declare.

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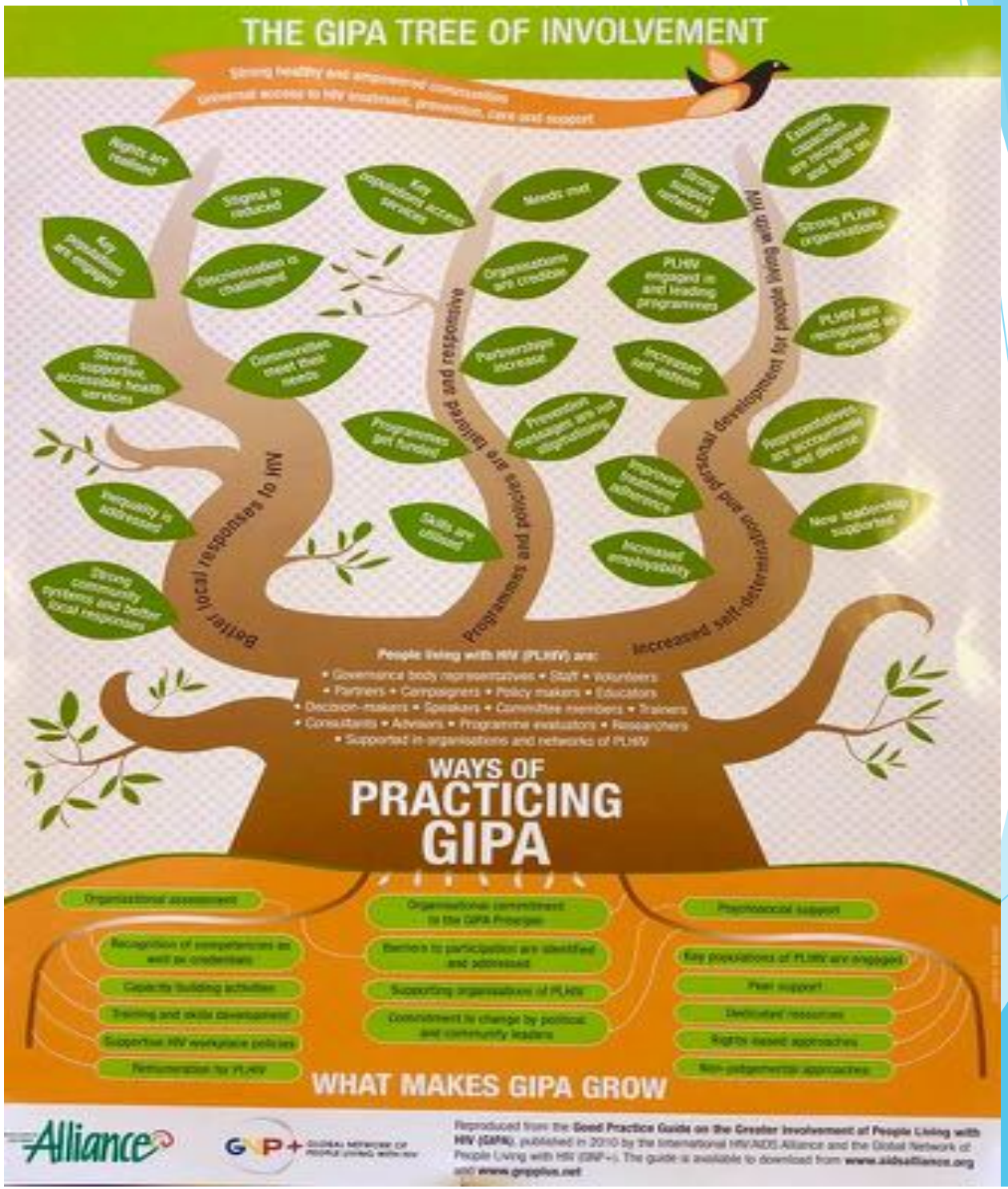
MEWA /GIPA

Meaningful Engagement of Women Living with HIV/Greater involvement of People Living with HIV

- Inclusion at all levels of project including conception, implementation, and evaluation.
- Reciprocal mentoring and capacity building respect knowledge and skills that are present, while maintaining awareness of power imbalances; acknowledge community knowledge, wisdom, especially expertise in their own lives.
- Ensure community represents populations being served and has expertise.
- Compensation and availability of resources to ensure meaningful contribution.
- Important this work belongs to the community: **NOTHING ABOUT US WITHOUT US**
- **Women living with HIV are the experts in their lives.**

Barriers

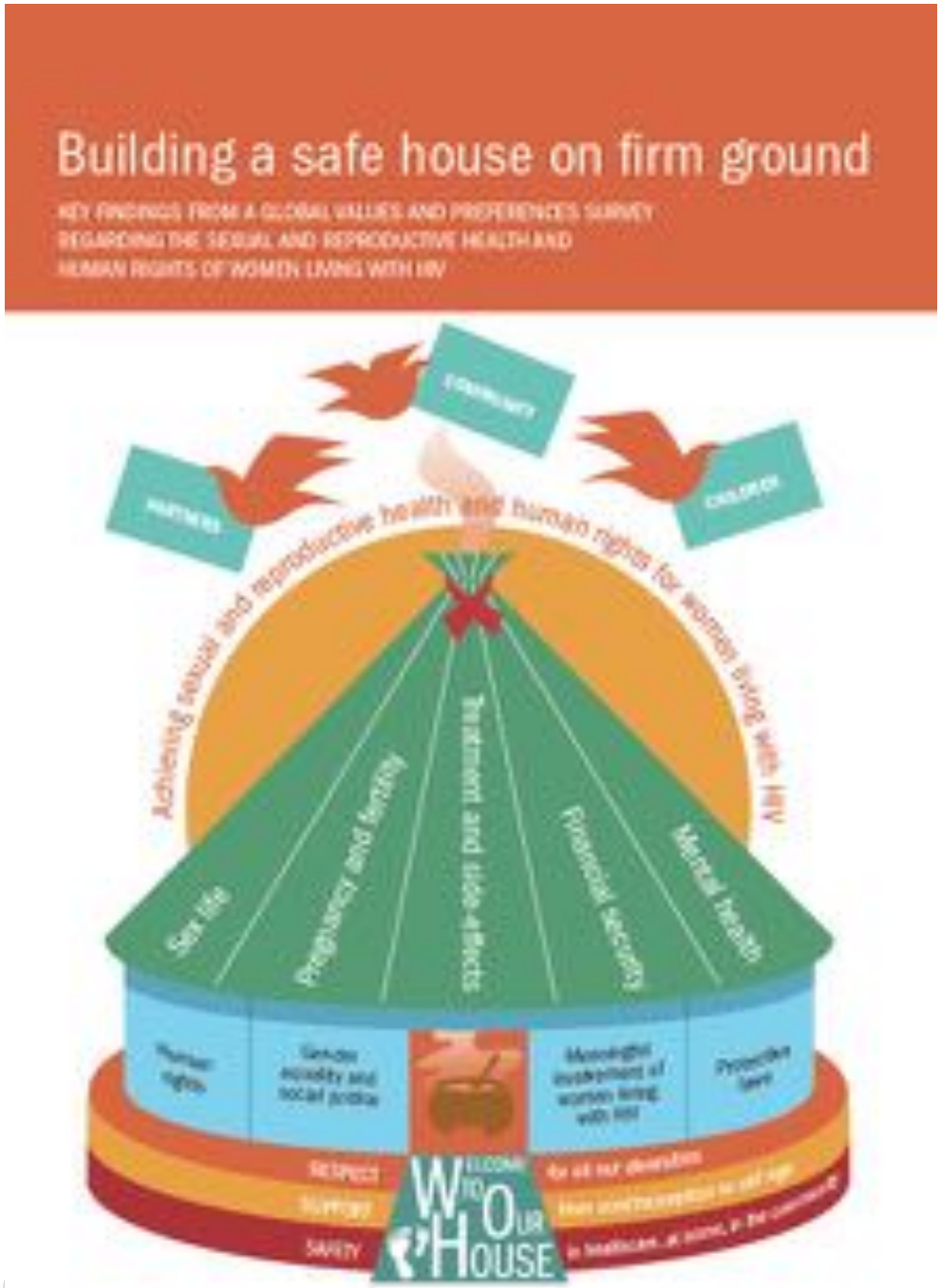
- In many environments stigma and fear impact the ability of WLWHs to engage
- A lack of economic and social power experienced by many WLWHs
- A lack of education, adequate resources and skills building for MEWA to have better impact
- Tokenization
- Lack of experience and adequate process
- Lack of resources
- Not recognizing power imbalances


