

**BEYOND THE HORIZON:
THE GREATER INVOLVEMENT OF PEOPLE LIVING WITH HIV/AIDS IN
WESTERN CANADIAN COMMUNITIES**

by

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ABSTRACT

The implementation of the Greater Involvement of People living with HIV/AIDS (GIPA) in northern communities can have many challenges. This research looks at the process around the implementation of GIPA in these communities. This includes looking at GIPA within the context of the definition of rural and north, and the social determinants of health that impact populations infected and affected by HIV/AIDS.

Using focus groups, service providers in western Canadian communities were asked specific questions regarding the implementation of GIPA in their communities. By applying this qualitative method I was able to explore the research using an Autoethnographical lens. Stories were shared and ideas were generated for strategies to address the issues around implementing the GIPA principle.

A thematic analysis looked at the importance of GIPA; the benefits of the involvement of people living with HIV/AIDS (PHA's); the challenges of working with PHA's; the existing barriers to PHA involvement; skills and capacities; and, the assistance needed for successful implementation. The results indicated that in smaller northern and rural communities the barriers exceed the capacity of AIDS service organizations to use GIPA to its greatest potential. Recommendations of this study include: advocating for a more supportive government; increased funding opportunities; and determining a way to share the experiences of GIPA among other rural and/or northern Canadian communities.

A little bit of this...a little bit of that...

How wonderful it is that nobody need wait a single moment before starting to improve the world. ~Anne Frank

Social work is a profession that aims to increase the well-being of people, both individually and collectively. Its roots are entrenched in a comradeship to achieve social justice. It is fueled by compassion, strength and determination. This is what I think of when I look back at the many years of the AIDS movement in North America. So many people have fought valiantly for justice and equality for those living with HIV/AIDS. Throughout the years many of them have passed and others have picked up their torches and carried on the fight. This thesis is a venue for me to not only challenge myself to learn new things, but also to self-reflect on my personal experiences and knowledge around HIV/AIDS. My opinions and biases are paramount to acknowledge in this profession as I strive to be a catalyst for change within the movement and the community work that I engage in.

I have chosen this topic because I have a personal connection to it. My knowledge around HIV/AIDS is very broad based and subjective. I have been HIV positive for 17 years. I have been involved in the AIDS movement for more than a decade. My involvement includes being a part of local, provincial and national organizations and groups.

The first organization I became involved with was in 2001 in Prince George, British Columbia. It was then known as AIDS Prince George. Since then they have changed their name to Positive Living North: No kheyoh t'sih'en t'sehena Society. I

volunteered there before I accepted a job as the peer support worker. It gave me an opportunity to learn more about the dynamics of the disease and how it affected different populations in unique ways. I have always been an eager student to learn more about things from different perspectives. I know that my experiences living with HIV are not the same as others, though we may share similarities. As I mentioned earlier, HIV/AIDS affects populations differently. Examples include, but are not limited to: Aboriginal, non-Aboriginal, women, men, seniors, youth, heterosexual, and same-sex attracted. Environment and geography should also be included in this breakdown. I think that every population of people living with HIV/AIDS has their own set of challenges. Not one is necessarily more significant than the other.

Since Positive Living North, I have been involved in groups provincially and nationally. I was on the board of directors for four years at the Canadian AIDS Society in Ottawa, Ontario. The Canadian AIDS Society acts as national voice for people living with AIDS and their allies. Its membership consists of more than one hundred AIDS service organizations across Canada. I was also a Canadian AIDS Society representative on the Canadian Treatment Action Council in Toronto, Ontario. I have had the opportunity to meet a great many people, from all walks of life, at the forefront of this movement.

I was also a representative on the board of directors of the Positive Women's Network based in Vancouver, British Columbia. They provide services to women both locally and provincially. It provided me an opportunity to take a closer look at, and become more versed around the issues that HIV positive women encounter. Some

of the challenges women face includes biological vulnerabilities, sexual stigma, power imbalances and invisibility among the infected.

In 2005 I started an organization in Prince George, British Columbia known as the Prince George New Hope Society. It was created for and by street involved women and youth. HIV/AIDS was just one of the many issues addressed. Over the years I have been involved in numerous committees and research projects that have added to my experiences, given me a voice, and shaped my practice. I feel honoured to have had the experiences that have shaped me and I remain very aware that not everyone has had such privilege.

In regards to my opinions, that is just what they are...my opinions. I am careful not to state anything that I cannot reinforce with either anecdotal or academic reference. By no means am I perfect or knowledgeable in all things. I am continually learning new things. It is important for me to be able to see beyond the things that I have learned because that is when growth happens. My thesis is based not only around my knowledge, but around the knowledge of others. I can only share what I have learned throughout my journey thus far. There is a whole wide world of knowledge out there ready for me to access and share with people. I do this to not only help myself, but to help those who have not found comfort in living within the construct of HIV/AIDS. Hopefully my research will be a valuable academic instrument that may be used by students and organizations across Canada.

A moment of silence...

a sheet of heartfelt dedication...

for those who fought valiantly and died of AIDS.



TABLE OF CONTENTS

ABSTRACT	iii
TABLE OF CONTENTS	viii
GLOSSARY	xii
ACRONYMS	xv
ACKNOWLEDGEMENTS	xvii
INTRODUCTION	xviii
CHAPTER ONE	1
Human Immunodeficiency Virus (HIV)	1
The Beginning	3
Statistics	4
HIV and Social Work	5
Greater Involvement of People Living with HIV (GIPA)	10
GIPA and the Northern Context	12
Definitions	12
The Challenges of HIV in the Rural and Northern Context	15
Moving Forward	18
CHAPTER TWO	20
GIPA Literature Review	20
Implementing GIPA	20
Benefits of GIPA	22
Challenges of GIPA	23
Social Determinants of Health	26
Income and Social Status	27
Social Support Networks	27
Education and Literacy	28
Employment/Working Conditions	29
Social Environment	30
Physical Environments	31
Personal Health Practices and Coping Skills	32
Healthy Child Development	32
Health Services	33
Gender	34
Culture	35

CHAPTER THREE	37
A Comparative Analysis	37
Study One.....	37
Study Two.....	39
Study Three.....	40
Comparative Analysis	41
CHAPTER FOUR	45
Research Methodology & Design	45
Introduction to Research	45
Research Method	47
Sample	50
Focus Groups	51
Process of Validation	53
Process of Analysis.....	54
CHAPTER FIVE	56
Findings	56
Whitehorse, Yukon.....	56
Grande Prairie, Alberta.....	61
Grande Prairie.....	64
Fort McMurray.....	65
Peace River	65
Smithers, British Columbia.....	69
Prince George, British Columbia.....	73
A Study Analysis.....	77
Importance of GIPA	77
Benefits to PHA Involvement.....	78
Challenges in working with PHA's	78
Barriers to PHA Involvement	79
Skills and Capacities.....	79
Assistance needed.....	79
CHAPTER SIX.....	81
Conclusion.....	81
REFERENCES	87
APPENDIX A.....	94
Focus Group Research Questions	94

Informed Consent to Participate in Research	96
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Till We Meet Again

Gone but never forgotten
Faces that we will remember forever
For the lives they had were not who they were
Friend, sister, brother, they were and will always be
Glitters that shine bright in the night sky
Waiting...
For the comfort of our prayers
The streets were only but a home for their lost souls
Wandering aimlessly
Searching for something or someone to believe in
They were warriors
Men and women standing in the face of a nation risen against them
Their stories will not be untold
Stamped out in the ashes of their deaths
This is not goodbye
Only till a moment in time when we meet again

Christal Capostinsky
April 2007

GLOSSARY

Advocacy: according to McClelland & De Pauw (2010), advocacy is “a process aimed at changing the attitudes, policies, laws and practices of influential individuals, groups and institutions for the betterment of people affected by the issue” (p. 53).

Client – according to the Canadian Association of Social Workers (2008), a client is “a person, family, group of persons, incorporated body, association or community on whose behalf a social worker provides or agrees to provide a service or to whom the social worker is legally obligated to provide a service”.

Community – A sense of belonging to something as a collective. This can be a place where people reside (a location) or something that requires participation. Some examples of community include towns, cities, ethnicities, common interest groups, and institutions.

Culture— culture has many complex definitions. I have learned that it is not just one thing or one way of understanding something. Culture is different for everyone as individuals and groups. It is the beliefs, values, traditions, community, skills, language and all the things that allow us to thrive in our lives. It reflects our history and traditions, as well as societal norms.

Discrimination – an outcome of stigma. According to a report from CATIE (see acronyms p. 13), “when people act on their prejudice, stigma turns into discrimination” (2010, p. 22).

Endemic – belonging or native to a population or region.

Harm reduction – for the purpose of this document, harm reduction means strategies for reducing harm from drugs and/or alcohol. Examples of this include

needle exchanges, injection sites and methadone programs and designated driving campaigns.

Heterosexism – the act of discrimination against homosexuals by heterosexuals with the belief that heterosexuality is the only acceptable choice.

Homosexual – This term was used in the research questions. This is no longer a politically correct term, especially when it relates to how people identify themselves. The terms that are currently used in its place are lesbian, gay, men who have sex with men (MSM), bisexual, transgender and questioning (LGBTQ).

Informed consent – according to the Canadian Association of Social Workers (2008), informed consent is a “voluntary agreement reached by a capable client based on information about foreseeable risks and benefits associated with the agreement” (p. 14). As social workers are bound by a code of ethics, informed consent should not be exploitive or harmful to the person giving consent. I.e. a person under the influence of drugs and alcohol cannot give informed consent.

Meaningful engagement—letting go of biases and expectations and truly having an open mind while engaging with others. Meaningful engagement is about listening to what people have to say and valuing their stories without manipulating their words into your own interpretation for your own purpose. It involves no exploitation.

Numeracy – the ability to work with numbers.

Populations – those persons who identify with specific people. i.e. Aboriginal, drug users, women, men, youth, etc. HIV affects every population in unique ways.

Poverty: the condition of lacking basic human needs such as food, clothing and shelter.

Skype – a software application through Microsoft that allows people to communicate with people through computers (phone calls, video calls, and instant messaging).

Stigma – a socially constructed phenomenon that is based on devaluing a person based on distinguishing characteristics set apart from acceptable social standards.

ACRONYMS

For all the various fields across the professional plane, we use acronyms. It can be frustrating for those who are newly walking into it, but it is the way of life in the social sciences industry. We cannot get around it. Sometimes I will be explaining something to someone and then the question is asked. "What does that stand for?" The challenge is not remembering the acronyms, but remembering what they stand for. I say this with great humour as I am confident that it has happened to many others before me.

APN+ - Asia Pacific Network of People Living with HIV/AIDS

APCASO - Asia Pacific Council of AIDS Service Organisations

AIDS – Acquired Immune Deficiency Virus

ASO – AIDS Service Organization

BCCDC – British Columbia Centre for Disease Control

BC-CFE – British Columbia Centre for Excellence in HIV/AIDS

CAS – Canadian AIDS Society

CDC – Centre for Disease Control

CATIE – Canadian AIDS Treatment Information Exchange

CHLN - Canadian HIV/AIDS Legal Network

CASW – Canadian Association of Social Work

CMA - Census Metropolitan Area

CA - Census Agglomerations

CBO – Community Based Organization

CCDIC – Centre for Communicable Diseases and Infection Control

DNA - Deoxyribonucleic acid

GRID – Gay related Immunodeficiency

GIPA – Greater Involvement of People Living with HIV/AIDS

HIV – Human Immunodeficiency Virus

IDU – Intravenous Drug Use/User

KS - Kaposi's sarcoma

MIPA – Meaningful Involvement of People Living with HIV/AIDS

MSM – Men who have sex with men

NGO – Non Government Organization

OHTN – Ontario HIV Treatment Network

PCP - Pneumocystis carinii pneumonia

PLHA/PLHIV/PHA – Person(s) Living with HIV/AIDS

PHAC – Public Health Agency of Canada

PLN – Positive Living North

PLNW – Positive Living North West

PHAC – Public Health Agency of Canada

RST – Rural and Small Town

RNA - Ribonucleic acid

UNAIDS - Joint United Nations Programme on HIV/AIDS

ACKNOWLEDGEMENTS

The past year and a half, since my journey towards achieving my Master of Social Work began, has been full of chaos for me. I have gone through periods of doubt, periods of vigor, and extensive periods of searching for motivation. My friends and family have always been there to cheer me on during these times. I need to acknowledge the people who have made this part of my academic journey possible for me.

