"TOWARDS ABORIGINAL HEALTH AND HEALING

(TAHAH)"

PROJECT EVALUATION REPORT / MAY 2010

Vancouver Native Health Society

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1. Back ground

"Toward Aboriginal Health and Healing" (TAHAH) was developed as an innovative treatment initiative that aimed to reduce disparities in HIV care and treatment through community-based initiatives, which built on experiential knowledge, community resources and strengths, and peer health advocacy. The project aimed to 1) reach HIV positive Aboriginal peoples living in the Inner City who were not accessing care and treatment through peer-based outreach programs and peer networking; and 2) to link HIV positive Aboriginal peoples with a holistic, comprehensive HIV prevention, care and treatment program which included not only medicine provision and treatment of the physical, but social, emotional, and spiritual support and advocacy through a part-time nurse, part-time social worker and community health advocates.

TAHAH program concomitantly addresses historical and cultural barriers and delivers primary health care / HAART¹ to marginalized, urban Aboriginal peoples – something that no other program in British Columbia currently offers with positive clinical and psychosocial outcomes.

Our project adapted the community-based model of care that Dr. Paul Farmer and colleagues used in resource poor settings of Haiti and in inner city communities of the USA (see original application for sources). Specifically, we adopted the peer model of care – where local, experiential members of our community received intensive training and capacity building, empowering them to work in their own communities, sharing personal strengths, knowledge and experience with living with HIV. They are longterm members of the community and can relate to participants who they might have shared histories and cultures with – including experiences with addictions, ARV²s, discrimination in the mainstream health care system, and living with extreme economic constraints. Our community health worker advocates, who themselves were often experiencing challenges with housing, addictions, and poverty, have been engaged in part-time work at VNHS³ through TAHAH since 2006. This is a significant commitment to their work, especially in a community that is characterized by high levels of staffing turnover. We are proud of their accomplishments with our team and agency; we owe the success of our project to their dedication, experience and skills in reaching out to highly marginalized participants from mainstream healthcare services.

This document provides some information on the TAHAH experience, challenges and lessons learnt based on the evaluation made and according to the template given by Public Health Agency of Canada (PHAC).

Information on Evaluation

This evaluation co-developed alongside of our program proposal has been supported since the onset at various stages by Dr. Treena Orchard (PhD), Dr. Mark Tyndall (MD ScD FRCPC), and Dr. Denielle Elliott (PhD). Staff (Denise Woodley, Monica Kumar, Doreen Littlejohn, Dr. David Tu, and Lukas Maitland) and included the evaluation by collecting and tracking clinical markers and psychosocial changes for our participants.

Both qualitative and quantitative methods have been used in this evaluation. The qualitative approach consisted of the questionnaire and interviews which were conducted during the evaluation.

To reflect the comprehensive and holistic model of our program, our evaluation includes a clinical record evaluation, interviews, and peer-evaluations. Our original planned evaluation (developed alongside of our

¹ HAART: Highly Active Anti-Retroviral Treatment

² ARV: Anti Retro Viral

³ VNHS: Vancouver Native Health Society

very initial application for funding) was not sustainable due to work demands of our staff, lack of enough resources, and the fact that our evaluators have moved to new positions in various locations.

2. Summary of Project Accomplishments

As originally proposed, our program facilitates access to primary healthcare, diagnosis by infectious disease specialists, treatment and social support at the Vancouver Native Health Society Clinic, the Positive Outlook Program (POP) which is HIV/AIDS multi-service program, and other community resources.

Primary Goal

For the large part, our focus has been on supporting our participants in accessing primary healthcare, infectious disease specialists, mental health support, harm reduction, treatment/ counselling services, social housing, income assistance/ employment, education/ leadership opportunities, reconnection with family/ home communities, and improved social relationships (among others) with the overall aim to assist participants to build a strong foundation of wellness and strength.

Activities:

Our activities evolve around an intensive one-on-one model of care that focuses on patient-centered care and autonomy. We aim to empower our APHA¹ participants with education, support, and peer-counseling to make informed decisions about their health and well being.

In this connection, medical services provided more than primary care so the community members connect with one another, cementing social relationships within the community as well as the service providers. Aboriginal participants reported that in the DTES they feel trust, respect and stability through their relationships with the staff. The social spaces and the convenience of location that these services provide could meet their basic needs. All aboriginal people who were interviewed reported a high degree of satisfaction with their care teams as well as their level of involvement in their care plans. Incorporating aboriginal healing practices into existing health services was another approach that the aboriginals strongly supported. The Royal Commission on Aboriginal Peoples highlighted that increasing the role of traditional medicine and healing in the lives of Aboriginal peoples is critical not just for good health but also in relation to the self-determination of aboriginal people.