THE GIPA TREE OF INVOLVEMENT
Better local responses to HIV
Programmes and services are tailored and responsive
Increased self-determination and personal development for people living with HIV
People living with HIV (PLHIV) are:
• Governance body representatives • Staff • Volunteers
• Partners • Campaigners • Policy makers • Educators
• Decision-makers • Speakers • Committee members • Trainers
• Consultants • Advisors • Programme evaluators • Researchers
• Supported in organisations and networks of PLHIV
WAYS OF PRACTICING GIPA
Organisational assessment
Recognition of competencies as well as credentials
Capacity building activities
Training and skills development
Supportive HIV workplace policies
Remuneration for PLHIV
Organisational commitment to the GIPA Principles
Barriers to participation are identified and addressed
Supporting organisations of PLHIV
Commitment to change by political and community leaders
Psychosocial support
Key populations of PLHIV are engaged
Peer support
Dedicated resources
Rights-based approaches
Non-judgemental approaches
WHAT MAKES GIPA GROW
Alliance
GNP+
Reproduced from the Good Practice Guide on the Greater Involvement of People Living with HIV (GIPA), published in 2010 by the International HIV/AIDS Alliance and the Global Network of People Living with HIV (GNP+). The guide is available to download from www.aidsalliance.org and www.gnpplus.net

World Health Organization

Consolidated guideline on **sexual and reproductive health and rights of women living with HIV**

Meaningful Community Engagement



- Core Team Members: Luisa Orza, Alice Welbourn, Susan Bewley, E. Tyler Crone, Marijo Vazquez

- GRG members: Nukshinaro Ao, Cecilia Chung, Sophie Dilmitis, Calorine Kenkem, Svetlana Moroz, Suzette Moses-Burton, Hajjarah Nagadya, Angelina Namiba, L'Orangelis Thomas Negrón, Gracia Violeta Ross, Sophie Strachan, Martha Tholanah, Patricia Ukoli, Rita Wahab.

http://salamandertrust.net/wp-content/uploads/2016/09/BuildingASafeHouseOnFirmGroundFINALreport190115.pdf

World Health Organization hrp

Creating an enabling environment: Good practice statement (GPS)

- **GPS A.1 (NEW):** Psychosocial support interventions, such as support groups and peer support, provided by, with, and for women living with HIV, should be included in HIV care.
- The intersecting nature of the challenges experienced by women living with HIV calls for multidisciplinary teams, including peer mentors, able to work across sectors relevant to HIV needs (global survey)

PEER SUPPORT, SELF-EFFICACY AND RESILIENCE

LESSONS LEARNED FROM THE WOMEN'S HIV EMPOWERMENT THROUGH LIFE TOOLS FOR HEALTH (wHEALTH) PROJECT

ALLYSON ION

PEER SUPPORT WORKS!

- Peer case managers, peer navigators, peer support programs = demonstrated effectiveness and improved outcomes
  - Improves mental health, social functioning, and coping skills
  - Reduces isolation
  - Enhances confidence to interact with health and social care providers
  - Opportunity for system redesign and alleviating demands on healthcare system
- Known in HIV community for a long time, research is catching up to community knowledge
  - Need for more contextualized knowledge about how and why peer support works, especially as a unique form of support for women in Canada

Albrecht & Peters, 1997; Campbell , Phaneuf, & Deane, 2004; Greene et al., 2015; Helgeson et al. 1999; Simoni et al., 2011

PEER SUPPORT APPROACHES

- Strengths-based approach:
  - **Assets over problems:** focus on the individual's inner strengths and external resources, people possess abilities, resources, and resilience to effectively cope with / address challenges
  - **Self-determination and person-centred:** services are oriented according to the self-identified needs of the person receiving support
  - **Peer partnership:** relationship is non-hierarchical and based on mutual respect and reciprocity
  - **Community knowledge is valued:** lived experience is acknowledged and builds community connectedness and resilience

Brun & Rapp, 2001; Rothman, 1994; Weick, 1983; Weick & Pope, 1988

PEER SUPPORT GOALS

- Increase accessibility of health and social services by strengthening woman's comfort and ability to navigate these services
- Increase sense of autonomy, self-determination, and ability to advocate on one's own behalf
- Foster hope, resilience, and community connectedness

Greene et al., 2015; Parrish, Burry, & Pabst, 2003; Passey et al., 2007;

PEER SUPPORTERS

- Lived experience & experiential knowledge
- Roles:
  - Outreach worker – engage, advocate, care planning, arranging for services, monitoring
  - Skills trainer / coach – relay knowledge, skills, and resources; foster self-management skills in women through mentorship
  - Advocate – forming and facilitating community-wide support networks
- With considerations for:
  - Self-disclosure, confidentiality, self-care, boundaries, personal values and attitudes

Parrish, Burry, & Pabst, 2003

WOMEN'S EXPERIENCES OF wHEALTH

"You know exactly what it's like to be on all these meds…the pain, the nausea, the depression sometimes…if somebody's not HIV, they get an idea…They're not there, you know, they're not the person living with it…trust me, it's different" (experiential knowledge)

"She's been HIV-positive for 18 years…she's doing well…I just think that's great…I have a career and still function and I don't want to give it up and she's showing me that I don't have to give it up" (role modelling / mentorship)

Greene et al., 2015

WOMEN'S EXPERIENCES OF wHEALTH

"I would have never known about those things…and getting me in touch with the right people at least I know, who I need to call to get into those programs…It takes a load off your mind." (referrals & access)

"I feel that you have brought me out of the cage, so I really feel free now…I have learned a lot, I have learned to stand my ground, I have learned to advocate for myself." (voice / automony / resilience)

Dale et al., 2014; Greene et al., 2015

PEER SUPPORT: CONSIDERATIONS FOR UPTAKE

- Defining "peer" can be complicated
  - Basis for matching / connecting peers?
- Macro / systemic issues
  - Racism, sexism, HIV-related stigma and discrimination (role of peer support to address through system redesign?)
- Whose knowledge is valued and accepted?
  - Authoritative knowledge
  - Medical model

REFERENCES

Albrecht, G., & Peters, K. (1997). Peer intervention in case management practice. *Journal of Case Management, 6*(2), 43-50

Brun, C., & Rapp, R. (2001). Strengths-based case management: Individual's perspectives on strengths and the case manager relationship. *Social Work, 46*(3), 278-288.