Si (with her whips and chains)
 My thesis committee
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 Diane
 Halijo
 First Friday Group
 My Facebook Groupies
 Jamie, Jennifer, Shelly & Alana for the great pics when I thought 'all was lost'
 My supportive colleagues at work
 Pacific Leaders through the BC Public Service
 Positive Living North
 Positive Living North West
 Blood Ties Four Directions Centre
 HIV North
 My sister Carrie ("You can do anything you set your mind to and don't let anyone tell
 you different")
 &
 Mom & Dad (Thanks for having faith in me)

A special thank you to my son Gabriel and fiancé Danton who have been there for me through the late nights, hysteria and nothingness. I love you both for giving so much up to support me through this.

INTRODUCTION

"AIDS. Probably the most single most powerful word of our era for evoking intense individual and societal responses. The reasons for this are often cited: fear, death, stigmatization, prejudice, discrimination, illness, suffering" (Somerville & Gilmore, 1992, xi). For thirty years society has not moved past this ideology that puts more and more people living with HIV/AIDS (PHA's) at risk of isolation and death. How can we move forward when the very thought of disclosure is a vital threat to the well-being of PHA's globally? I talk about AIDS as though it is an everyday occurrence in the world. Well it is. More than 33 million people in the world are infected with HIV and more than 5,400 people die every day from AIDS (World Vision Canada, 2012).

Today HIV appears to attract more attention than AIDS because it is said that we have moved to a place where it is seen as a chronic disease and less people are dying of AIDS due to medications available on the market. Do not let this fool you. People are still dying of AIDS every day around the world. Many of them still die in isolation and with shame. If I can change this for one person with the work that I do, then I will have honoured those who have passed and those who are still fighting the fight in this politically challenged world that we live in. I write from experience in working in the HIV/AIDS movement for more than a decade and living with the disease for 17 years.

People living with HIV in northern communities face different barriers, not only as positive people, but also in regards to participating in HIV programming in their communities. In a report by the Ontario HIV Treatment Network (OHTN), one man

from a northern town said “It’s totally different than living in a large city where you have options, here you only have one option and that’s it. That’s a big barrier for a lot of people, disclosure” (2007, p. 21).

In exploring this different reality, this document will provide an overview of HIV in Canada. It will look at HIV within geographic locations, as well as discuss the social determinants of health. All of these things relate to the Greater Involvement of People living with HIV/AIDS (GIPA) principle and the barriers that communities face during implementation. By providing a literature review, I will look at the different facets of implementing GIPA. Throughout the decades of the HIV/AIDS movement, we have definitely seen a powerful stance taken by people living with HIV around the world. They continue to be a part of a vast social movement that is inclusive to medical breakthroughs, program development and implementation, policy change, and education and awareness. If only this could be channelled more effectively into the northern context.

Though my general research topic is HIV/AIDS, I have narrowed it down to implementing the GIPA principle from the perspective of service providers. In order to gain a better understanding of how geographical location affects people living with HIV/AIDS, I decided to focus on northern and rural communities in western Canada. My research question is: *How is GIPA implemented in northern and/or rural Western Canadian communities in spite of barriers to services?* The title of my research project is *Beyond the Horizon: The Implementation of the Greater Involvement of People Living with HIV/AIDS in Northern and/or Rural Canadian Communities from the Perspective of Service Providers.*

I would like to quickly make mention of the pictures used in this document. Originally when I went out and conducted my research it was during July, August and September. These months are considered the summer season. I had taken many pictures while travelling to these communities. Unfortunately due to technical reasons, and my lack of care, I lost all the photos. Naturally this created instant panic because the pictures provide a reflection of the northern context. Thankfully, I had friends come forward with pictures of their own that I was able to use. This is not ideal, as the storytelling from the photos will not be the same. At the very least, the reader should get a sense of what is meant by north. I was also able to find some pictures on the internet that I used with permission. The reason why I am bringing this up is that in some of the pictures there is snow. In the regions where I conducted my research, there is snow for approximately 6 to 7 months of the year. Hopefully this helps you to understand the results of my research a little better. It creates different challenges for people living with HIV/AIDS in north. Sometimes the weather, compounded with geographic location, can be burdensome.

I love pictures and I enjoy taking them. Pictures tell stories and are a great Autoethnographical tool. Sometimes pictures tell the stories that words cannot. (Capostinsky, 2013).

"Visual data complement textual data and sometimes supercede the benefit of textual data because visual data make long term impressions on viewers" (Chang, 2008, p. 109).

In chapter one I will introduce you to HIV/AIDS and the history behind it. What is this disease and where did it come from? I will share some alarming statistics about infected populations and how social work plays a role within addressing the issue of HIV/AIDS. Who is responsible for doing something about it and what can be done?

Lastly, I will introduce you to the greater involvement of people living with HIV/AIDS (GIPA). What is GIPA and why is it important? There are so many questions to ponder. Not one is more important than the other. They all share one thing in common: an epidemic that is relentless in its path of destruction.

CHAPTER ONE

Human Immunodeficiency Virus (HIV)

HIV is the Human Immunodeficiency Virus. Acquired Immune Deficiency Syndrome (AIDS) is not the same as HIV. Some people develop AIDS from HIV if their immune system becomes deficient plus they have an opportunistic infection as listed from the Centre for Disease Control (CDC) in the United States (Stolley & Glass, 2009). There are many types of opportunistic infections related to HIV/AIDS. Opportunistic infections are viral, fungal, bacterial and protozoal diseases (Averting HIV and AIDS, "HIV Opportunistic Infections", 2013).

In Canada, the equivalent to the CDC would be the Centre for Infectious Disease Prevention and Control (CIDPC). It is a branch of the Public Health Agency of Canada that monitors the HIV epidemic in Canada. British Columbia has the BC Centre for Disease Control (BCCDC), an agency through the Provincial Health Authority. British Columbia is also home to the BC Centre for Excellence in HIV/AIDS. The Centre for Excellence has been a leading institution for developing, monitoring and disseminating research and treatment programs for HIV.

For some people it takes years to develop symptoms of HIV as we now have what is known as antiretroviral therapy to suppress the virus. Today, in 2011, it is no longer seen as a death sentence to be living with HIV. Is this really the reality for everyone in all populations? Is it fair or even accurate to make a blanket statement like this? It sounds great in theory, but it is deceptive. So much has been done over

the past 30 years. We have come so far and the last thing we want to do is minimize the seriousness of the issue.

Though the medical responses to HIV/AIDS have come far over the years, people need to know that AIDS does still affect many people. Since 1983 approximately 21,000 people in Canada have died while infected with HIV or AIDS (Public Health Agency of Canada, 2007). Though many people are now living longer with the virus, so many continue to succumb to AIDS related illnesses because they lack the social determinants of health.

It is shocking that in such a prosperous country like Canada people continue to die because of the lack of basic life necessities and access to healthcare.

The truth is that Canada – the ninth richest country in the world – is so wealthy that it manages to mask the reality of poverty, social exclusion and discrimination, the erosion of employment quality, its adverse mental health outcomes, and youth suicides. While one of the world's biggest spenders in health care, we have one of the worst records in providing an effective social safety net (Mikkonen & Raphael, 2010, p. 5).

Generally speaking, AIDS affects people living in poverty and addiction: people with limited or no access to medications, or those who are unable to stabilize in their environment to create adherence to medications. In some cases, the body is just not resilient enough to continue to support the virus. One journal states “there is growing evidence that a high proportion of the ongoing AIDS mortality in the developed world is due to poor access to therapy among disadvantaged or marginalized populations” (Wood et al., 2003, p. 2420). Yet with all the research indicating this, our leaders still fail to recognize this and act on it.

The Beginning

AIDS has a long history around the world. It has transitioned over decades from the terms 4-H disease (Haitians, homosexuals, hemophiliacs and heroin users) to GRID (gay-related immunodeficiency) to AID (acquired immunodeficiency disease) to HIV/AIDS (human immunodeficiency virus/acquired immunodeficiency syndrome). It has been written that AIDS stems from various types of African monkeys whose genetically mutated DNA and RNA infected at least 19 people between 1950 and 1972 (Engel, 2006). People were dying all over the world from what is now known as *Pneumocystis carinii* pneumonia (PCP) and Kaposi's sarcoma (KS) (2006). These are categorized today as opportunistic infections. At the time it was unknown why people were dying, only years later when looking back on these cases were they able to identify it as early cases of AIDS. According to the Public Health Agency of Canada, the first diagnosis of AIDS was in 1981 in the United States, in Canada it was a year later (2007).

**Ignorance
Equals
Fear**

What prompted the research and medical world into action was the rampant infection rate among gay populations in San Francisco and New York in the 1980's, as well as the pure panic from American citizens who were afraid they could get it from holding hands, sharing glasses, swimming pools, busses and restaurants (Engel, 2006, pp. 25-30). There was so much stigmatization towards infected populations at this time. Risk groups and target populations were identified as high risk of contracting the disease. These groups became known as the "Four-H Club": homosexuals, Haitians, heroin addicts and hemophiliacs. It was further portrayed

that people 'outside' of these groups were safe; yet, people still lived in fear. However, this left out recipients of blood transfusions and babies born in utero (Grmek, 1990). When I think of this disease in the world as it is today, one would think that given time people would come to understand the disease and that the stigma and discrimination would lessen. One would think that people would be more educated in light of all the worlds' medical advances. Sadly this is not the case. People fear what they do not know.

Statistics

There are many statistics available on the World Wide Web. It is important that when looking for statistics to go to sources that have accurate information; hence, for this paper, I will often refer to the Public Health Agency of Canada (PHAC). The following statistics were released in 2008. There have been no updates released at this time.

According to PHAC, "approximately 65,000 Canadians were estimated to be living with HIV infection at the end of 2008" (2010, p. 6). Men who have sex with men (MSM) continue to be the highest risk of transmission for HIV and account for 44% of new infections (2010). Women account for about 22% of the national total and represent 26% of new infections nationwide (2010).

"Aboriginal people continue to be over-represented in the HIV epidemic in Canada and represent about 8.0% of all prevalent HIV infections" (PHAC, 2010, pg. 5); however, they only represent 3.8% of the entire Canadian population (2010). Therefore, the "overall new infection rate among Aboriginal people is about 3.6 times higher than among non-Aboriginal people" (2010, pg. 6).

Many of the northern communities in BC and Alberta comprise of Aboriginal populations. This is important to remember when looking at the barriers to Greater Involvement of People Living with HIV/AIDS. Culture and geographic location contribute to its implementation within the Aboriginal population. As for people who are living with HIV in Canada and are from countries where HIV is endemic, they represent 14% of the HIV infected population

(PHAC, 2010).

HIV and Social Work

What is social work? Social work is about working with people, communities and systems to create social justice and provide caring and supportive environments. I also refer to it as social work caring. When I

decided to enter the field of social work it was

because I had the passion and commitment to

help others. During my educational journey I came to understand that most of the

other people in the field shared the same values. Together we learned about

addiction, mental health, poverty, government, disabilities, violence, abuse, trauma,

inequality and all the things that create marginalization and facilitate oppression. I

began to understand how difficult it was for many people to exist in a world of

patriarchy, deficient policies, racism, stigma, fear, mainstream culture and class

segregation. I had experienced many of these earlier in my life during a time when I

was trying to “find myself”, but I never understood it quite as clearly as when I was on

A very heartwarming experience I had last week was when I was car shopping online and came across a prospective vehicle. A member was in the drop-in centre and knowing he has an abundance of knowledge with regards to buying and selling vehicles, I asked his opinion. He was thrilled and we spent the next hour sitting together on the computer car shopping and him telling me all the tricks and the trades of buying vehicles. It was informative, fun and a bonding moment (relationship building).

Focus group participant, 2012

my educational journey. Social work caring should not be discriminative or egocentric.

Earlier on in my educational journey, I took my experiential knowledge and used it to help others at street level in my community. I had lived through the devastation

In a national study conducted in 2003, tolerance toward people living with HIV was assessed.

The results of the survey show that stigma and discrimination continue to affect people with and at risk for HIV.

- 18% of Canadians felt that people who have HIV/AIDS should not be allowed to serve the public in positions like hairstylists.