For the large part, we were able to complete our goal. We have worked with participants to assist them in accessing care, improving their general well being, social conditions and physical health, notably engaging them with HIV care/ treatment.

Secondary goal:

Our secondary goal was to continue training, supporting and building capacity among our experiential community health advocates and APHAs as peer counsellors.

Activities:

Three HIV positive Aboriginal people were hired and trained to work as *community health advocates*. These individuals participated in training in 2006 and 2007 that included harm reduction prevention, basics in HIV treatment (types of medications, side effect management, the need for adherence in ARV therapy), confidentiality, emotional support, self-care/professional boundaries, and HIV/Hepatitis C prevention. The peer health advocates, respected in our community for their shared histories and common understandings of issues not only pertaining to Aboriginal health, but also to the specifics of the Downtown Eastside community, built on their inner strength, knowledge and empowerment to assist their

¹ APHA: Aboriginal person living with HIV or AIDS

own communities. Under the guidance and supervision of the social worker, they connected with APHAs living on the street and others currently not accessing services. They also assist with research projects at Vancouver Native Health Society, organize Positive Outlook Program membership focus groups/circles, and volunteer at the Women's Wellness group on Wednesdays. In this connection we had a research and training component which included:

- 1. field trips;
- 2. mapping of the communities and of specific issues and knowledge regarding health and research;
- 3. journaling and field notes;
- 4. visual ethnography "Life Beyond This";
- 5. focus groups and interview schedules;
- 6. coding and analysis;
- 7. conferences;
- 8. stories and plays;
- 9. learning about the topic;

In summary, the project successfully has assisted the majority of our participants to increase their CD4 count, decrease their plasma viral load, stabilize their income (primarily through PWD provincial assistance), and find secure/affordable housing. For more information please see the appendixes 2 and 3.

3. Project implementation Challenges

Overall we believe that TAHAH is a tremendous success but we did experience challenges. In summary some of the main challenges we faced were:

- 1. <u>Human resources issues</u>: e.g., hiring and keeping qualified and capable staff; not enough staff time to complete necessary work. For participants that are street involved, chronic and acute substance users, mentally ill, homeless, unemployed, and living in poverty this requires significant amount of human resource hours and thus we maintain a small caseload and restrict intake of participants to those most in need of our services.
- 2. <u>Financial resource issues</u>: e.g., project costs are higher than originally estimated; planned funding did not come through. We have attempted to maintain our original staffing team: a half time nurse, a half time social worker, and community health advocates (trained experiential peers). Due to funding cuts we were unable to sustain the nursing position but we were able to hire an elder for a few hours each month who offers support and counselling to our participants and the larger participant base at the Positive Outlook Program.

In summary, significant and ongoing wait times, organizations running at over capacity, and a lack of knowledge about aboriginal culture and lifestyle were the negative aspects to accessing health care in the DTES.

The project planning, implementation or process as well as administrative issues were not serious challenges. We did not have difficulty in reaching to the project's target population by volunteers. However, being able to maintain cultural safety or cultural sensitivity in the programming was a challenge. The number one issue the aboriginals discussed regarding their identity and accessing health services is discrimination, a multifaceted interplay between discrimination based on race, discrimination based on being HIV and/or HCV positive, and discrimination from lining in this neighbourhood.

4. Lessons learned

What did you learn about what worked?

Vancouver Native Health Society whose philosophy of care and support for urban Aboriginal peoples echoes our own – focusing on self-respect, autonomy, holistic health and well-being has supported our program. Our program adapted to our participants' needs. In part this is a result of a large degree of flexibility in our programming model. This flexibility allowed us to adapt our scheduling, appointments, and outreach to the needs of participants.

One-to-one time with participants, over many months, although fiscally expensive, proved to be critical in maintaining the relationships with our community health advocates and participants. The participants targeted for enrolment are individuals that are least likely to engage in services and whose eligibility for our program was based on their lack of engagement with mainstream healthcare. Engaging participants into primary health care services and AIDS care requires the development of therapeutic, trusting relationships – requiring time, patience and resources. Although we were limited by our budgeted expenditures, we believe this strategy produces very positive outcomes.

Lastly, we owe our successes in part to our larger philosophy of health and well-being that addresses the social determinants of health. Without safe and affordable housing, a reliable source of income, a family doctor who understands the complexities of addictions, mental illnesses and poverty-related illness, it is impossible to consider treatment for HIV/AIDS. Our approach, by helping participants find housing, address income (in order to make food/nutritional purchases), and facilitating appointments with primary care practitioners is key to our successes with our participants.