Campbell, H., Phaneuf, M., & Deane, K. (2004). Cancer peer support programs - do they work? *Patient Education and Counseling, 55*(1), 3-15.

Dale, S. K., et al. (2014). Resilience among women with HIV: Impact of silencing the self and socioeconomic factors. *Sex roles, 70*(5-6), 221-231.

Greene, S., Ion, A., Kwaramba, G., Mwalwanda, M., Caswell, J., Guzha, E., & Carvalhal, A. (2015). "Trust me, it's different": Experiences of peer case management of women living with HIV in Ontario, Canada. *Canadian Social Work Review, 32*(1-2), 73-93.

Helgeson, V., Cohen, S., Schultz, R., & Yasko, J. (1999). Education and peers discussion group interventions and adjustment to breast cancer. *Archives General Psychiatry, 56*, 340-347.

Parish, M., Burry, C., & Pabst, M. (2003). Providing comprehensive case management to urban women with HIV/AIDS and their families. *Affilia, 18*(3), 13-24.

Passey, M., Sheldrake, M., Leitch, K., & Gilmore, V. (2007). Impact of case management on rural women's quality of life and substance use. *Rural and Remote Health, 7*(710).

Rothman J (1994). *Practice with highly vulnerable clients*. Englewood Cliffs, NJ: Prentice Hall.

Simoni, J. M., Franks, J. C., Lehavot, K., Yard, S. S. (2011). Peer interventions to promote health: conceptual considerations. *American Journal of Orthopsychiatry, 81*(3), 351-359.

Simoni, J. M., Nelson, K. M., Franks, J. C., Yard, S. S., Lehavot, K. (2011). Are peer interventions for HIV efficacious? A systematic review. *AIDS Behav, 15*, 1589-1595.

Weick A (1983). A growth-task model of human development. *Social Casework*, 64, 131-137.

Weick A, Pope L (1988). Knowing what's best: A new look at self-determination. *Social Casework*, 69, 10-16.

RESOURCES

- wHEALTH Manual – Strengths-Based Peer Case Management approach - http://sgdwebsites.com/clients/wHealth/wp-content/uploads/2013/09/wHEALTH-Manual-FINAL.pdf
- Supporting Mothers in Ways that Work - http://www.catie.ca/en/resources/supporting-mothers-ways-work-resource-toolkit-service-providers-working-mothers-living-hiv
- Qualitative findings from wHEALTH (impact of Peer Case Management on women living with HIV) - https://www.erudit.org/en/journals/cswr/2015-v32-n1-2-cswr02278/1034144ar/

Exploring social ecological pathways from resilience to quality of life among women living with HIV in Canada

Carmen LOGIE, Angela KAIDA, Alexandra DE POKOMANDY, Erin DING, Nadia O'BRIEN, Uzma AHMED, Lu WANG, Tracey CONWAY, Val NICHOLSON, Mona R. LOUTFY, On Behalf of the CHIWOS Research Team

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Resilience & Social Ecological Frameworks

- **Social ecological frameworks:** complex interactions between persons and their social & structural contexts influence health (Stokols, 1996)

- Social ecologies contribute to **resilience** (positive growth in contexts of stress & adversity) (Ungar, 2011)

CHIWOS

Resilience & Social Ecological Frameworks

- Women living with HIV experience significant stress & adversity
  - social-environmental contexts of stigma, discrimination, and economic insecurity (Kumar, Gruskin, Khosla, & Narasimhan, 2015; Logie, Ahmed, Tharao, & Loutfy, 2017; Loutfy et al., 2015)
- Resilience is associated with positive health outcomes for people living with HIV (Farber et al., 2000; Fumaz et al., 2015; McGowan et al., 2017)
  - This includes physical and mental health-related quality of life

CHIWOS

Resilience & Health-Related Quality of Life

- Social ecological factors may influence pathways from resilience to HR-QoL, such as HIV disclosure concerns & economic insecurity
  - HIV disclosure concerns are associated with poorer well-being and quality of life, & poorer mental health among persons living with HIV (Blalock, McDaniel, & Farber, 2002; Bhat et al., 2015; Degroote, Vogelaers, & Vandijck, 2014; Fekete, Williams, Skinta, & Boqusch, 2016; Hernansaiz-Garrido & Alonso-Tapia, 2017)
  - Economic insecurity is associated with poorer quality of life & mental health (Douab et al., 2014; Riley et al., 2011; Riley et al., 2012)