- 44% of Canadians felt that people who have HIV/AIDS should not be allowed to serve the public in positions like dentists and cooks.

- 11% of Canadians felt that people who got HIV/AIDS through sex or drug use got what they deserve.

- 8% of Canadians felt that they could not be friends with someone who has HIV/AIDS.

- Six scenarios were used to create a "comfort scale"; one in 4 Canadians demonstrated a low level of comfort with HIV/AIDS, 41% demonstrated a moderate level of comfort and 35% had a high level of comfort.

(Canadian HIV/AIDS Treatment Information Exchange, 2010, p. 22)

of addiction, violence, homelessness and

disease. It was this journey that gave me the insight to help others still trailblazing down that path. Provincially and nationally I provided a voice for those who were not being heard. My passion and commitment was evident and I

immensely enjoyed all the work that I was involved in. Then a light went off in my head and I thought to myself that I could be doing so much more if I worked within a system that 'maybe I could change at a larger level'. So I

decide to work for the provincial government. I did this because, for me, social work is about challenging myself as a professional. It is about

pushing the boundaries and learning all that I can; four years later I am heartsick and

completely burnt out. Did I create change? The answer is both yes and no. I like to think that I did create some change at the micro level; however, the government is a system that is well protected both inside and out. Sometimes even immune to

change. Do not get me wrong, there are many good things that happen within government systems; however, there are also many people that fall through the cracks and do not get the help and/or services that they need. Social work caring is the ability to keep learning and accept that change comes in all sizes.

One thing that I have learned is that there is no one-size-fits-all solution. Every individual in this world is unique: every person, family and child. They all require individual assessments and planning suitable to them and their needs. Planning and assessments that they should be directly involved in. It frustrates me to realize that not everyone thinks this way. Social work caring is about resilience.

We all come from a place of learning. We all seek or have mentors in our life to help us navigate through the policies and politics of different issues that are meaningful to us. For me it was important to stay focused and not allow the taint from others to shape my understanding and practice. We are all accountable for our own lives and how we decide to use the education we acquire.

The experiential voice is a powerful voice. When I say experiential I mean people who 'learn through experience'. Though the complete list is exhaustive, some examples include: the people with addictions, the survival sex workers and sexually exploited youth, the women who have suffered from violence, the people living with HIV/AIDS, the young and old who are disabled. They have more than book knowledge and they deserve to be valued and respected for their courage to come forward. Though everyone's personal experience is different, there are various consistencies throughout. Social work caring is about learning from those who are grounded in the issues that we are fighting to transform.

Power is something that is consistently sought and often misused. When people are given a little, it is a natural feeling to want more. However, when it gets to the point that one is working towards their own agenda and not in collaboration with others, then it becomes a problem. I see it as a cancer within the helping profession. It strengthens those on top of the hierarchy and seeks to diminish the voices of those working frontline and the populations they work with. Social work caring is about recognizing power imbalances and honoring the populations you work with.

Social work has been a part of HIV/AIDS from the beginning. Hoe (1998) states “for the social worker, there is a vital need for development of knowledge and action regarding the psychosocial, economic, and the political issues that frame how we think and respond” (p. xi). HIV/AIDS is very much a social issue; therefore, it is clear to see how it could become a part of social work in the larger context. HIV is not only caused by a virus. It is caused by

many things such as poverty, discrimination, fear, power imbalances, addictions, and social attitudes (Canadian Association of Social Work, 1997). Social workers advocate for the needs of PHA's; they strive to change economic hardships for a better standard of living (Midgley, 1996); and, they fight governments that implement

I accompanied a PHA to his first HIV/AIDS conference. It was a CAAN conference in Toronto. He was really not feeling well and was experiencing massive bloating (water retention). He was so self-conscious of his looks. Once the conference started, he went one way and I another. Every time we would meet up he was more excited than the last—filling me in on this and that. When he met other PHA's during smoke breaks they shared lots between them, talking about medications, etc. I could see how empowered he was. He never spoke again at the conference on his appearance. He forgot all about it because he was so involved in the conference. He also let go of any homophobia he had and embraced gay culture. He then went on to join the board of CAAN representing the Yukon as a PHA. He is still involved in this type of work.

Focus group participant, 2012

the policies that continue to oppress the HIV population. Social work is about standing up for others in many different settings and in many different ways.

When we look at changing the way HIV/AIDS affects the quality of life of PHA's it is more tangible to look at the medical context rather than the social context.

However, for the most part, it is the role of the social worker to understand and break

down the social barriers that prevent PHA's from

attaining basic needs for survival. As social

workers, we work in community, government,

health and political arenas. We all work to

achieve the same things, but the way we go

about achieving them may look different. For

example, counselling provides individual comfort

for those living with and affected by HIV/AIDS,

while addressing the legislature can create policy

change at the national level. No matter how we

decide to use our skills and talents as social

workers, we can create change and provide

supports on many different levels. Social work

caring is about advocacy.

The highlight of my job is getting to know the members. They are all unique and special in their own ways. They have a lot to teach others and they really appreciate having us to talk to. I went to a doctor's appointment with one member and when she was talking to the doctor she had said that when she is out on the street, walking home or wherever she is going that nobody acknowledges her. The only time people talk to her is when she has money. They don't talk to her (just behind her back that she is crazy) because she is always "talking to herself" when she is praying out loud. When she comes to Positive Living North she feels welcome. People talk to her and hug her. She is human. This makes her feel special and in turn makes me feel special.

Focus group participant, 2012

When we talk about social work and caring we cannot forget to talk about self-care. It is very important for social workers to take care of themselves so that they can work effectively with others. "The energized, motivated social worker will provide better services to clients than the emotionally drained practitioner" (Walsh, 2009, p.

76). In my experience, burn-out comes from large caseloads, vicarious trauma, long hours, and limited resources. The helping profession is not a profession in which one gets much acknowledgement in the work that they do, nor do they get rich doing it. Helping others is something that comes from within people. It is about wanting to make the world a better place for even just one person, or one issue. Social work caring is about passion and dedication.

Greater Involvement of People Living with HIV (GIPA)

Social leadership from many different countries came together 19 years ago to shape what came to be known as Greater Involvement of People living with HIV/AIDS (GIPA). What is GIPA? The GIPA principle, was declared at the Paris Declaration in 1994. GIPA is a set of principles adopted by the United Nations in 1999 that aims to increase the involvement of people living with HIV in making decisions that affect their lives (Joint United Nations Programme on HIV/AIDS, 2007). The principles include:

- To support the greater involvement of People Living With HIV and AIDS (PLWHA) through initiatives to strengthen the capacity and coordination of networks of PLWHA and Community Based Organizations (CBOs) stimulating the creation of a supportive political, legal and social environment;
- To involve PLWHA fully in decision making, formulation and implementation of public policies;
- To protect and promote the rights of individuals, in particular those living with or most vulnerable to HIV/AIDS, through legal and social environments;
- To make available necessary resources to better combat the pandemic including adequate support for PLWHA, NGOs and CBOs working with vulnerable and marginalized populations;
- To strengthen national and international mechanisms connected to human rights and ethics related to HIV/AIDS;
- To protect and promote human rights in our work; and,

- To apply public health principles within our work,
(Canadian AIDS Society, 2009, Mod 1, pp. 1-2).

One of our HIV positive members, who hadn't used drugs in several years, experienced what he called 'a major relapse'. I had only known him sober and witnessing his fear and vulnerability when he came for harm reduction supplies (on the verge of withdrawing), was challenging. After a week with no word from him, he showed up at the agency sober and asked when he could start volunteering again. He spent the little money he had that day to buy us our favourite coffees to show his gratitude. We sat there together understanding and appreciating each other.

According to a toolkit developed by Asia-Pacific Network of People Living with HIV/AIDS (APN+) and Asia-Pacific Council of AIDS Service Organisations (APCASO), GIPA aims "to make the fight against HIV/AIDS a priority; to protect and promote the rights of individuals; to make available the necessary resources; and, to work in a spirit of true partnership with PLWHA as well as affected communities" (2005, p. 9). The GIPA principle is

Focus group participant, 2012 not something that organizations need to adhere to in order to receive funding; however, in Canada if an organization wants to be endorsed by the Canadian AIDS Society (refer to page 4), then they must adhere and prove adherence to the GIPA principle. It is all about accountability. This is a way to facilitate the process of implementing GIPA within organizations nation-wide, as well as supporting organizations to see the benefits of this inclusion. Endorsement from organizations at the national level can be a benefit for local community organizations. In recent years, due to government priorities, it has been challenging for local organizations to struggle to keep their doors open. Benefits from national endorsement include the inclusion of local issues at the national level, access to up-to-date educational materials, fundraising support, and advocacy and policy change at the national level. If I could sum GIPA up into a simple sentence, it would be that

GIPA is a way to create life changing circumstances and outcomes in society through the meaningful engagement of PHA's.

GIPA and the Northern Context

Definitions

What is meant by the northern and rural context? For the purpose of this discussion northern alludes to geographical location, whereas rural emphasizes population statistics. There are many definitions for both northern and rural; however, not one has been universally adopted (Pong, DesMeules, Heng and Lagacé, 2011).

Traditionally, rural was defined as having populations under 2,500 people (Ginsberg, 2005). The definitions from Statistics Canada include "rural and small town (RST)" (du Plessis, Beshiri, Bollman, and Clemenson, 2002 and Pong et al., 2011). RST refers to populations living outside the commuting zones of larger urban centres, specifically outside census metropolitan areas (CMA) which consist of 100,000 or more people in the urban core, and census agglomerations (CA) which consist of 10,000 to 99,999 people in the urban core.

Statistics Canada recently changed the term urban to population centre. According to Statistics Canada there are small population centres (1,000 – 29,999), medium population centres (30,000 – 99,999) and large population centres (100,000 +) (2011). Population centres are based on concentrations of high density and rural areas are based on a dispersion

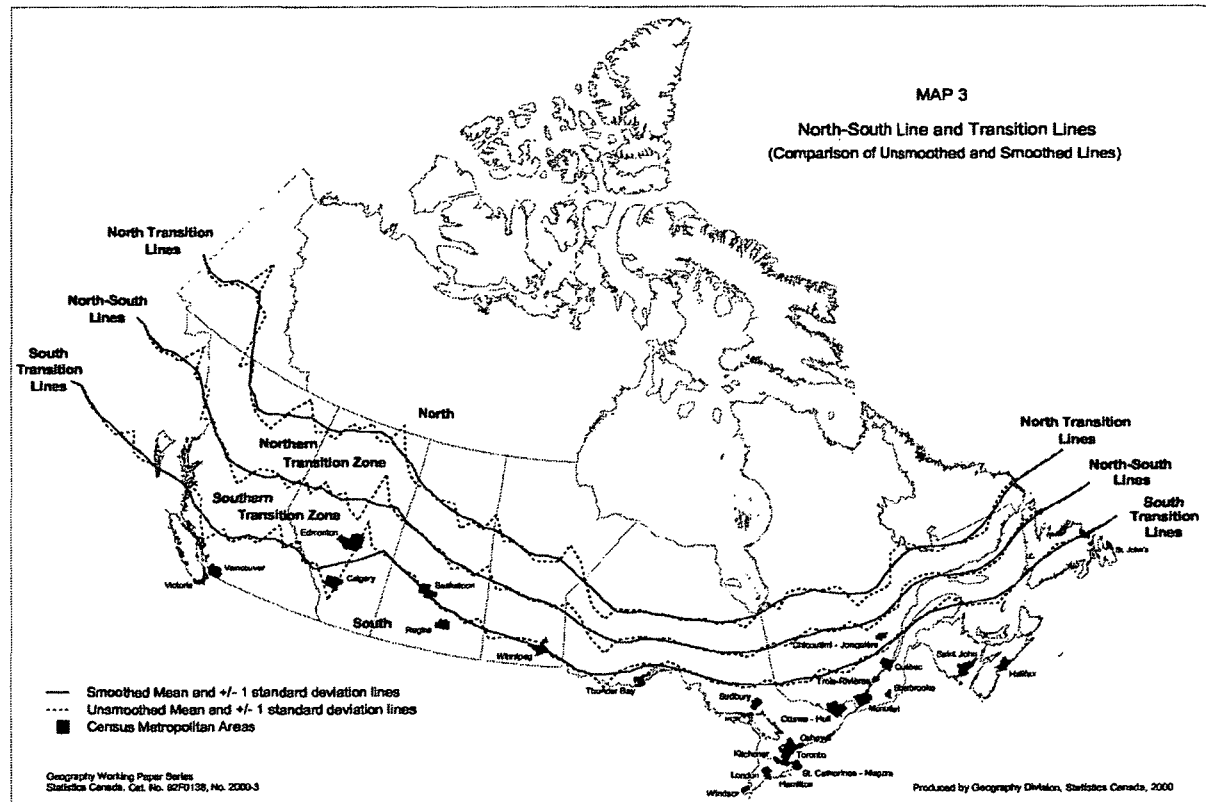


Looking down on Whitehorse, Yukon from Grey Mountain. Picture courtesy of Jen Sugden, 2013

of low density (Puderer, 2009). According to du Plessis et al., (2002, p. 1), a benchmark when defining rural would be “the population living in towns and municipalities outside the commuting zone of larger urban centres (i.e. outside the commuting zone of centres with population of 10,000 or more)”. However, there are so many other factors to consider when describing population centres and rural areas. Such factors include the needs and experiences of people in communities (Puderer, 2009) as well as social policy issues and economic development (Ginsberg, 2005).