What did you learn about what didn't work?

Our philosophy of care, which respects participants' autonomy in their care, was not necessarily shared by other community and public health services to which we referred participants. Our approach to assist and support participants in making their own decisions regarding their health and well-being had positive outcomes but sometimes participants were not ready to begin treatment. Some doctors believed they could refer 'noncompliant' patients to our program and expected us to 'convince' them to start treatment and 'enforce' their pharmaceutical adherence. This was inconsistent with our philosophy of care to respect patients' decisions about their healthcare even when we may not agree. Health care providers too often focus on HIV as the main priority but patients may be prioritizing other parts of their lives, including other health issues like diabetes, nutrition, cancer, or arthritis. It was a challenge to convey our programs priorities and philosophy of care with various doctors who had different expectations.

In part, this matter speaks to a larger issue – that is the 'ethics of patient autonomy.' There is often great debate about the ability of patients to make 'the right' decisions about their well being when they suffer from untreated mental illnesses, developmental challenges/ acute addictions, or combinations of. It was an on-going challenge for our staff and those we collaborated with in trying to ascertain and understand decisions about refusing treatment, especially when patients were ill and/or dying.. The eligibility criteria for enrolment into our program were dependent upon a lack of ARV use and low CD4 counts. Primarily our participants were aware of their status for many years but refused treatment and care. These were amongst the most difficult people who were referred to the program and we could successfully convince them to get the treatment. In the future, we would request funding for a part-time consultant, on a per need basis, who specializes in ethics/cognitive impairments/patient autonomy.

Similarly, although our program valued the strengths, experiences and skills of the community health advocates, sometimes they felt undervalued within the larger organization. It has been a challenge for them to transition from being simply "participants" at the POP program to being valued, experiential peer support workers. The challenge has been felt by all – for our own team it involved a learning curve

regarding the amount of supervision required (or not required), the amount of support needed, and figuring out how to fit into our program. For the community health advocates they needed to get accustomed to new responsibilities of their positions, including self-care and support for one another in their work. Lastly, it was a challenge for the larger organization to recognize our APHAs as employees who had access to office space, and client files, that previously were inaccessible. This included negotiating appropriate workspace for them, access to computer space, and involving them in staff meetings. We were unable to sustain adequate training and support for our community health advocates. As experiential peer members of our community, they require support, on-going supervision, and regular up-dated training modules – largely a challenge due to a lack of human resources and funding shortages. Hiring peers as community health advocates requires significant resources in terms of staff support, training and supervision. Our social worker was stretched with basic administration, bureaucratic, and front-line work with participants.

Lastly, although we were pleased to receive funding in 2008-2009, to hire an elder, this component became a challenge to incorporate him into our programming due to inadequate funds. Unable to hire him to work a sufficient number of hours each month, his integration into our team was not as successful as we expected. Our own community health advocates did not access his services and, although he offered support to the larger organization, this became a challenge with our program.

What could you do differently in future projects?

We believe for future success an increase in cross agency communication regarding philosophies of care and how to collaborate affectively in providing best service to participants, even when philosophies of care differ.

We seek to incorporate cultural components from the onset and increase liaison with Aboriginal leaders in health regarding the best way to do this. Our community health advocates reported to us that they believed our collaboration and liaison process required improvement. Although we are situated on traditional Coast Salish territory, defining what constitutes "Aboriginal" healing practices is a challenge when working with very diverse, urban Aboriginal peoples, many who do not share cultures, histories, or languages. Our community health advocates reminded us that "pan-Indian" practices are not shared among all Aboriginal communities.

Lastly, we would try to involve the community health advocates more from the onset with patient enrolment, patient care, and support. As time passed in our project, we realized we could have expanded their rolls. More hours and more responsibility were requested by CHA with the eventual plan to exit income assistance and seek additional education. With additional training and support, CHA are capable and well-suited to take on more responsibilities.

5. Organization's capacity

According to the template provided by the Provincial Health Agency of Canada the below questions are answered as following:

Is your group stronger now than it was at the beginning of the project?

There is definitely a great change in the strength of the staff comparing to the beginning. We all have learned much about the community, their needs, how to respond to their needs and cultural issues. Besides, the staff is improved in their knowledge and skills after all training and researches done in this program. Our community health care advocates reported more self-awareness, increased personal responsibility for their health/ well-being and increased self-confidence in their community care and support workers roles.

Have you created a database to collect data?