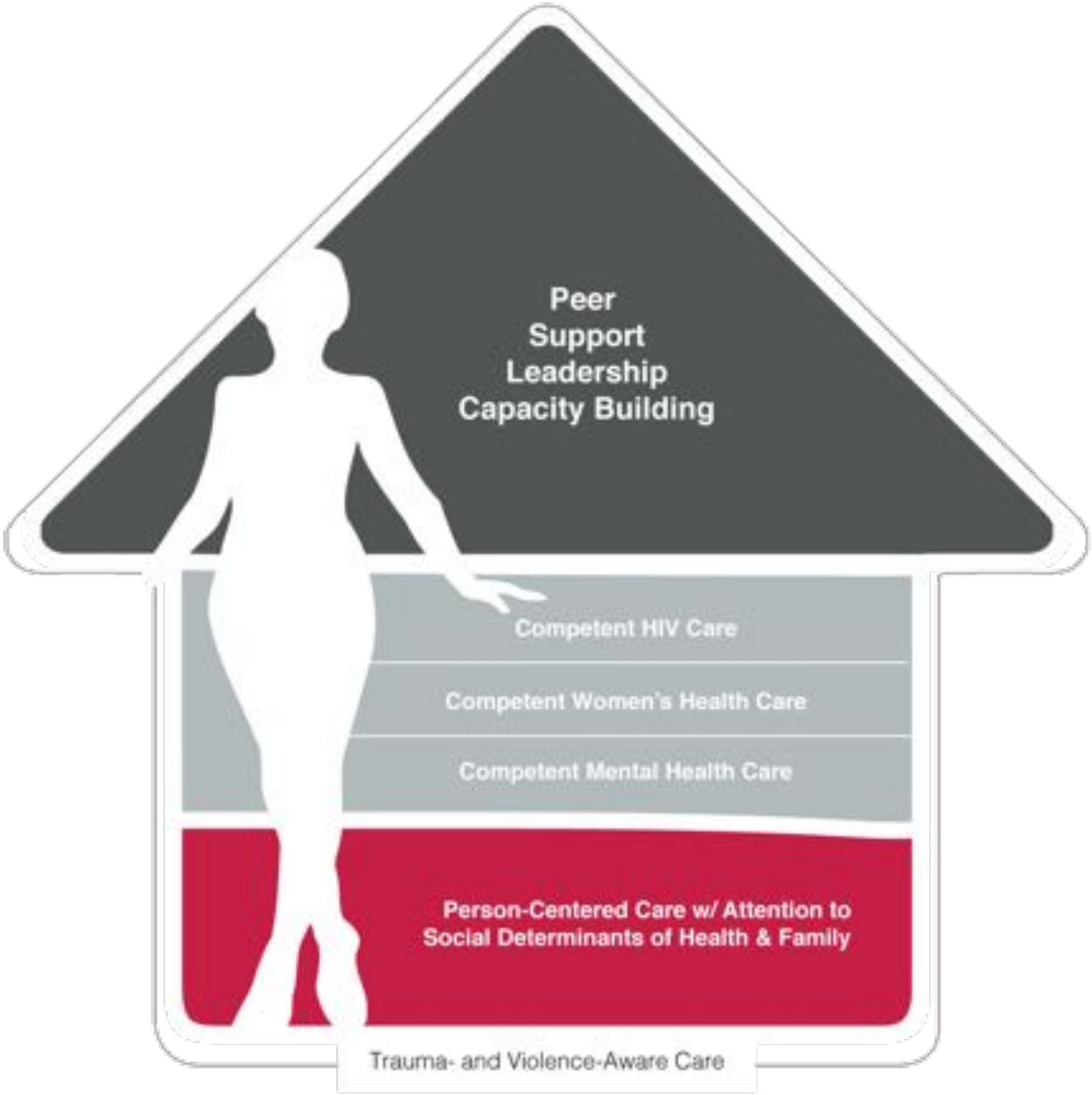
CHIWOS

Resilience: What fosters it?

- Studies with children with HIV have shown resilience is dynamic, shaped by and shaping interactions with the environment
- Community level factors such as social support can promote resilience (e.g. Earnshaw, Lang, Lippitt, Jin, & Chaudoir, 2015)
- Women-specific HIV services may improve women's self-worth & self-advocacy (Carter et al., 2013)
  - This is an underexplored pathway to resilience
  - Women's Centered HIV Care (WCHC) prioritizes women's unique needs, is strengths-based and person centered

CHIWOS

Women Centered HIV Care Model– The House



Across the Life course of women
covering age-related issues

CHIWOS

Knowledge Gaps

- Pathways *to* resilience are less studied with women living with HIV
- Social and structural factors (such as HIV disclosure concerns, economic insecurity) may mediate the relationship between resilience and quality of life: this has been understudied
- This information can help us to build resilience as well as to understand its relationship with larger social ecological factors

CHIWOS

Objectives

- To understand pathways *to* resilience and pathways *from* resilience to HR-QOL among WLWH in Canada:
  1) Examine pathways from social (social support) & structural (WCHC) resources to resilience
  2) Examine pathways from resilience to mental & physical health-related quality of life through social (HIV disclosure concerns) & structural (economic insecurity) factors

CHIWOS

Study Design

- CHIWOS
- Baseline data from longitudinal cohort study
- Multi-centred (ON, QB, BC)
- Community-based research
- Non-random, purposive sampling:
  - Peer research assistant networks and word-of-mouth
  - HIV clinics; AIDS Service Organizations; CBO
  - Provincial CHIWOS Community Advisory Board networks;
  - CHIWOS National Steering Committee networks;
  - Social media

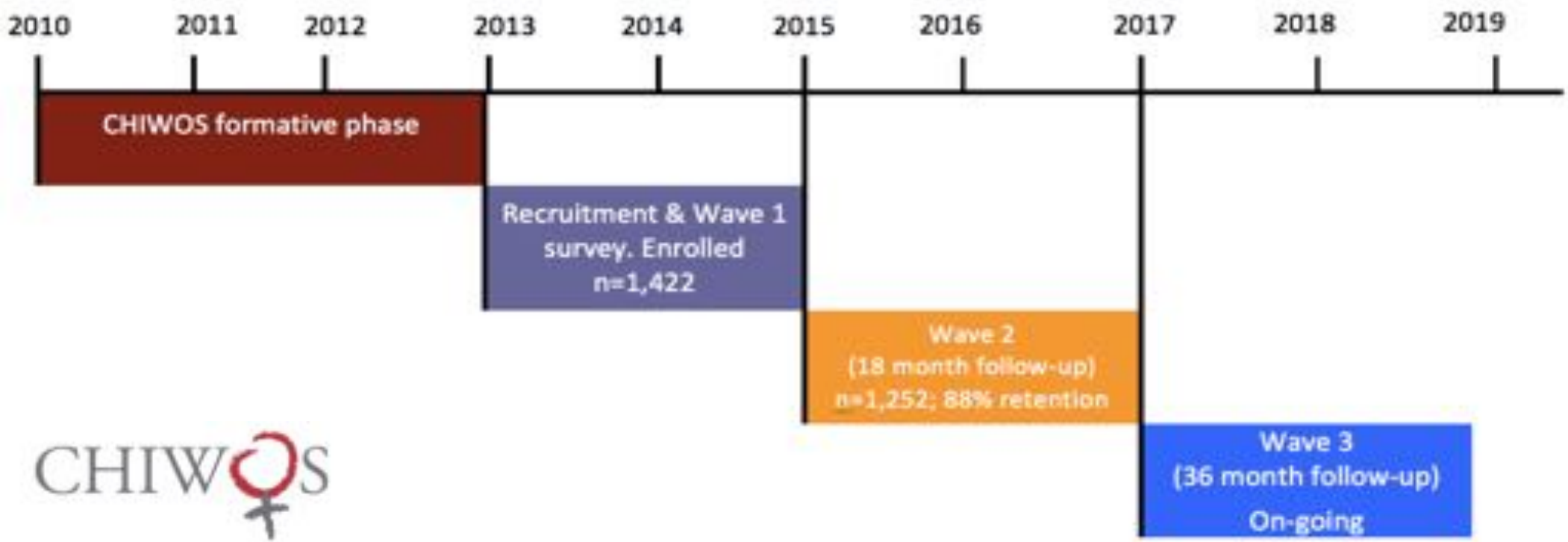
CHIWOS

PLOS | ONE

RESEARCH ARTICLE

Cohort profile: The Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS)