The definition of what constitutes for northern Canadian communities has proven to be just as complicated, influenced by both geography and politics. There is not one universally accepted definition due to the fact that people will define it in terms of their knowledge, experiences and specific purposes. Bone (1992) defines north as two regions, the arctic and the sub-arctic. This leaves out a vast area of what others have constituted as north, including factors such as “climatic and physical attributes, economic structure and population settlement patterns between the territories and the northern parts of Labrador, Quebec, Ontario, Manitoba, Saskatchewan, Alberta and British Columbia” (McNiven & Puderer, 2000, p. 1). Other researchers defined north as 60 degrees north referring to the Yukon, North West Territories and Nunavut. McNiven and Purderer (2000) delineated the term north by using a method known as the north-south line or threshold (as shown on the map below). The north-south line delineation is very complex and “reflects the combined social, biotic, economic and climatic aspects of all the lines” (2000, p. 10). According to Vincent and Fick (2000),

geographers Chuck McNiven and Henry Puderer of Statistics Canada defined "northness" using 16 characteristics, such as how often you have to flick on the furnace; the limits of permafrost, boreal forest, railways and all-season roads; number of agricultural growing days; climate; and accessibility to urban centres.



North-South Line Delineation (McNiven & Purderer, 2000)

In my experience in living in northern British Columbia and interacting with people from communities across Canada, people define their environments in terms of their experiences. Sometimes they will define their communities as both urban and rural (as noted in chapter four). In the 'real' world, northern definitions depend on transportation, geographic location, weather conditions, isolation (geographically and socially), population, social and health services, industries, consumerism and more. One can live in a dispersed population of 80,000 people, but not have access

to city transit because they live outside city limits or poor transit schedules within the city limits. One may live in a community of 15,000 people with no transit services at all. One may live in a small community of 6,000 people, but there are no services and few stores due to it being an oil industry town where people periodically commute from the rigs to the cities that are several hours away. One may live in a small city with a population of 30,000 people, but there are few doctors and healthcare services which cause them to drive two hours (or in many cases, longer) to the next city to get services (even this scenario depends on transportation and social isolation). When referring to north (in the map above) Prince George is located within the southern transition zone, far from the northern transition zone, and even farther from what



Yukon River from downtown Whitehorse, Yukon. Picture courtesy of Jen Sugden, 2013.

is known on the map as a tangible term of 'north'. Yet we are known as the Northern Capital of British Columbia? This is a clear example of fragmented ideology of how the north is defined and by who defines it.

The Challenges of HIV in the Rural and Northern Context

I think that there are definitely more repercussions with GIPA when you enter smaller rural communities in the North. It is unknown exactly how many people living with HIV/AIDS (PHA's) live in rural communities across Canada (Veinot, Harris, Bella & Challacombe, 2011), but one thing for sure is those PHA's who do live in the north face greater health challenges. According to the Canadian AIDS Treatment and

Information Exchange (CATIE), "If the percentage of PHAs in rural areas is similar to the percentage of PHAs in the country as a whole (20%), then approximately 13,000 PHAs live in rural Canada" (Veinot et al., par. 3, 2011). However, it is also cautioned that this could be an over-representation because many PHA's move to urban cities where there are more services and supports (2011). Unlike urban cities where there are a lot of services available for marginalized populations, in northern communities there may be little or no services. Often there may be a lack of experienced doctors, peer support and AIDS service organizations (Olivier, 1998). Often PHA's must travel to larger cities to see specialists and order medications. Sometimes they may have no transportation to do this; therefore, they are not receiving services pertinent to good health promotion.

Imagine that, as a PHA, you move back to your community of 1,500 people. There is no AIDS service organization and the nursing program only runs one day a week. There is one doctor in town that has no knowledge around HIV/AIDS. There are no programs or services that would support you in town (whether this is perceived or actual). As far as you know, you may be the only one living with HIV in your community. This creates extreme isolation (Olivier, 1998) considering that many PHA's get a sense of belonging through peer support from other PHA's. In regards to GIPA, how does one come forward and participate in something meaningful to them when there is nothing to participate in? Yes, if more people were aware of HIV/AIDS and the possibility that their community is affected by it, there may be more supports to help PHA's. However, at this point, in this situation, there is not. Nobody

knows but the PHA. Now let us look at the concrete barriers for PHA's in the northern context.

Northern communities may be geographically isolated. This creates limited access to healthcare and other services for PHA's. Many people in Northern communities may feel like HIV/AIDS is not an issue (Olivier, 1998) because it does not affect them. They are isolated and there may be a lack of education and awareness of HIV/AIDS. "Misinformation in rural communities tends to fall into three categories: (1) information that challenges the local existence of HIV; (2) mistaken notions about how HIV is transmitted; and (3) unsubstantiated claims about treatment and cures" (Veinot, Harris, Bella & Challacombe, 2011, p. 3). The lack of professional support services impedes personal growth for PHA's. Limited or no transportation further isolates them. Instead they may feel at a loss for where or whom to go to for help. This would in turn foster the shame, guilt and embarrassment of living with HIV. This causes extreme isolation for people, who in these circumstances, are living with HIV/AIDS.

Other barriers for PHA's in northern communities include the fear of rejection or being ostracized from their communities and personal supports. This can happen within any population in smaller northern communities. For the past decade I have heard stories, over and over, about how people living with HIV were forced from their communities and forever shunned from all they knew. It makes it challenging because it silences PHA's. Silence means the perpetuation of ignorance in our northern communities. Without knowledge, we cannot prevent the spread of this disease.

Moving Forward

Are we moving forward? The Canadian government, through the Federal Initiative to Address HIV/AIDS in Canada identified eight key populations to develop discrete approaches to address HIV/AIDS. These populations included: people living with HIV/AIDS, gay men, people who inject drugs, Aboriginal peoples, prison inmates, youth at risk, women, and people from countries where HIV is endemic. According to the Public Health Agency of Canada, “the Federal Initiative provides funding for prevention and support programs reaching key priority populations, as well as research, surveillance, public awareness, and evaluation (The federal Initiative to Address HIV/AIDS, 2012). What it fails to mention is the fact that the federal government severely cut the budget to the initiative. This means that many HIV/AIDS programs across Canada have been permanently closed, while others struggle to provide services because they are underfunded.

Over the years, the face of HIV/AIDS has changed. There is a relatively constant flow of new medications, treatments and supports for people living with HIV/AIDS (PHA's). Social workers have been a part of systemic change over the years, but there is still much more to accomplish for those who are still living with the disease. Due to the global pandemic of HIV/AIDS, policies have been drafted to support PHA's.

GIPA, a principle that supports the involvement of PHA's at all levels of participation, has helped to support PHA's and strengthen their voices within a world that continues to marginalize and oppress them. The way that GIPA is implemented is instrumental to the success of PHA's and their involvement across the globe.

However, in light of this principle that has shown success and unifies a population that faces many difficulties, there are still many barriers that communities, organizations and programmes face in order to maximize the GIPA principle. These barriers appear to be different for northern communities and include, geographic and personal isolation, lack of services for PHA's, limited access to healthcare, disproportionate transmission rates, and cultural obstacles.

In order to get a better understanding of best practice around GIPA, much more research needs to be done with groups who have implemented the GIPA principle. In the meantime, the HIV/AIDS movement will continue to move forward in supporting changes around supports, healthcare, social and policy change, and law reform to improve the lives of those living with and affected by HIV/AIDS.

The following chapter will provide a literature review around GIPA that includes implementation, benefits and challenges. The social determinants of health enable us to measure what populations are at risk of HIV/AIDS. It also shows the importance that the role of social determinants plays in the lives of PHA's. Therefore, chapter two provides us with an overview of the social determinants of health. Note the challenges of GIPA implementation when the social determinants are lacking in people's lives.

CHAPTER TWO

GIPA Literature Review

Since the inception of the Greater Involvement of People Living with HIV/AIDS (GIPA) in 1994, there have been several publications written to teach people how to implement GIPA within their communities, organizations, projects and programmes. Some of this literature includes *The Good Practice Guide: Greater Involvement of People Living with HIV (GIPA)*, *One Foot Forward: A GIPA Training Toolkit*, and *“Valued Voices” GIPA Toolkit: A manual for the Greater Involvement of People Living with HIV/AIDS*. From a global perspective, HIV/AIDS is a crisis with no bounds. There is a definite need for meaningful involvement from people living with HIV/AIDS (PHA's); however, there is little or no commitment from authorities and organizations to ensure this happens.

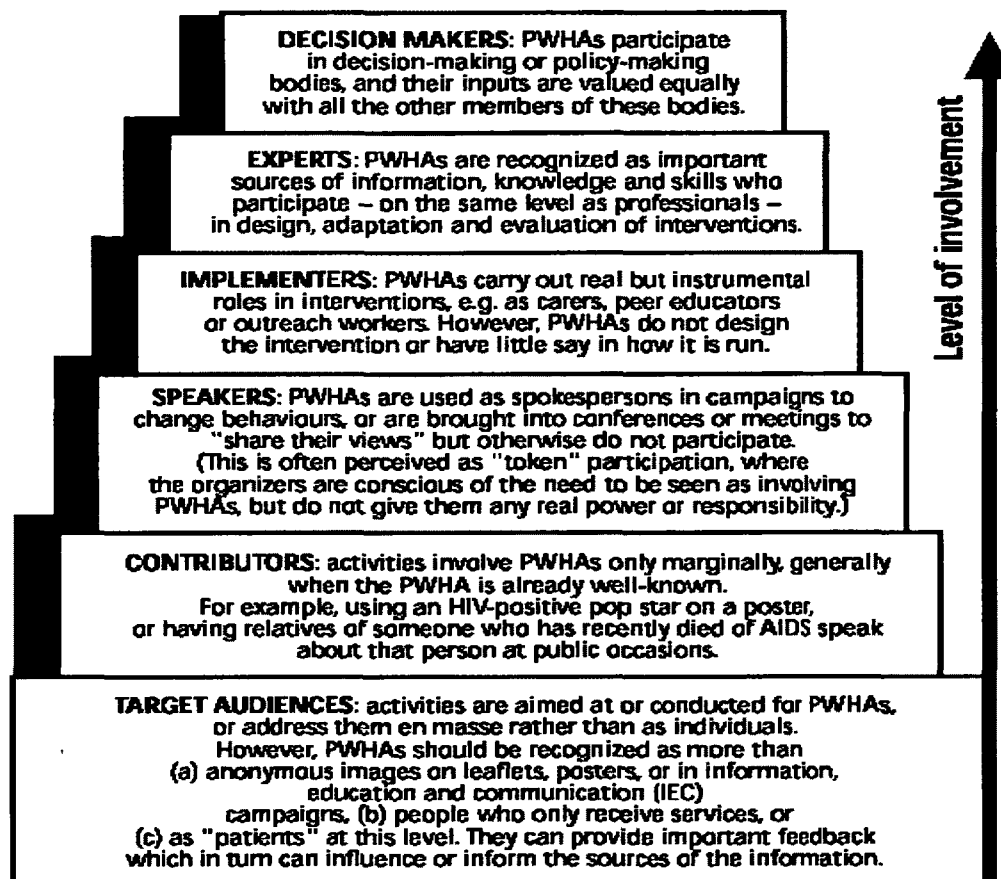
Implementing GIPA

There are many ways that GIPA can be implemented. Given that there are so many ways to involve PHA's in meaningful HIV work, choosing a project and/or organization should take careful consideration. Some of the things to look at when assessing one's involvement in an organization are:

- a) Do they offer and support the social involvement of PHA's and how they do this?
- b) Do they involve PHA's fully in decision making and implementation?
- c) Do they protect and promote the rights of individuals through legal and social environments?
- d) Do they make available necessary resources to combat the pandemic?
- e) Do they strengthen national and international mechanism connected to human rights and ethics for PHA's?
- f) Do they protect human rights within their work?