No, there was no need since shared a database with the VNHS clinic.

6. What difference did it make that you did this work?

This past year the British Columbia provincial government announced that it was providing CA \$48 million dollars to address HIV/AIDS care for individuals identified as hardest-to-treat. Urban and off-reserve Aboriginal people are included in this proposal. Our program, originally developed based on community-based models of care in resource-limited communities, has clinical evidence illustrating its success; however, our program is not identified as a likely recipient for any part of the \$48 million dollars. Instead, the BC Centre for Excellence in HIV/AIDS, a research consortium whose focus is primarily research, with some care and support and little experience working with urban, or rural/reserve, Aboriginal communities. Additionally, to our knowledge, there are no Aboriginal researchers or staff, allocating the funds.

Twenty-four of our Aboriginal clients provide evidence of our successful project. Please note that three more individuals started our program last month and so full data not available at this time. Without the program, it is likely that these individuals would be critically ill, deceased, or suffers from the complications of advanced AIDS. We assisted them in finding secure and (often) supportive housing, stabilized their income assistance through PWD¹, and connected them with AIDS care specialists.

7. Short term Outcomes of the Non-Reserve First Nations, Inuit and Métis Communities Project Fund

To what extent did this project increased individual capacity to engage in healthy sexual practices amongst vulnerable sub-population?

FOR OUR PATIENTS: Some FOR OUR CHA: GREAT

To what extent did this project increased individual capacity to engage in injection drug use harm reduction practices amongst vulnerable sub-population?

PATIENTS: Some CHA: GREAT

To what extent did this project increased access to and use of diagnostic, care, treatment and social supports for those infected with HIV and other related diseases and conditions?

PATIENTS: Great CHA: Great

To what extent did this project-increased capacity to provide sexual health and/or injection drug use harm reduction initiatives amongst service providers?

N/A.

¹ PWD: Persons With Disabilities

Appendix 1

Table 1: Clinical outcomes

Client	Intake	CD4 intake (First reading closest to intake)	CD4 (exit or current)	pVL intake	pVL (exit or current)	ARVs intake	ARVs now
100195 (Deceased: 3/4/2008, AIDS)	?	40	90	404		-	-
100249	28-Feb- 07	180	140	68		NO	YES
101254	7-Jan-07	10	620	45	35	NO	YES
101446	18-Sep- 09	90	430	3222	3375	NO	Moved
102005	22-Aug- 07	10	120	1000010	35	NO	NO
103299	2-Jan-08	240	360	35	0	NO	YES
105843	7- Jan- 07	20	210	45	35	NO	YES
105884	29-Mar- 08	150	220	72400	45754	NO	YES
106402	14-May- 09	50	110	185129	0	NO	YES
107272	31-Jan- 08	90	170	425	35	NO	YES
108732	16-Oct- 08	340	300	45	0	YES	YES
109531	24-Nov- 09	290	150	379000	500000	NO	YES
109597	23-Feb- 07	320	160	35	35	NO	YES
110008	8-Mar-07			35200	118	NO	YES
110246	15-Feb- 07	180	500	45	35	NO	YES
112088	12-Apr- 07	240	350	35200	0	NO	YES
112261	21-Aug- 08	10	30	48200	35	NO	YES
112375	14-Feb- 08	400	750	45	35	YES	YES
113367	12-Jun- 07	130	250	1430	45	NO	YES

Client	Intake	CD4 intake (First reading closest to intake)	CD4 (exit or current)	pVL intake	pVL (exit or current)	ARVs intake	ARVs now
113571 (Deceased: 7/20/2008, AIDS)	7-Nov- 07	20	N/A	75100		NO	NO
116259 (Deceased: 7/17/2008, AIDS)	30-Oct- 07	170	N/A		N/A	NO	NO
117044	2- Apr- 08	510	830	594	35	-	YES
118293	9-Nov- 09	10	90	170540	1866	NO	YES
118298	16-Oct- 08	60	220	861000	181	NO	YES
120128	3-Apr-07	120	420	104455	35	NO	YES
120193	1-May- 07	140	310	45	35	NO	YES
120573	3-May- 07	220	290	59599	35593	NO	NO
121845	6-Sept- 09	30	90			-	YES