Mona Loutfy[1,2,3]*, Alexandra de Pokomandy[4,5], V. Logan Kennedy[1], Allison Carter[6,7], Nadia O'Brien[4], Karène Proulx-Boucher[5], Erin Ding[7], Johanna Lewis[1,8], Valerie Nicholson[6], Kerrigan Beaver[1], Saara Greene[9], Wangari Tharao[10], Anita Benoit[1,3], Danièle Dubuc[5], Jamie Thomas-Pavanel[1,2], Paul Sereda[7], Shahab Jabbari[7], Jayson H. Shurgold[6,11], Guillaume Colley[7], Robert S. Hogg[6,7], Angela Kaida[6], on behalf of the CHIWOS Research Team[¶]

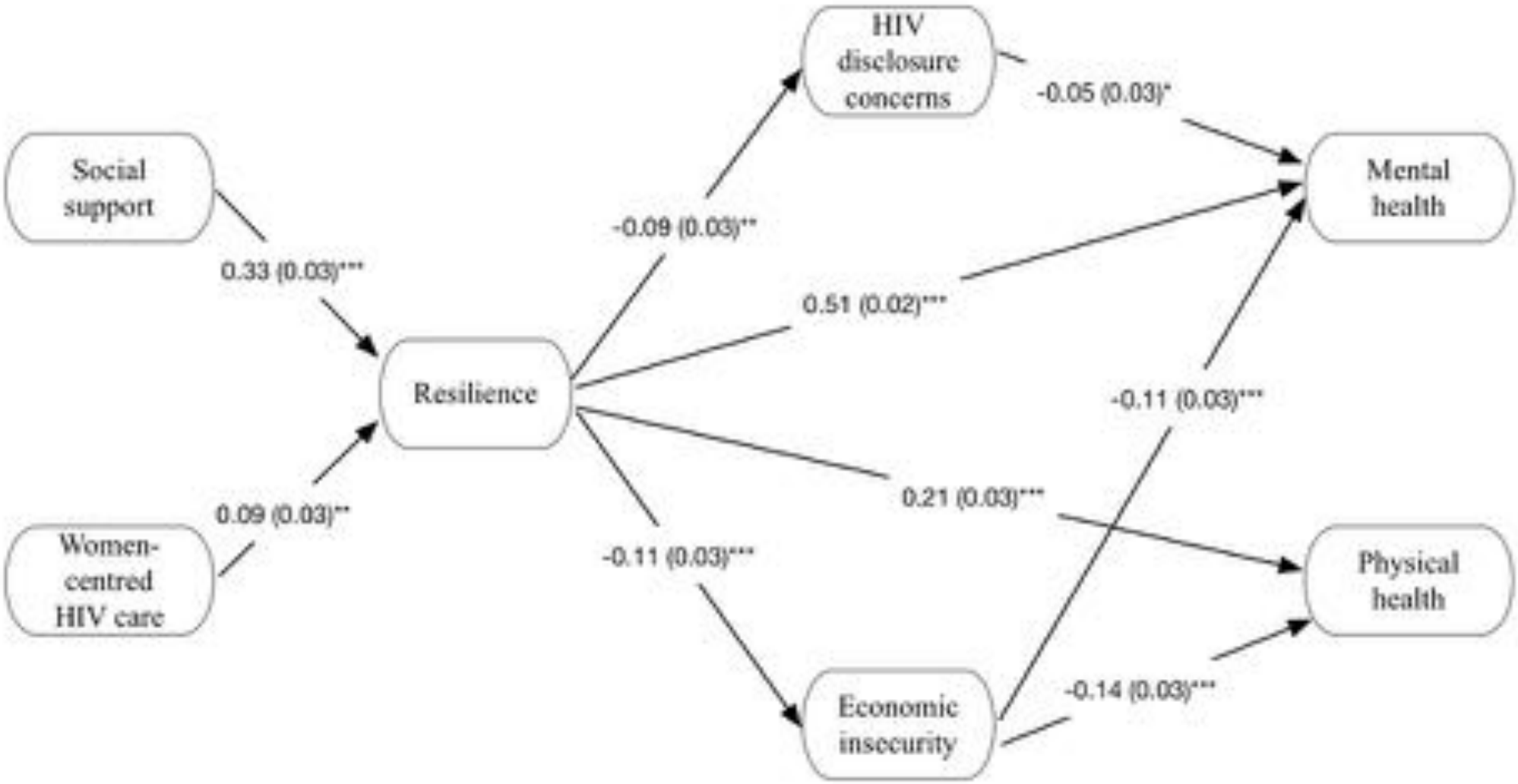


Methods

- Validated measures to assess:
  - Health-related quality of life (HR-QoL) (SF-12) physical & mental health; Resiliency Scale, personal competence and self-acceptance (RS-10) (Wagnild & Young, 1993); Social support (MOS-SSS); WCHC (Carter et al., 2013); economic insecurity (food/housing); & HIV disclosure concerns (HAT-QOL)
- Unadjusted & adjusted linear regressions to estimate regression coefficients of HR-QoL and resilience
- Structural equation modeling maximum likelihood estimation methods to test direct effects of a) social support & WCHC on resilience, b) resilience on HR-QoL, and c) indirect effects of resilience on HR-QoL via economic insecurity & HIV disclosure concerns

Table 1. Parameter estimates of HR-QoL (mental health and physical health) among women with HIV in Canada

Parameter	Coefficient (95% CI)	Critical Ratio	P	Standardized Estimate
Resilience on:				
Social support	0.60 (0.50-0.69)	8.26	<0.001	0.33
WCHC	0.20 (0.10-0.30)	3.04	<0.001	0.09
Mental HR-QoL on:				
Resilience	0.92 (0.84-1.00)	15.38	<0.001	0.51
HIV disclosure concerns	-0.18 (-0.32-(-0.04))	-1.98	<0.05	-0.05
Economic insecurity	-1.27 (-1.86- (-0.68))	-4.38	<0.001	-0.11
Physical HR-QoL on:				
Resilience	0.39 (0.29-0.48)	6.19	<0.001	0.21
HIV disclosure concerns	-0.08 (-0.24-0.08)	-0.61	0.321	-0.02
Economic insecurity	-1.41 (-2.06- (-0.77))	-4.78	<0.001	-0.14
HIV disclosure on:				
Resilience	-0.06 (-0.09-(-0.03))	-2.55	<0.001	-0.09
Economic insecurity on:				
Resilience	-0.01 (-0.02-(0.01))	-2.75	<0.01	-0.11


HIV disclosure concerns
Social support
Mental health
Resilience
Women-centred HIV care
Physical health
Economic insecurity
0.33 (0.03)***
0.09 (0.03)**
-0.09 (0.03)**
0.51 (0.02)***
-0.05 (0.03)*
-0.11 (0.03)***
0.21 (0.03)***
-0.11 (0.03)***
-0.14 (0.03)***

CHIWOS

Summary of Findings

- Social support & receiving WCHC were associated with higher resilience among WLWH
- Resilience was associated with improved physical & mental HR-QoL among WLWH
- Lower resilience was associated with higher economic insecurity, which was in turn associated with lower levels of mental & physical HR-QoL
  - economic insecurity a partial mediator
- Lower resilience was associated with increased HIV disclosure concerns, which in turn was associated with lower levels of mental HR-QoL
  - HIV disclosure a partial mediator