- g) Do they apply public health principles within their work?
(Canadian AIDS Society, 2009, Module 2)

The GIPA pyramid below explains how PHA's can be involved at every level of an organization.



(Joint United Nations Programme on HIVAIDS, 1999, p. 3)

Something else to consider is that not everyone is comfortable with disclosing their serostatus. Disclosure is not always necessary. PHA's should be able to openly disclose their serostatus; however, they also have a right to be involved in community without disclosing their serostatus (Satpathy, 2003). One of the most important things to realize is that disclosure cannot be undone. There can be serious

consequences to disclosure. Mawar, Sahay, Pandit & Mahajan (2005) state the disclosure of one's serostatus cause social supports to mitigate negative effects of stress such as "perceived discrimination, disgrace, disharmony, concern about insurance and employment, a desire to protect oneself and others emotionally and from violence" (p. 476). No matter how GIPA is implemented, ongoing supports are

needed for PHA's to ensure a healthy engagement process.

When I straightened out my life I reached a point where I wanted to stand up and stand out: be a role model for others. I basically 'outed' myself through provincial and local media (radio, print and television), events, and networking opportunities. Years later when I was ready to settle down and start the next journey in my life, my past kept coming back to haunt me. I struggled with dating and worried that my son would be at risk in the school system (bullying). When I started my career, I feared stigma and discrimination from my colleagues. I was all over the internet and it seemed like so often people would come up to me and say "hey, I know you. I've heard you speak before." I remember periods of time when I went through bouts of depression and mourning. I just wanted my anonymity back.

Christal Capostinsky

Benefits of GIPA

The framework of GIPA has lasting benefits for those who have worked endlessly to promote GIPA beyond the tokenism standpoint. PHA's are the experts in their own lives and have much to offer the communities around them (Asia-Pacific Network of People Living with HIV/AIDS (APN+) & Asia-Pacific Council of AIDS Service Organisations (APCASO), 2005). Being a part of community and being involved in meaningful work gives individuals a sense of value and belonging. According to the

Encyclopaedia of AIDS, "there is nothing better than direct experience, which can be considered a kind of expertise if accompanied by the skill to communicate well" (Satpathy, 2003, p. 291).

Not only are there subjective benefits to GIPA, but communities, regions and nations as a whole can benefit. Some of the benefits include: making services more

relevant and personalized; interventions become more credible and compelling; PHA perspectives create advocacy for human rights; bolsters the self-confidence and physical health of PHA's; and, fosters a decrease in stigma (APN+ & APCASO, 2005). The International HIV/AIDS Alliance and Global Network of People Living with HIV take it one step further to declare that it

enhances the effectiveness of policies, programs and services because they become grounded in the lived experience, a most powerful tool (McClelland & De Pauw, 2010). Who better to perform the tasks around creation, implementation and evaluation of programs and services than those who have the knowledge from lived experience? This is not to

"GIPA is one of those things that is a brilliant principle, brilliant philosophy, but does not operationalize very well in small communities, northern communities and remote communities where HIV has a much stigmatizing meaning as it once did in the 1980's in larger centres".

Focus group participant, 2012

say that it cannot be carried out by non-PHA's; however, it becomes more meaningful and effective when there is input from PHA's. Though everyone's personal stories differ, they all share similar obstacles as PHA's.

Challenges of GIPA

So now that I have explained the mechanics around the implementation and benefits of GIPA, we can peruse the challenges of this multifaceted concept. I will not attempt to explain all of the challenges. I will, however, look closely at a few of them. I will explain many of the challenges in further detail in chapter three. The first challenge is anonymity. It can be difficult to publicly disclose one's serostatus (Satpathy, 2003, p. 294). The more people that know about someone's HIV status, makes that person vulnerable and lose a sense of personal control (APN+ &

APCASO, 2005). Depending on one's cultural and ethnic background, being open about your serostatus can be difficult (Joint United Nations Programme on HIV/AIDS (UNAIDS), 1999). Sometimes precautions need to be made to protect people from discrimination that can be socially or physically violent (UNAIDS, 1999). People can be cruel, especially when they respond out of fear. A famous quote by Honor De Balzac states "Cruelty and fear shake hands together" (ThinkExist.com, 2013). From this one can assume that we, as humans, react hurtfully towards others out of fear brought on by our own ignorance.

The second challenge is getting organizations to participate in recruiting the involvement of PHA's. This may be because of prejudice, discrimination, or the lack of education around the effectiveness of GIPA or the ability of PHA's (UNAIDS, 1999). Oftentimes, GIPA can be misused in organizations and PHA's become tokenistic. Patterson states, "GIPA is not the tokenism that occurs when programs and organizations allow people living with HIV/AIDS (PLHAs) to participate marginally as speakers or symbols" (Patterson, 2005, p. 31). To me, tokenism is akin to a symbolic gesture. Something with little meaning or value to what an individual is able to bring to "the table" so to speak. The confounding dilemma behind this is that often organizations, or the leadership within organizations, are not even aware that they are facilitating this. Hence, there becomes a lack of education, collaboration (Satpathy, 2003) and awareness among people working with PHA's. It is very important to be aware, at all times, how your words and/or actions are impacting those around you. The International Community of Women Living with HIV/AIDS states "while the GIPA principle is widely accepted in theory, our experience is that

the views and voices of HIV positive people still tend to be overlooked or ignored” (The International Community of Women Living with HIV/AIDS, 2008, p. 67).

A third challenge is finding people with the skills needed to participate in effective ways using GIPA (Satpathy, 2003). Since the inception of GIPA, there have been many training toolkits created for organizations to teach PHA's and the people supervising GIPA how to engage in effective GIPA strategies. PHA's should ultimately focus on their areas of skills and if skill development is a part of this, then PHA's need to be supported in doing this. GIPA can be empowering for the people involved, but it can also create burnout due to stress and pressures of being involved in something that is so close to a person's heart (Joint United Nations Programme on HIV/AIDS (UNAIDS), 1999). This correlates with the absence of sufficient environments for PHA's within the organization (Satpathy, 2003).

The fourth challenge noted in literature was policy constraints within organizations (UNAIDS, 1999). Organizations may have inadequate employment policies that address the healthcare needs of PHA's (this would include travel restrictions and the lack of healthcare insurance) (APN+ & APCASO, 2005). The fact remains that there is no standardized employment policy for PHA's. It is left up to the employer to make decisions that constitute the moral and ethical obligations of the organization towards the people employed therein. This creates a huge barrier for those who already face stigma and discrimination on a larger scale.

What do many of these challenges have in common? They pertain to organizational capacity and sustainability (Satpathy, 2003) rather than the subjective challenges that PHA's may face on a more individual and personal level. De Goei

and Groverman, conclude that “stigma and discrimination, funding constraints, low skill levels of PLHIV, belonging to a minority or marginalised group, poverty, lack of understanding and clarity on what GIPA is, gender inequalities in access to education and services and lack of workplace policies” (2009, p. 4) are all barriers which were found in an exploratory study on the opportunities to improve the incorporation of the GIPA principle.

The background provided by this brief examination of these three toolkits illustrates how groups and organizations could implement the Greater Involvement of People living with HIV/AIDS. Later on I will look at three different global studies regarding the outcomes of GIPA implementation. I do this as a way to strengthen my research findings in and to compare the similarities and differences found. I anticipate many similarities because across the globe there are so many paralleled issues that PHA's face on an ongoing basis. What I will be looking for are the differences, if any, in regards to geographical location and environments.

Social Determinants of Health

The terms social determinants of health and key determinants of health are used interchangeably in the human sciences. For the purpose of this document, I will use the term social determinants of health. According to a backgrounder provided by the World Health Organization (WHO),

The social determinants of health are the circumstances in which people are born, grow up, live, work and age, and the systems put in place to deal with illness. These circumstances are in turn shaped by a wider set of forces: economics, social policies, and politics (2008).

People living with HIV/AIDS (PHA's) come from all walks of life. They have been raised in lower, middle and upper class families. As mentioned earlier in this

document, *HIV/AIDS does not discriminate*. Therefore, when service providers are delivering services for PHA's they see people from all walks of life walking through their doors. Each individual is uniquely affected by the various social determinants of health.

Income and Social Status

Income influences a person's status in society. It influences which neighbourhoods we will live in; determines our social status; impacts our ability to seek higher education; affects our access to health services; and, ultimately sways our 'privilege' in society. The healthiest populations are those in societies which are prosperous and have an equitable distribution of wealth (Public Health Agency of Canada (PHAC), 2003). Poverty is an ongoing issue for people living with and at risk for HIV in Canada. Not only does it cause Canadians to be vulnerable to HIV, for those who live with it they are at risk of having their disease progress quickly as a result of having a lower quality of life (Canadian AIDS Society, HIV and Poverty Information Sheet Series, 2004). This is complicated because depending on the population that a PHA identifies with (specifically IDU, prison, and minority) it can be challenging to gain employment due to lack of education and/or work experience. Sometimes it may be that their personal issues get in the way of accessing a good quality of life.

Social Support Networks

What is a social support network? The word social is intertwined with the world around us in context with other human beings. When we describe social support networks, we can look at them as supports around an individual that has meaning for

them. We, as humans, need to be grounded in social phenomena. It is a part of our survival. Depending on where one is geographically, it will affect how social supports play into their life. For example, if someone lives in a rural community and is fairly isolated besides having a few friends and family, they will most likely rely on those people for their social needs. When it comes to being diagnosed with HIV/AIDS, there is much stigma and discrimination attached to it that it becomes common for people to isolate themselves, even from friends and family. Ultimately, this affects ones' emotional, spiritual, physical and mental needs. According to the Public Health Agency of Canada, "The caring and respect that occurs in social relationships, and the resulting sense of satisfaction and well-being, seem to act as a buffer against health problems" (Public Health Agency of Canada, Key Determinant 2, par. 1, 2003). This makes it more important for PHA's to have a solid social network.

Education and Literacy

Education provides opportunities for people. It is a predictor for social class, privilege and influence. When we are provided an education it lends to other determinants of health such as income, social status, personal health, and employment.

Education contributes to health and prosperity by equipping people with knowledge and skills for problem solving, and helps provide a sense of control and mastery over life circumstances. It increases opportunities for job and income security, and job satisfaction. Education improves people's ability to access and understand information to help keep them healthy (Public Health Agency of Canada, Key Determinant 3, par. 1, 2003).

Without an education, our options are limited. People with a higher education tend to be healthier, are more able to enact changes in the Canadian employment market, and, are more understanding of how to promote their health (Mikkonen & Raphael, 2010). Education gives us a purpose. It allows people to have a choice in their own destiny. It generates creativity, passion and knowledge. Knowledge is power and power gives us a sense of control in our lives.

The majority of people living on the margins of our society do not have the opportunity for post-secondary education. Why is this? There are many reasons. Most of these reasons are beyond their control. You may disagree with me, but I speak from years of working with these populations and I have constantly seen the same outcomes year after year.

There are families who live in poverty and suffer from drug and alcohol abuse. The children in these families often grow up without the skills they need to be productive citizens in society. They, themselves, revert to addictions, crime and other harmful risky behaviours. I understand that this happens in other social classes as well; however, the way that it is managed looks different.

Employment/Working Conditions

Unemployment, underemployment, stressful or unsafe work are associated with poorer health (Public Health Agency of Canada, Key Determinant 4, par. 1, 2003). People living with HIV/AIDS are much more likely to be unemployed than people in the general population (Canadian HIV/AIDS Legal Network (CHLN), 2005). HIV was formerly seen as a chronic illness. Since medications have been used to treat the disease, it is now seen as an episodic illness.