Appendix 2 Table 2: Psychosocial outcomes

Client	DOB	Intake	Exit	Housing intake	Housing now	Income intake	Income now	Addiction support
100195			Decease d: 3/4/2008 , AIDS					
100249	27- Nov-76	28-Feb-07		NFA	Recover y	PWD	PWD	Drug court tx
101254	10-Jan- 76	7-Jan-07		NFA	S.Apt	PWD	PWD	Methadone
101446	9-Jan- 68	18-Sep-09		NFA	SRO	PWD	PWD	Treatment
102005	16-Jan- 68	22-Aug-07		NFA	S-SRO	PWD	PWD	
103299	5-Sep- 71	2-Jan-08		SRO	Apt.	PWD	PWD	Referred.
105843	27-Apr- 60	2-Jan-07		SRO	S-SRO	PWD	PWD	Counselling
105884	9-Aug- 73	29.Mar.08		NFA	Apt.	PWD	PWD	
106402	28-Oct- 64	14-May-09		NFA	S-SRO	PWD	PWD	
107272	30- Sep-63	31-Jan-08		SRO	S-SRO	PWD	PWD	Referred to tx.
108732	6-Mar- 61	16-Oct-08		SRO	S-SRO	PWD	PWD	
109531	24-Oct- 79	24-Nov-09		NFA	Apt.	IA	PWD	Contemplating
109597	4-Jun- 75	23-Feb-07		NFA	Apt.	PWD	PWD	
110008	24- Feb-79	08-Mar-07		SRO	Care facility	PWD	PWD	
110246	14-Oct- 67	15-Feb-07		Apt.	S-SRO	PWD	PWD	
112088	26- Feb-84	12-Apr-07		NFA	Apt.	IA	PWD	methadone
112261	21- Mar-66	21-Aug-08		NFA	Apt. (lux)	PWD	PWD	
112375	19- Dec-80	14-Feb-08		NFA	Apt. with partner	PWD	PWD	methadone
113367	3-Apr- 80	12-Jun-07		NFA	S-SRO	PWD	PWD	
113571	6-Oct- 82	07-Nov-07	Decease d: 7/20/200 8, AIDS			IA	PWD	

Client	DOB	Intake	Exit	Housing intake	Housing now	Income intake	Income now	Addiction support
116259	25- Dec-64	30-Oct-07	Decease d: 7/17/200 8, AIDS	Apt.		PWD	PWD	
117044	07-Jun- 56	02-Apr-08		SRO	S-SRO	PWD	PWD	
118293	5-Nov- 81	9-Nov-09		SRO	S-SRO	IA	PWD	methadone
118298	26- Aug-69	16-Oct-08		NFA/SRO	S-SRO	IA	PWD	Counsellor
120128	1-Dec- 75	3-Apr-07		SRO	S-Apt	PWD	PWD	
120193	24- Mar-71	1-May-07		SRO	S-SRO	IA	PWD	
120573	11- May-66	3-May-07		NFA	Apt.	IA	PWD	Methadone
121845	04- May-72	11-Mar-09		NFA	Apt.	PWD	PWD	

Appendix 3Table 3: Activities

Activities	Status Update
Worked with existing participants to improve their overall health status	Care and Support As committed, we assisted participants in making health related appointments, social welfare/ housing appointments, and accompanied clients to appointments. We made hospital/ home visits, and outreach participants in person/ by phone.
	TOTAL participants from the onset of our program: 30.
Participants accessing primary care	All participants in our program connected with a primary health care physician and all completed routine blood tests.
Participants accessing HIV specialist care and other medical specialists	This quarter 50% of current caseload saw specialists. Of 30 participants, 1 person refused medications, 22 people on ARVs, and 3 deceased. Currently, 3 participants struggle with adherence but continue to develope plans to increase adherence.
Improved housing – transitioning participants from no fixed addresses to apartments, supportive single room occupancy hotels, or into treatment facilities.	All current participants are housed in a hotel room; 11 live in supportive SROs, 3 living in social housing, 8 in hotels/apartments. Of those not in social housing, most completed applications for housing (often many applications). All participants are accessing maximal income assistance.
Social connections: Reconnecting with home and family	1 people attended detox and 1 person living in recovery home. 2 participants connected with home communities. 2 participants returned for visits home. 1 woman has reconnected with children in care.
Provide support to participants for increased access to community services	Themes addressed in community service referrals: Health, Housing, Income assistance, Harm Reduction strategies, Juridical-legal, Daily needs, HIV Prevention, and Psycho-Social support. Connected all participants with GP, all participants visited a HIV specialist this quarter and completed regular blood work.
Participant accessing elder support (if desired)	50 % of all TAHAH participants engaged with elder one-on-one.
CHAs facilitate members meeting and talking circles with the Positive Outlook Program.	Monthly talking circles (3 this quarter) with average attendance of 10-20 people, 5-15 of whom are TA-HAH participants.