CHIWOS

Recommendations

- Integration of community factors (social support) and structural factors (WCHC) into policy and program delivery to foster resilience among WLWH
- Resilience is a protective factor with physical & mental health benefits: yet HIV-related stigma and economic insecurity compromise HR-QoL
- Building capacity for resilience must be conducted in tandem with strategies to reduce HIV-related stigma and address root causes of economic insecurity

CHIWOS

References

- Bhat, U., Cherian, A. V., Bhat, A., Chapman, H. J., Lukose, A., Patwardhan, N., ... Ramakrishna, J. (2015). Factors affecting psychosocial well-being and quality of life among women living with HIV/AIDS. *Nitte University Journal of Health Science*, *5*(4).
- Blalock, A. C., Mcdaniel, J. S., & Farber, E. W. (2002). Effect of employment on quality of life and psychological functioning in patients with HIV/AIDS. *Psychosomatics*, *43*(5), 400-404.
- Carter, A., Loutfy, M., de Pokomandy, A., Colley, G., Zhang, W., Sereda, P., ... Kaida, A. (2017). Health-related quality-of-life and receipt of women-centered HIV care among women living with HIV in Canada. *Women & health*, 1-21.
- Degroote, S., Vogelaers, D., & Vandijck, D. M. (2014). What determines health-related quality of life among people living with HIV: an updated review of the literature. *Archives of Public Health*, *72*(1), 40.
- Douab, T., Marcellin, F., Vilotitch, A., Protopopescu, C., Préau, M., Suzan-Monti, M., ... Spire, B. (2014). Health-related quality of life of people living with HIV followed up in hospitals in France: comparing trends and correlates between 2003 and 2011 (ANRS-VESPA and VESPA2 national surveys). *AIDS care*, *26*(sup1), S29-S40.
- Fekete, E. M., Williams, S. L., Skinta, M. D., & Boqusch, L. M. (2016). Gender differences in disclosure concerns and HIV-related quality of life. *AIDS Care, 28*(4), 450-454.
- Fumaz, C. R., Ayestaran, A., Perez-Alvarez, N., Muñoz-Moreno, J. A., Moltó, J., Ferrer, M. J., & Clotet, B. (2015). Resilience, ageing, and quality of life in long-term diagnosed HIV-infected patients. *AIDS care*, *27*(11), 1396-1403.

CHIWOS

References

- Hernansaiz-Garrido, H., & Alonso-Tapia, J. (2017). Internalized HIV stigma and disclosure concerns: Development and validation of two scales in Spanish-speaking populations. *AIDS Behavior, 21,* 93-105.
- Kumar, S., Gruskin, S., Khosla, R., & Narasimhan, M. (2015). Human rights and the sexual and reproductive health of women living with HIV–a literature review. *Journal of the International AIDS Society*, *18*(6S5).
- Logie, C. H., Ahmed, U., Tharao, W., & Loutfy, M. R. (2017). A Structural Equation Model of Factors Contributing to Quality of Life Among African and Caribbean Women Living with HIV in Ontario, Canada. *AIDS research and human retroviruses*, *33*(3), 290-297.
- McGowan, J. A., Brown, J., Lampe, F. C., Lipman, M., Smith, C., & Rodger, A. (2017). Resilience and physical and mental well-being in adults with and without HIV. *AIDS and Behavior*, 1-11.
- Riley, E. D., Moore, K., Sorensen, J. L., Tulsky, J. P., Bangsberg, D. R., & Neilands, T. B. (2011). Basic subsistence needs and overall health among human immunodeficiency virus-infected homeless and unstably housed women. *American journal of epidemiology*, *174*(5), 515-522.
- Riley, E. D., Neilands, T. B., Moore, K., Cohen, J., Bangsberg, D. R., & Havlir, D. (2012). Social, structural and behavioral determinants of overall health status in a cohort of homeless and unstably housed HIV-infected men. *PloS one*, *7*(4), e35207.
- Stokols, D. (1996). Translating social ecological theory into guidelines for community health promotion. *American Journal of Health Promotion, 10*(4), 282-298.
- Ungar, M. (2011). The social ecology of resilience: Addressing contextual and cultural ambiguity of a nascent construct. *American Journal of Orthopsychiatry*, *81*(1), 1-17.

CHIWOS

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Honoring the Story Medicine of HIV+ Indigenous Women "In Research" (The Visioning Health Example)

Doris Peltier – VH II National Coordinator
Canadian Aboriginal AIDS Network

Canadian Webinar Series on Implementing the WHO Guidelines on Sexual Reproductive Health and Rights for Women Living with HIV (March 9th, 2018)

Acknowledgements

Why Visioning Health?
A Pathogenic Perspective

Visioning Health I

VH I Project Goals

1) Create safe space / opportunity for HIV+ Indigenous women to tell a different kind of story (their own story)
2) Create new knowledge & knowledge products that were strengths-based, culturally-relevant and gender-specific
3) Positively and immediately impact participants and communities
4) Develop social supports/social networks for women locally and across Canada

Research Questions

1) What does it mean to be ‘healthy’…?

2) What are the strengths and assets that help to create, support or maintain your ‘health’?

3) What is the role of ‘culture’ and ‘gender’ and their intersections with other SDoH in creating, supporting or maintaining health?

4) What are the policy and practice implications of our work?

Project Design

- Decolonizing / Indigenous Methodologies
  - CBPR
  - Arts-informed / Storytelling
  - Health-focused / Strength-based
- Women-Centred/GIPA
- Pop Health Framework
  - Broader SDoH
  - Social Ecological Model
  - Ceremony / Circle

Strategy of Inquiry (n=13)

"Virtual' Group (n=4)
Digital Photos
Group Orientation + 9 Skype Weekly Meetings; 3 Sharing Circles
(3 months)

Toronto Group (n=5)
Digital Photos
Group Orientation + 10 In-Person Bi-weekly Meetings;
3 Sharing Circles
(6 months)

Montreal Group (n=4+2)
Drum-Making
Group Orientation + Drum-making
3 Sharing Circles
(4 days)

In-Person All-Groups Meeting to Celebrate, Share, Compare, Analyze, Recommend
(1.5 days)

Community-engaged, culturally relevant and participatory knowledge translation and exchange (on-going) Eg., Visioning Health Lodge, Photo Exhibitions, Policy Discussions, Co-presentations to community and academy

Health for HIV+ Indigenous Women:
A Strengths-Based Perspective

What Else Did Women Say About VH?

- VH was "life-saving", "a healing journey", "good medicine".