Some of the reasons why it is difficult for PHA's to gain and maintain employment are due to variations in disability and health status, health and disability costs, and stigma and discrimination (CHLN, 2005). Factors in the workplace that shape health outcomes include job security, work environment, occupational stress, work hours, and, personal job growth (Mikkonen & Raphael, 2010). This makes it more

precarious for PHA's in the

workforce as many do not

disclose their status out of fear for repercussions. Employment

standards do not always take into

"Historically, many gay and lesbian individuals fled small-town and rural American seeking community and social resources in urban areas. Those who stay in rural areas, return to rural areas, or seek out country living face many difficulties because of social, political, and religious conservatism"
(Kulkin, Williams & Woodruff, 2005, pg. 429)

consideration people with episodic illnesses and most places of work do not have an employee HIV/AIDS policy.

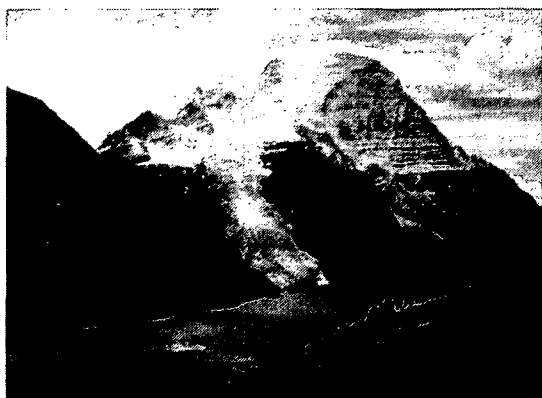
Social Environment

Social environments create a better quality of life for people. They are mentally, physically, spiritually and physically supportive. Social environments are both personal and communal. They can provide people with the means to move beyond personal challenges and to 'in the moment' be capable of living free from weights in their personal lives. In short, social environments enable people to manage life's crises, which in turn, assist them to stabilize through being a part of and participating in something greater than themselves (Guilford, 2000). People need to feel a part of something greater, even if that 'greater' is a small piece of their community. It gives them purpose.

Physical Environments

When looking at HIV/AIDS we should take into consideration the geographic location. Many people living with HIV/AIDS face risks to their health due to their geographical location. According to the 2006 Census, “Nearly half (47%) of all Aboriginal people in Canada live either on-reserve or in a rural area, which includes remote areas, small towns, villages and other populations with less than 1000 people” (Statistics Canada, Physical Environments, par. 2, 2006). This correlates with the statistics regarding the Aboriginal population mentioned earlier in the document.

The north can be a harsh place to live due to extreme weather conditions, poor roads, and wildlife, not to mention a lack of healthcare professionals, transportation, counselling services and confidentiality (Jackson & Reimer, 2008). These are all barriers to preventing access to treatment. There are so many small communities



Picture taken Mount Robson Area
(Rural/Remote areas)
© Christal Capostinsky, 2011

along the highways in northern British Columbia. Often when driving, you will pass a community and not even know it because the markers (signs) are hard to see and there are only a few buildings alongside the highway. The people in these communities often have to travel an hour or more just to get to a market to purchase food supplies.

Geographical location is not the only aspect to include when discussing physical environment. Other things under this subject include shelter, air quality, community,

transportation and safety. All of these factors significantly influence our physical and psychological well-being (Public Health Agency of Canada, 2003). If we have poor health to begin with, it makes it all the more important to seek supports and address the issues. One might think that a solution would be to move to a larger community that will meet your needs. As reasonable as it might sound, it is not always an option. It is where their homes are situated. Their families are close by. Their employment is non-transferable. There are often many varying reasons. For younger people the culture shock of a big city can be a dangerous temptation that leads to crime, drugs and violence.

Personal Health Practices and Coping Skills

How people live their lives and the choices they make will affect their longevity and well-being. Poor health practices include alcohol, drugs, smoking, unsafe sex, risky driving, diet, coping skills, and more (Public Health Agency of Canada, 2003). This can be a predictor for HIV/AIDS or it may sometimes come afterwards with poor coping skills and/or neglect of self-care. The skills and capacities of individuals are derived from early childhood development. People from marginalized and/or disadvantaged populations have an increased risk of contracting HIV/AIDS. It has been my experience in working with people living in poverty and marginalized populations that their health practices and coping skills are lacking. This increases their vulnerability to HIV/AIDS.

Healthy Child Development

A number of studies and reports have been developed in accordance to childhood development and risk implications of HIV transmission. There are a

number of findings from these reports. Children raised in lower income families enter adulthood with lower socio-economic status and poorer health (Case, 2001). Rates of Childhood sexual abuse among HIV infected persons are increased compared to general populations (Allers et al, 1993). Of all the literature pertaining to this, the key factor is not that children who experience trauma, abuse and neglect in childhood will contract HIV in later years, but rather that children who experience this in childhood are more likely to engage in high risk activities as youth and/or adults. This in itself increases their risk for contracting HIV/AIDS. There are a number of programs that have been developed for families with young children as a means to promote healthier children and healthier families.

Health Services

Health Services are crucial to our physical well-being. All of us need access to healthcare. It is what enables us to live healthy lives. Health services comprise of a variety of professionals across the medical sector, including mental health and naturopathic options. The larger the community, the more choices we have for our health needs. It is important to note that although there are health services in our communities, not everyone accesses them. This happens for many different reasons. Lack of trust, poverty, social isolation, mental health problems, and poor standards of care are just few of these reasons.

People living with HIV/AIDS require a higher standard of health care, which means the availability of knowledgeable health care practitioners. This is not always possible. In situations like this, the patient may have to travel a distance to receive adequate healthcare. Transportation may not be the only barrier to achieving the

necessary care. Physical health, mental health, addictions, childcare, literacy, and financial issues also impact the ability to access treatment.

Gender

Gender matters in health and care. The point may seem obvious, but it has only recently been acknowledged in health policy and research. – Pat Armstrong, 2009 (as taken from Mikkonen & Raphael, 2010, p. 44).

Gender is a relatively new concept introduced to the social determinants of health. Out of fact, not spite, it is important to note that “women experience more adverse social determinants of health than men” (Mikkonen & Raphael, 2010, p. 44). Generally speaking, women carry more responsibility for raising children and taking care of housework. Women also work in lower paying jobs and face more discrimination in the workplace, (2010). In much of the literature gender and race are parallel to one another. Women from minorities are more vulnerable. Some of the reasons women are more vulnerable include: biological susceptibility; lack of economic resources; power imbalances in relationships which may lead to abuse and/or violence (Public Health Agency of Canada, 2006).

“There is also evidence that gay, lesbian, and transgendered Canadians experience discrimination that leads to stress that has adverse health effects” (Mikkonen & Raphael, 2010, p. 44). There are policies that governments can put in place to reduce the gender inequality; however, these are things that social workers are still fighting for today. Whatever the circumstance, it seems that there is still so much more to change when we think about how far we have come in regards to gender inequality.

Culture

Culture is not only customs and beliefs that come from within family traditions. They are also created by the outside world and placed on us as human beings. Chang (2008) states two components of culture within the autoethnographical method: the first being that “culture outside individuals considers culture as a bounded whole, with which a group of people is defined and characterized” (pp. 17-18). Secondly, Chang states that culture is within “people’s minds” (p. 20). Though there are different perspectives pertaining to this, I perceive this as how people themselves define culture within their own lives and experiences.

In keeping with the topic of HIV/AIDS, health can be affected by one’s socio-economic environment. This is largely determined by dominant cultural values that contribute to the perpetuation of conditions such as marginalization, stigmatization, loss or devaluation of language and culture and lack of access to culturally appropriate health care and services (Public Health Agency of Canada, 2003). There are exceptions to the rule; however, for the majority of people who come from minorities that face stigma and discrimination it can be challenging to get beyond the pre-defined cultural norms.

The culture of ‘social norms and traditions’ create barriers due to gender roles, religion, and sexual practices. For example, in many African countries, women are not allowed to use contraception and are at increased health risk due to the lack of power they have in relationships (Scott, 2009). Another example could be religious beliefs that prohibit the use of medicines and medical practices.

Chapter three provides a comparative analysis of three similar global studies around GIPA. Though diversity within countries is apparent, it is also important to look at the similarities that people face in light of the diversity. When it comes to the destruction caused by HIV/AIDS, maybe we are not so different after all.

CHAPTER THREE

A Comparative Analysis

For the purpose of comparison for the study in this thesis, I have chosen three other global studies to summarize. The first study looks at HIV/AIDS in five very distinct countries: Benin, Brazil, Cambodia, South Africa, and Ukraine. The second study focuses on PLHA and GIPA in Burkina Faso, Ecuador, Zambia and Maharashtra State, India. The final study follows GIPA in Cambodia, India and Indonesia. The following is a summary of each study:

Study One

OUT OF THE SHADOWS: Greater Involvement of People Living with HIV/AIDS (GIPA) in Policy (Stephens, 2004)

This particular study reviewed the legislative and policy commitment in relation to GIPA. The researchers interviewed senior policy makers and leaders of the national PLHA movement or network in each country. Twenty-five semi-structured interviews were conducted in five countries. The issues looked at included GIPA awareness, PLHA involvement in national planning, benefits of involvement, and barriers and challenges to PLHA involvement.

The findings included:

1. Awareness of GIPA – While many people understood what the GIPA principle represents, there were different interpretations of the term GIPA.
2. Involvement – There was consistent PLHA involvement at the national level in all countries.

3. PLHA Identity and Representation – a key factor that affects PLHA

involvement was a person's right to confidentiality versus the need to publicly disclose in order to promote GIPA. Another finding was the idea of collaborating with non HIV positive allies.

4. Benefits of GIPA - For PLHA's, involvement can lessen shame, stigma,

isolation, and depression; furthermore it can increase self-worth and re-establish social relations. The study also notes that when it comes to policy involvement, PLHA's have the knowledge of understanding what works when it comes to service implementation. This finding created a bridge from policy development to implementation at the frontline. Other benefits included greater HIV/AIDS awareness, more focused research, and more effective HIV/AIDS communication strategies. It also determined that GIPA creates improvement at the policy level around the capacity of various sectors to respond to HIV/AIDS. Lastly it benefits organizations by lending legitimacy to the cause and promoting the management of health policy.

5. Barriers to GIPA – Stigma and discrimination are consistent in all of the study countries. The lack of skills, articulacy and knowledge around HIV/AIDS at the personal level and policy level continues to be a barrier. The GIPA principle is unsupported by, or ill-defined, in policy and legal frameworks leading to uncertainty in defining and interpreting responsibilities in implementation. A more detailed understanding and rationale for GIPA at the policy level is still elusive. While the principle of involvement may enjoy significant support

among some policymakers, promoting it as an effective instrument of the broader HIV/AIDS response is problematic.

Study Two

Greater Involvement of PLHA in NGO Service Delivery: Findings from a Four-Country Study (Horizons, 2002)

This study used both qualitative and quantitative methods. Data collection included individual and group interviews, focus group discussions, observation, service statistics, and a questionnaire. There were 745 participants consisting of HIV positive and negative service users, NGO staff, and volunteers, and such key informants as policymakers, health professionals, and community leaders. In all four countries, PLHA's were involved in the participating NGOs as service providers, service users, or both. Combining all countries involved, there was approximately 37.5% PLHA representation in the study. Criteria examined in regards to PLHA participation included time spent on and regularity of activities; remuneration: financial, material, technical and psychological; skills used; skill development provided by organizations; scope and autonomy of decision making; and, level of visibility: both internal and external.

The research teams used a participatory approach throughout the study, whereas the NGOs in each country were actively involved in study design, implementation, and validation and interpretation of the findings. At the start of the study an orientation workshop was held in each country. This allowed participants to become familiar with basic research concepts such as rationale, process, relevance, and methodology. At the end of the study, another workshop was held in each country

to give data analysis and interpretation so that strategies could be identified to increase PLHA involvement.

The findings included:

1. There are four distinct types of PLHA involvement: access to services; inclusion; participation; and, greater involvement.
2. Involvement in NGO activities can have therapeutic effects for PLHA.
3. PLHA involvement strengthens NGOs.
4. The socioeconomic context strongly influences PLHA involvement.
5. PLHA involvement should not be equated with public disclosure and visibility.
6. Greater PLHA involvement requires creating a supportive NGO environment.