- VH helped women "connect"
  - with self
    - *"I haven't really been able to help but grow from this process…[it's] healing in lots of ways because of the ability to be able to express without having to use words." (KL)*
  - with others
    - *"it can be very lonely living with HIV. Sometimes I feel alone, even on a busy street. I feel isolation. But since being in this project I don't feel so alone." (Tonie)*
  - with community
    - *"[VH] helped to first understand my own life-story and my relationship to HIV/AIDS. Then new understandings are developed to create community support for newly-diagnosed Aboriginal women" (Liz)*
  - with culture
    - *"I learned that you know, I am a culturally and spiritual being. I am a spiritual being and that was an awakening. An awakening of identity" (Krista)*

“Get out of my chair!”
VISIONING HEALTH

Integrated, Culturally-Relevant & Community-Engaged KTE

Visioning Health II

VH II – Goals, Objectives & Data Collection

Participating in VH was itself health-enhancing => VH II

- VH II funded in July 2015
  - Goal: to develop the VH Model as a health intervention for Indigenous women living with HIV – *with leadership by Indigenous women living with HIV.*
    - VH I women as co-researchers
    - Women's council
    - VH I women as Community Research Coordinators
  - 7 sites across Canada + PASAN, 2 engagement styles
  - Increasing adaptation towards Indigenous arts/culture AS intervention, ie, land-based practice
  - Instruments development (connectedness, social support, self & communal mastery)
  - Assessment and Evaluation

VH II – Regional Teams Training

VH II – Northern Ontario

Visioning Health II – British Columbia

Visioning Health II - Regina

Visioning Health II – What's Next

- Analysis and Interpretation of Evaluation and Assessment on-going
- Apply what we learn to training for next 4 sites
- Roll-out 4 sites (MB, AB, QC, SK2)
- VH II – PASAN
- Analysis of all 7/8 sites
- VH Model available to all community orgs
- KTE

VH II – Partners and Funders

University of Victoria

uOttawa

All Nations Hope Network

elevate NWO
HIV | AIDS | HCV | HARM REDUCTION

WCHRI
WOMEN'S COLLEGE RESEARCH INSTITUTE
Health care for women | REVOLUTIONIZED

Healing Our Nations

UNIVERSITY OF SASKATCHEWAN

Ka Ni Kanichihk Inc.
"those who lead"

McMaster University

ONTARIO ABORIGINAL HIV/AIDS STRATEGY

Shining Mountains Living Community Services

Red Road HIV / AIDS NETWORK

CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

the CTN
CIHR Canadian HIV Trials Network

le Réseau
Réseau canadien pour les essais VIH des IRSC

Thank You / Miigwech

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Coming Soon!
www.visioninghealth.ca

Ontario
Ministry of HEALTH AND LONG-TERM CARE

ASAAP
ALLIANCE FOR SOUTH ASIAN AIDS PREVENTION

MAC AIDS FUND

MORE THAN FICTION

POZ WOMEN SHARE THEIR STORIES

ASAAP & ELAN

About ASAAP:

- Ethnoracial ASO in Toronto since early 90s
- Provides Support, Education and Community Development
- www.asaap.ca

About ELAN:

- ASAAP's first support program exclusively for female-identified clients began in 2011
- High representation of women in our client base with complex needs
- Why ELAN

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Origins

- **More than Fiction began with South Asian POZ women**
- Since 2011 women of ELAN have participated in various research studies and did not want be “subjects” of another study; but they did want to share their story in their own words
- They voiced their desire to formally write and share their stories with their peers
- We responded by applying for funding from MAC AIDS Foundation; the project was also supported by the AIDS Bureau, Ministry of Health and Long Term Care
- We were honoured to support their storytelling vision as the project rolled out

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Why Storytelling?

- An organic process where authors have ownership – Greater Involvement & Meaningful Engagement of People Living with HIV
- Culturally relevant; how communities learn from each other
- Creative, fun but also requires tremendous self-reflection
  - What does this say about me?
  - What do I want to say to the world?
- Can be a safe and accessible means to building community
- Memorializes & validates the resilience of South Asian POZ women through story-sharing

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The Project

Guided by a Project Advisory Committee we first developed a project charter that outlined:

- Terms of participation
- Workshop schedule
- Consent and confidentiality
- Honorarium

8 women signed up for full participation through:

- 4 creative writing workshops
- 2 photo art workshops
- 2 story sharing and book design sessions

4 more women signed up to:

- Contribute their stories outside of workshop participation

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The Project

Workshop Planning

- A total of 8 workshop sessions were planned with women to build skills in storytelling, photo art and creative writing
- These sessions also provided means of sharing and learning from peers
- Community artists were invited to develop curriculum and facilitate sessions, they included:
  - spoken word artist, poet, and author, Sheniz Janmohamed
  - arts facilitator, photographer, and graphic designer, Zahra Agjee
- Tensions and barriers were also present

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The Anthology

What did we achieve?

A collection of 12 personal narratives including:

- *A Life of Service and Caring*
- *The Accident that Changed my Life Forever*
- *Prose for the Man with the Harley*
- *Channeling Fear into Support & Education*
- *Living with Love for 30 Years*

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Themes

Each story represents a unique contribution but also reflects some universal themes: love, romance, intimacy, sex, sexuality, identity, parenting, spirituality, migration, education, self-care…

"All I knew at the time was that around me, people with HIV were dying and that I too was dying. I wanted to experience a Harley ride before my time was up. I was determined to meet its owner."

Prose for the Man with the Harley
by Anjalee Aman

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Writing Styles

"Some days as I watch my toes sink into the warm white sands, I can also hear the joyous sounds of a wedding ceremony or a summer gathering of friends. The beach brings people together, and as I listen and observe, all those special memories people are forming become part of mine too."

My Beach Oasis, My Paradise Moment

By Esta Noche

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Navigating Identities

"Whenever you talk of these things, I trick myself into dreaming that dream with you, like I could just forget for a moment that I actually adore women, that I'm gender-fluid, and…that I'm HIV positive."

Letter to my Mother

By Neel

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Intersectionality

And each addresses barriers and struggles: HIV disclosure, gender-based violence, stigma and discrimination, poverty, mental health challenges, and the day-to-day living with a chronic illness…

"I cope with my illness one day at a time. Sometimes I am ok, sometimes I am down. I am alone a lot, wondering what each day will bring…It tears me up inside knowing that I have an illness I can't even talk about with the people closest to me."

To Whom it may Concern

By Savitri

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Hope

"My mind is always full of plans. Now I am doing some more training in the areas I'm interested in. I have already planned my next step. I know that my life can stop anytime and anywhere but I will continue planning for my future, so that I can fulfill my life's purpose."

A Life of Service and Caring

By Archana

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Feedback from the Writers

"I no longer felt shame about my experience."

"I felt I was the only one going through hell, but after reading the other stories, I thought it was remarkable that these women survived. If they could do it, I could do it."

"Gave me a sense of enjoyment, tranquility."

"Gave us an idea on what our group still needed to work on in our relationships with one another."