Study Three

Challenges to the Meaningful Involvement of HIV-Positive People in the Response to HIV/AIDS in Cambodia, India and Indonesia (Paxton & Stephens, 2007)

This study, similar to the study in 2004 by David Stephens, examines challenges to HIV-positive people's involvement in AIDS policy making and project design and implementation in Asia. The study consisted of forty-eight semi-structured interviews with targeted key informants from three countries. The criteria for participation was that they were in positions of moderate to high level decision making at state or national level. Half of the participants were PLHA's. Interviews were audiotaped, transcribed and analysed using thematic analysis. Interviews looked at levels of involvement; challenges and barriers of GIPA implementation; examining AIDS related stigma and how it impacts PLHA involvement; and, assessing necessary tools to sustain effective and healthy involvement.

After completing this study, findings showed consensus that there was a lack of confident, articulate and skilled positive people to take on positions of responsibility that GIPA was lacking due to a range of diverse factors:

1. Stigma and Discrimination
2. Medical Support
3. Lack of Counselling
4. Financial Survival
5. Lack of Skills Training
6. Tokenism and Exploitation of Positive People by NGOs
7. Constraints of Government
8. Benefits of Involving People with HIV in the Response to AIDS

Comparative Analysis

All of these studies implemented some form of GIPA in the research process. It is apparent that they understood the importance of GIPA but wanted to delve further into the context of the lived experience in different countries. While each of these studies was unique in their own project, they all shared similarities. Some of these similarities included the constraints of government; financial survival; PLHA supports in regards to GIPA; the risks associated with public disclosure and visibility; stigma and discrimination; lack of skills; and, the benefits of involving PLHA's in the response to AIDS.

Stigma appears to be a common issue among all of the studies. "In all countries, respondents said the greatest barrier to GIPA is the stigma of being identified as positive" (Paxton & Stephens, 2007). "The stigmatization and discrimination of

people infected and affected has been a universal experience that people with HIV/AIDS around the globe have shared. The extent of HIV/AIDS-related stigma and the quality of the response to this stigma are perhaps the central factors determining the progress of GIPA” (Stephens, 2004). Horizons states “PLHA are highly stigmatized in all four countries because of the association of HIV/AIDS with certain behaviors and population groups” (2002). It seems that no matter we do, stigma continues to be an issue at the forefront for PHA’s. This is often a result of lack of education among the general public; furthermore, the crisis of the AIDS epidemic in pre-ARV time (1980’s-mid 1990’s) painted a picture of AIDS that was horrific and instilled fear in many people. It was a death sentence. In light of this, it is very challenging to shake these images from the minds of the general population.

Increasing the knowledge of PHA’s is important to perpetuate the HIV/AIDS movement. We need to have ongoing involvement of PHA’s in order to maintain the voice of HIV/AIDS. As it stands worldwide, this has become a barrier. “A fundamental requirement and an implicit demand of GIPA is to increase the knowledge base of PLHAs” (Stephens, 2004). “Positive leaders, particularly people involved in policy making, may not have the confidence or skills to sustain positions of responsibility, or may get overburdened. Many are thrust into positions without training and with little regard for the technical support they need to contribute effectively” (Paxton & Stephens, 2007). It is imperative for organizations to build the capacity of PHA’s through education and skills training (Horizons, 2002). We cannot expect PHA’s to contribute effectively to policies and programs if they do not have the necessary skills to undergo such valuable contributions.

GIPA is an important tool because it gives PHA's a sense of empowerment and adds meaningful context to programs, policies and services. "The value of GIPA is that it allows the human face and voice of the epidemic to be present and heard in all analyses, planning, and discussions about the epidemic" (Stephens, 2004). "The GIPA Principle suggests an agenda of empowerment through recognising and supporting the voices of positive people in decisions that most affect them" (Paxton & Stephens, 2007). Horizons found congruencies among their participants that spoke to empower PHA's through involvement in NGO activities (2002).

These reports were interesting because they show similarities to my research in northern Canadian communities. While the idea of GIPA has been around for more than 20 years, it has evolved differently in each country researched. They show similarities in barriers and benefits, but maintain a clear definition of how to implement it to the benefit of their particular population. GIPA was clearly explained both historically and in definition. The similarities to this study include barriers such as stigma and discrimination, lack of government funding and the absence of skills training. The benefits include PHA involvement strengthening ASO's, therapeutic for PHA's, and more effective HIV programs/strategies.

My study differed from the above projects because I did not incorporate GIPA during the research process. I did not ask participants of their HIV status, nor did I need to ask them. As someone who has been living with HIV for many years, I wanted to hear from the service providers.

For me, one of the important things to acknowledge is tokenism within AIDS service organizations. I did not expect to hear this from the service providers during

my focus group sessions. I can think of two different reasons for this. First, it is not something that organizations would acknowledge happening in their agency. They may not want to own up to it, or they might not even realize that they had contributed to it. Second, it is hard to see tokenism when you are on the outside looking in.

Tokenism is something that is felt by the person(s) who are being exploited. If you do not see it happening, then most likely you won't even think twice that it could be happening in the agency. Those of you reading this might be thinking "why would someone enable tokenism?" Well, if involving PHA's makes your organization look good, why think twice about how you are doing it? I must clarify for the readers that intentional tokenism is not as common as unintentional tokenism. I have to believe that for the most part, people work in good faith and are morally good.

The following chapter discusses my research methodology and design. I do not think that it is the results of the research that are necessarily meaningful, but rather the process in getting there. The chapter discusses my research design from beginning to end; furthermore, it looks at my thought processes throughout.

CHAPTER FOUR

Research Methodology & Design

“As researchers, we dutifully record the stories of our informants; as writers we translate their stories into acceptable academic prose” (Tierney & Lincoln, 1997, p. 23).

Introduction to Research

Initially, the objective of this research was to assess the involvement of people living with HIV/AIDS within service organizations in ‘northern and rural communities across Canada’. It studied the barriers that people living with HIV/AIDS face in regards to their involvement, as well as how to address them within the global context of the definition of the GIPA principle. The project was meant to assist not-for-profit organizations nationally to implement better practice around GIPA in their communities. It was intended to be a gateway to facilitate meaningful dialogue around this issue with many participants across Canada.

In saying this, I experienced stumbling blocks throughout the research process. One of them was the distance between Eastern Canada and Prince George. Originally I intended to hold focus groups in Western Canada and introduce Eastern Canada to the research by conducting an analysis through surveys. The focus groups were completed by September 2012; however, as the months went by, the response through surveys was limited and I found that the responses coming back were not as bountiful in content as compared to the focus groups. It is challenging to gather data qualitatively when conducting surveys. I do not find it to be a meaningful

research tool because there is no interaction involved between researcher and participant.

I am comfortable the way the research was decidedly conducted. I think that had I used surveys, as originally planned, it would have compromised this research. The value came from the meaningful conversations during the focus groups. This is something that cannot be captured while conducting surveys. At one point, I was so interested in gathering as much information as possible, when realistically I should have been looking at the data in terms of the value of storytelling. The value is not about how much information is collected, but rather it is about the processes (including meaningful engagement) that bring about the details of the stories shared.

The few answers that I received back from the surveys were impersonal and rushed. I understand this. As a former service provider, I recognize the importance of people's time. How many surveys, interviews and focus groups do we have to participate in before the cause is deemed justifiable to support? There is a perception out there that issues are over-researched and under-serviced. I know this because working in the field there is always so much research being done but very little implementation of solution based programming. How much more do we need to know about HIV before we receive adequate funding to provide the services for prevention, support and education? As rhetorical as these questions might be, I do have an answer which will come forth in the conclusion. We, as people need to choose the battles that we engage in. The AIDS movement is one that has meaning for me.

I had hoped that I would receive enough feedback because the nature of my topic is quite new. There is some academic research globally around GIPA, but in Canada, not so much. We, in the movement, know what GIPA is. We know what the barriers are. We know what needs to be done. Unfortunately, unless academic research is initiated, fewer people will learn about the needs surrounding this issue.

Originally I had planned for this to be a Canadian study that encompassed communities from the East Coast to the West Coast. Eventually, I decided that this project was just too big to achieve within the timelines I set out for myself, so I redirected towards a Western Canadian study. This was something that was much more realistic and manageable within the objectives that I set out to accomplish. For me it was a question of time, resources and commitment. A future study is always a possibility. This is a stepping stone to that path.

Research Method

The research was conducted using qualitative methods. Qualitative research looks at understanding the social phenomena by focusing on the participant's interpretations (Bryman & Teevan, 2005, p. 144). It uses words rather than quantitative data.

Autoethnography is an approach to research and writing that seeks to describe and systematically analyze (graphy) personal experience (auto) in order to understand cultural experience (ethno)" (Ellis, 2004; Holman Jones, 2005). I chose to use autoethnography as my method because I wanted to share my own experiences and knowledge in a way that is academically credible. Autoethnography is a "research method that utilizes the researchers' autobiographical data to analyze

and interpret their cultural assumptions” (Chang, 2008, pg. 9). Culture is not always about traditions and customs, it is about lived experience. For me the lived experience includes the “autopathography” (Chang, 2008, pg.47) of my life. When I wake up every day, HIV is always present in my life. Some mornings it kicks me in the ass with bouts of vomiting and severe nausea. However, no matter what the day brings, I need to plan in accordance to the symptoms present. I do not have the privilege of taking days off work if I am not feeling well. The bills need to be paid. The activism does not stop because my body feels like crap. It has now just become a part of my existence. I accept it because it is what it is.

Chang (2008, pg. 64) asks a profound question in regards to the researcher’s cultural perceptions, “what cultural baggage do you bring to the research encounter?” Cultural baggage....My cultural baggage is what strengthens my research. Through autoethnography I am able to share my lived experiences using a highly effective research tool. I am always aware of the bias that could hinder my perceptions and create unrealistic insights. I have the many instructors throughout my educational journey to thank for this. They kept me on my toes, so to speak, and fostered my ability to accentuate my bias to my own benefit. Recognition is the first step in acknowledging our lived experience. The second step is separating the ‘self’ from ‘other’. Every human experience is different. It is what makes us unique as individuals. Yet it is the generalized similarities that bind us together in camaraderie. I will allow myself that assumption because it feeds the sense of belonging that I need to co-exist in a world so full of chaos.

How people live speaks of culture. I value the knowledge that I have gained over the last seventeen years living with HIV/AIDS, as well as the last decade that I have spent working in the HIV/AIDS movement. Through autoethnography I am able to be the main narrator and use the experiences from others, as well as my own, to strengthen my knowledge (Chang, 2008). Using my knowledge along with anecdotal knowledge through others, textual knowledge and knowledge through a literature review, I am able to triangulate the information into academic fact (2008).

According to Held (1980), the purpose of theory is

to analyse and expose the hiatus between the actual and the possible, between the existing order of contradictions and potential future state. Theory must be oriented, in short, to the development of consciousness and the promotion of active political involvement (pg. 22).

In my research I have used a critical theory lens. Many of the populations that I have worked with have faced oppression in many different ways. I have found that it has been a natural response to look at social issues from this perspective. Anderson (2011) states "Critical theories aim to empower the oppressed to improve their situation" (Ch. 2, par. 10). It is clear that a person can see this when comparing critical paradigms to other paradigms. Critical theory looks at issues in its entirety. In order to understand something it is essential to break it down to see how it is socially constructed. If we understand how oppression is constructed, then it brings us one step closer to empowerment. Critical Social Theory results in planned change. The intention of this research is to use it as a means to look at the challenges of GIPA and create an awareness that will allow for better implementation of this principle in northern communities.

According to Anderson,

to serve their critical aim, social theories must (a) represent the social world in relation to the interests of the oppressed—i.e., those who are the subjects of study; (b) supply an account of that world which is accessible to the subjects of study, which enables them to understand their problems; and (c) supply an account of the world which is usable by the subjects to study to improve their condition (2011, Ch. 2, par. 10).

My research aims to cover all three points of social theory. I am invested in GIPA as a positive person and use my education to represent other people living with HIV/AIDS (PHA's). This research will be made available for HIV positive people to access. Furthermore, the goal of this study is to create awareness so that PHA's can improve the world they live in.