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Impact

- Results of Story-Sharing for Sexual Health Study demonstrated the significant impact that personal narrative as opposed to fact sheets can have on understanding the determinants of health
- Participants develop capacity in narrative writing and they are seeking avenues in which to continue this area of development
- The anthology has been used at multiple outreach and workshop sites demonstrating its value as an educational resource
- More Than Fiction Vol. 2 invited mixed gender group C2C and explored resilience against backdrop of social determinants of health – featured at Opening Doors Toronto 2018
- Volume 3 is in the works and seeks to bring poz folks and allies together in a conversation about advocacy and access

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The Authors

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Leadership and capacity building for People living with HIV

Kath Webster

PLDI, Lead Trainer

CHIWOS PRA

Positive Leadership Development Institute™

L'Institut de Développement de Leadership Positif

- PLDI is a national partnership between the Pacific AIDS Network (PAN) the Ontario AIDS Network (OAN) and Coalition d'organismes communautaires québécois de lutte contre le sida (COCQ-SIDA)
- Has expanded to Australia and New Zealand!
- PLDI is dedicated to supporting a rising generation of HIV positive leaders
- We are funded by the Public Health Agency of Canada, PLDI supporters- Mac AIDS, RBC and ViiV Healthcare.

Supporting people living with HIV/AIDS to:

Realize leadership potential
Increase capacity to participate meaningfully in community life
While having FUN!

There are three modules:

1. **Core Leadership Training**
   - Who am I as a leader?

2. **Bored? Get on Board!**
   - Board governance training

3. **Communication Skills Training**
   - Public speaking and effective communication

but … It's much more than a weekend workshop!

PLDI™
Positive Leadership Development Institute™

Explore Self-Awareness and Personal Values

"It's an incredibly empowering series of workshops that have application in multiple areas of your life, not just work - even your personal life and living with HIV."

Build Community Awareness

"It is tailored to people living with HIV to deal with some of the more difficult subjects, like stigma and what that means to live with HIV and be out with your status."

"I never belonged to anything, and now I belong to something."

Develop Leadership Skills

Inspire a shared vision

Model the way

Enable others to act

Challenge the process

Encourage the heart

"The training changed me. I'm more vocal and assertive."

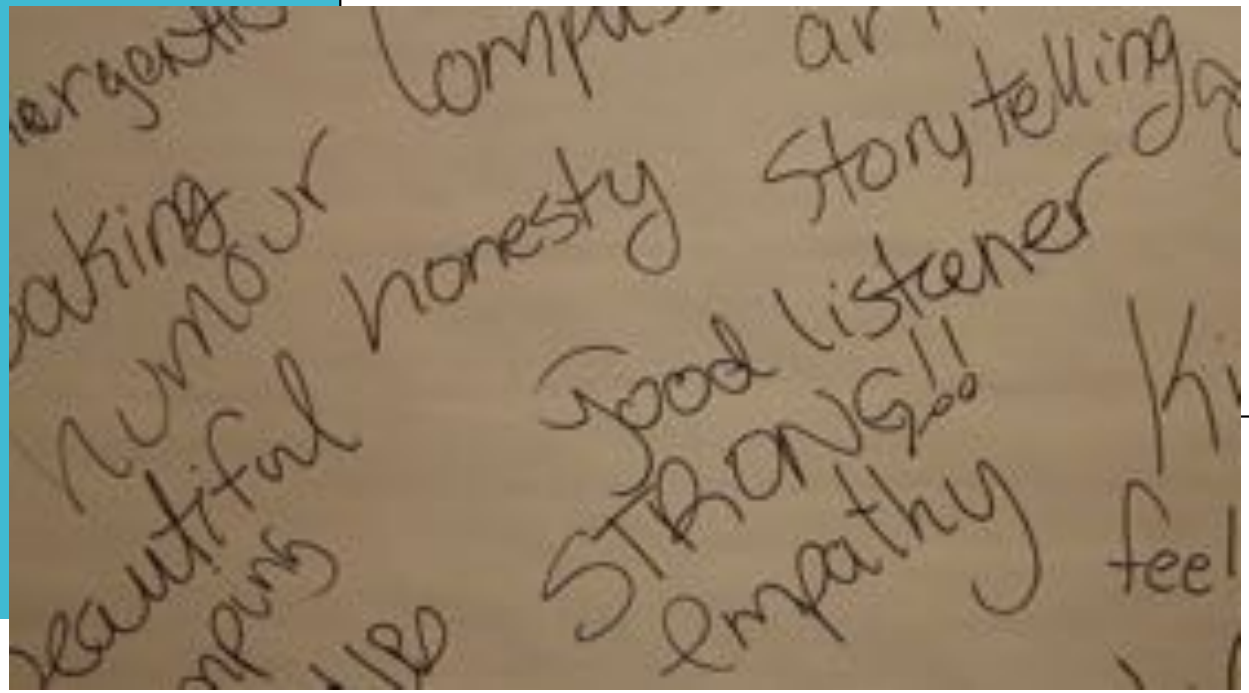
"I'm not as fearful to try new things."

PLDI Impact:

- Increase in GIPA
- Skills & confidence building
- Realize potential

As a Peer Trainer …

- Facilitate & Mentor
- Highlight the Wisdom in the room
- Lead your own life = self-efficacy



Positive Leadership Development Institute™

Challenges for Peer Leaders

* Recruiting and supporting youth and women to attend training
* Maintaining ongoing connections & engagement: Now what?
* Changing hats?

Key Takeaways

- Provide opportunities for skills building
- Clearly define roles for peer leaders
- Meaningfully involve people living with HIV at all stages. Diversity is a strength!

Resources

1. How do PLDI trainings change people?" from PANBC on Vimeo: https://vimeo.com/114594196
2. PAN PLDI website: https://pacificaidsnetwork.org/training-leadership/positive-leadership-development-institute-pldi/
3. OAN PLDI website: https://oan.red/pldi/
4. Australia PLDI website: http://pldiaustralia.org.au/
5. Five practices of leadership: http://www.leadershipchallenge.com/

Discussion

Reminder:

Please type your questions into the text box at the bottom of your screen.

If your question does not get answered, please check back on the uploaded link (provided below). We will review and answer any remaining questions, and post alongside the recorded webinar.

The Webinar will be posted in the HRP Video Library:

https://www.youtube.com/channel/UCFNsy8viIjdvy9gB8M30M3A

IBP video library:

https://www.gotostage.com/channel/965084607443925509

Save the Date!

Canadian Association for HIV Research conference (CAHR) in Vancouver:

Developing a national action plan to advance the sexual and reproductive rights of women living with HIV

Thursday, April 26th: 1PM-4PM PST

Objectives:

- Present overview of Canadian Webinar Series and discuss key policy, programming, and research considerations
- Engage in inter-sectoral small group discussions regarding key action items to inform national action plan to advance the SRHR of WLWH

Contact Sarah Watt (sawatt@sfu.ca) for registration details!

Thank you!

For more information about the Canadian Webinar Series, please contact:

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Social Sciences and Humanities Research Council of Canada
Conseil de recherches en sciences humaines du Canada
Canada

World Health Organization
CHIWOS
BC WOMEN'S HOSPITAL+ HEALTH CENTRE
CRCPN
WOMEN'S HEALTH IN WOMEN'S HANDS COMMUNITY HEALTH CENTRE
human reproduction programme hrp research for impact
IBP Initiative
Scaling up what works in family planning/reproductive health

Closing Words

CHIWOS