Through the process of “data collection, data management and data analysis” (Chang, 2008, pg. 122), I was able to create meaning within the constructs of the research I facilitated. Each step in this process informs the other. They each intertwine to produce analytical and interpretive data (Chang, 2008). The process was fun as I was able to decide what information I wanted to share and how it would best benefit the reader.

Sample

The only requirement for participants was that they work in northern community AIDS Service Organizations. I predetermined four communities in Western Canada to participate in focus groups. Agency directors in Smithers, BC, Prince George, BC, Grande Prairie, AB and Whitehorse, YK were contacted to request participation in the study. The unexpected benefit from this was that Grande Prairie had two satellite locations that participated. This meant that instead of having four communities

involved, I ended up with participation from six communities. All of these communities were diverse in geographic location.

Focus Groups

“Social Scientists have used various forms of group interviews since at least the 1920’s” (Morgan & Krueger, 1998).

Focus Groups		
Community	Date	No. of Participants
Whitehorse, YK	July 19, 2012	4
Grande Prairie (Satellite locations through Skype – Fort McMurray, AB and Peace River, AB)	August 20, 2012	3
Prince George, BC (Satellite location through teleconference – Smithers, BC)	September 18, 2012	12

I facilitated focus groups with service providers from northern/rural AIDS service organizations. According to Morgan & Krueger (1998), focus groups “are a research method for collecting qualitative data, they are focused efforts at data gathering, and they generate data through group discussions”. It was not my intent to conduct focus groups with known HIV positive persons, thus I did not ask for persons to disclose their status. My questions adhered to service provision (see appendix A). All participants were over nineteen years of age. The focus groups allowed service providers to share their knowledge and understanding of access to services for people living with HIV/AIDS, the Greater Involvement of People Living with HIV/AIDS (GIPA) principle, and strengths/limitations of implementing GIPA in their community.

All participants were required to sign a document pertaining to informed consent and given the opportunity to withdraw their participation at any given time without consequence. It should be noted that no person withdrew their consent during the research.

Initially, I planned to tape record the focus groups. I ended up not tape recording this project for three different reasons. First, it has been my experience that the level of comfort lessens when people know that they are being tape recorded. Second, I did not want to chance any potential malfunctions to the tape recording process and/or run into poor sound quality for transcription. Lastly, as not having an assistant, this would have been much more work for me to transcribe taped sessions that were at least one hour in length. Though some might argue that I would have better recorded information, to mitigate this issue I asked the participants to speak slow and pause when I needed more time to write. As this research was not new to me, I had an advantage in understanding the issue. It could be said that I had my own hypothesis and used this research as an academic instrument to validate and share the information that I already possessed.

For me, as an HIV positive Aboriginal woman, it was such an empowering experience to sit down with a group of people and talk about how important it is to work with PHA's. The meaningful discussion that comes from discussions such as this is invaluable. "An important assumption held by autoethnographers and qualitative researchers in general is that reality is neither fixed nor entirely external but is created by, and moves with, the changing perceptions and beliefs of the viewer" (Duncan, 2004, p. 30).

Process of Validation

Pyett (2003) states “in qualitative research, we seek not to measure but rather to understand, represent, or explain something, usually some fairly complex social phenomenon” (p. 1170). This is where storytelling is a valuable tool. It is crucial for me, the researcher, to understand the meaning behind the stories. I am a means for the participants to relay their information according to their understanding. It is just as valuable for me to share my views as long as their stories do not get lost in my own interpretations. Qualitative research is a new phenomenon – way of studying things – in the research world.

In using autoethnography, I was able to include my own narrative voice in this document. This was the part that was important to me because I did not want to just do research “for the sake of doing research”. I wanted it to encompass the stories and words of those at the forefront doing the work with people living with HIV/AIDS. In the beginning it was challenging because there are many different ways to use autoethnography. The great thing about autoethnography is that there is no individual style that is “inherently superior than the other” (Chang, 2008, p. 148).

The advantage I had when I walked into the focus groups to do my research was my HIV status. The people at the table were aware of my experience of living with HIV as well as my experience within the HIV/AIDS movement. That assisted in building rapport with the focus group participants. I was there to collect data, but I already had my own data collection through other similar research and the knowledge I obtained from speaking to people from communities across Canada for the past ten years. I should clarify though; I had no intentions of assuming I knew it

all. I was only looking to verify what I had already learned. I was also open to the idea of learning new things throughout this process. Expecting the unexpected is good practice when it comes to conducting research.

Process of Analysis

The biggest challenge for me during the research process was to set aside my thoughts and responses in order to hear what the participants had to say. When I say this, I mean “really hear” them. It was not about my interpretations, but rather how they viewed what was happening in their own communities. There was a lot of discussion around their input because I wanted to make sure that I was sharing their stories without misinterpretation. In the process of analysis with qualitative data, our interpretations are “tested by further examination and checking, including the examination of our own role in the construction of meaning” (Pyett, 2003, p. 1171).

When conducting the focus groups I took hand-written notes during the group discussion. Following the focus groups, I sent the transcriptions to each of the participants to review what was transcribed. I asked the participants to clarify our conversation, make changes and/or delete comments. This was done to ensure that I understood their words to the best of my ability as a researcher. After feedback was received, I sent them a draft of my research results (as it includes quotes in narrative form using their voice) for final review.

“Coding represents a key step in the process” (Bryman & Burgess, 1994, p. 5). I spent the time analyzing the data in my home environment. I covered the walls with paper and wrote down the participants responses on each paper. For duplicate answers, I would place a check mark so that I was able to spot patterns and

frequencies. I typed up my findings rather quickly because I did not want to miss anything in this process. I did not read too much into the data, as it was fairly black and white (which may have been due to my experience). For me the biggest concern was demonstrating a clear picture of northern and rural Canadian communities. It is so much more challenging working within communities that are vastly different geographically, economically, culturally and socially. This was the most important piece of my research: to assist the reader to understand the 'complexities of the AIDS response' in northern and rural communities. After the final copy was completed and published, I sent all participating agencies copies of the document. All documentation will be securely stored for seven years and then shredded.

CHAPTER FIVE

Findings

Whitehorse, Yukon



The picture to the left was taken outside of the AIDS Service Organization (Blood Ties Four Directions) in Whitehorse. Used with permission. Courtesy of Blood Ties Four Directions Centre, 2013.

Whitehorse, also known as the Wilderness City, has a population of approximately 25,000 people. It was incorporated as a city in 1950 and became the capital city of the Yukon in 1953. The land area of Whitehorse is 413.48 square kilometers and sits at an elevation of 640 meters. The



The city of Whitehorse (above) is used with permission. Courtesy of Adam Van Dusen, 2013, <http://flyindutchman.blogspot.ca>

economic landscape includes mining, transportation services, tourism, and government services (Whitehorse Travellers Guide, 2008).

Focus Group Demographical Questions

The focus group took place at Blood Ties Four Directions Centre (picture shown above). It was a small group consisting of four staff from the organization. Two participants identified Whitehorse as both northern and rural. One participant noted that their reasoning was due to the organization delivering services to rural areas around Whitehorse. The other two participants identified Whitehorse as a northern community. According to the participants, Blood Ties Four Directions Centre provides services to eight HIV positive people living in Whitehorse. They also provide services for people who are diagnosed with Hepatitis C and those who are co-infected with both Hepatitis C and HIV. These numbers significantly increase their client population.

WHAT ARE OUR SERVICES?

Outreach
 Advocacy
 Counselling
 Financial assistance
 Transportation
 Legal assistance
 Food program/nutrition
 Harm reduction
 Housing
 Facilitating skill development
 Speaker bureau
 Governance

(Blood Ties Four Directions, 2012)

Of the eight PHA's accessing services, five of them are Aboriginal and three are Caucasian. Two are women and six are men. They do not have any HIV positive clients that identify as being transgendered. The majority of clientele accessing services are heterosexual; however, they have one client who identifies as homosexual (please refer to page 48) and one as two-spirited. Thirty-eight percent, or three people are active drug users. When I use the term 'active' it means that they have used drugs within the last six months.

**GIPA =
 Nothing
 About Us
 Without Us**

Qualitative Questions

My trip to Whitehorse was the farthest north in Canada that I have ever travelled. The geographic location alone gave me an appreciation for the challenging work that happens with PHA in the northern communities. Blood Ties Four Directions Centre sees GIPA as a meaningful engagement tool that only serves to enhance the current work that organizations do with their clients. It is about PHA's having involvement in programs, decisions, peer-based support, and governances. Furthermore, it builds capacity within the organization to provide the services that clients want and need. GIPA is a fairly recent addition to the organization. There is always the hope that it becomes bigger, but they understand that it is also about building capacity to provide GIPA in a meaningful and effective way.

Previously they had PHA involvement on their board of directors. They have PHA volunteers that help out in the kitchen on Wednesday lunches. Other ways they implement GIPA is through drug user support groups and PHA speakers with outreach on the road (outlying communities). They continue to try to find opportunities for positive clients to attend conferences and skills building events. According to one participant, "it feels like right now we are using GIPA more than we ever have (i.e. programs, volunteering, and board involvement)" (personal communication, July 19, 2012).

Why GIPA is important:

- a) Gives PHA's a say in the organization and the services provided;
- b) People living with HIV need to feel that they are invested in something;
- c) It provides a sense of responsibility to PHA's: it is really encouraging.
- d) It facilitates meaningful involvement;
- e) It is important too so that a person continues to hold value within themselves;
- f) It's about learning new things and it also keeps their self-esteem up;
- g) It helps people to be role models for other people who aren't there yet;
- h) Shows people they are valued and have skills;
- i) Gives them opportunities to show their skills and experiences. There are gaps in services. Services are provided by the 'white' population and many clients are aboriginal; and,
- j) GIPA is important because it helps the clients understand the organization better as well. When clients are more involved in the organization they gain a better understanding and then become champions for the organization. It's a two way relationship and does something for the organization as well.

The benefits of involving people living with HIV/AIDS include:

Insight PHA's bring
 Increase accessibility
 Relevant programs
 Peer mentoring
 Story telling
 Relationship building
 Skill/Capacity building
 Identifying gaps in services
 Diversity
 Good representation
 Good evaluation technique
 Gives more credibility (with communities and those we serve)

When asked about the challenges that Blood Ties Four Directions Centre face when working with PHA's they unanimously agreed that challenges do exist. Some of these challenges include:

- a) Board governance policies (teaching people how to understand them);
- b) Capacity – skill sets, literacy, computer skills, and numeracy;

- c) Organization has limited resources to build on those skills (both human and monetary);
- d) Drug/alcohol issues (reliability related to lifestyle);
- e) Challenging for the staff to understand the processes of why it is challenging and how to turn it into something positive; and,
- f) Managing the expectations of the PHA.

Barriers to PHA involvement in AIDS service organizations:

[Note: This question may appear similar to the previous question but it is in fact different. The last question pertains to the challenges that employees have in regards to working with the PHA population. This question pertains to what the service providers think are the barriers that prevent PHA's from becoming involved in AIDS service organizations.]

- a) Stigma (people don't want to come here [the organization], never mind being "GIPA-ized");
- b) Street involved community is very small (word can spread quickly i.e. lack of anonymity);
- c) Lack of transportation;
- d) Isolation (rural isolation);
- e) Cost of transportation;
- f) We don't know who's not coming here and why they are not. Stats are based on who is accessing services. The real question is how many people are HIV positive and not accessing services;
- g) We have a few HIV positive white guys who are working, have supportive partners/people in their lives, healthcare, etc. They don't need our services, and; and,
- h) Stigma/discrimination among the different populations of clientele.

When asked if people living with HIV/AIDS have the necessary skills and capacities to take part in the different areas within the organization, the answer received was both yes and no (equally). The participants agreed that some PHA's potentially have the capacity and skill for peer support; however, they also acknowledged the importance of not having problematic and/or chaotic drug/alcohol issues in their lives.

Group participants discussed that, in light of organizational capacity, they could not have someone involved who needed training from the ground level. It was also mentioned that some skills aren't transferable. This means that some people might be good out in the community speaking but not in the office working. Other skills that would be important for PHA's to possess include professionalism, boundaries, self-reflection, stability and literacy. Literacy skills would include computer, communication and numeracy.

The kind of assistance that their organization would need in order to help promote and implement GIPA include: a government sponsored step-student type program (where the government pays half the salary); funding commitment (takes at least two years to get the concept working effectively); and, to see examples of organizations that have successfully implemented GIPA (specifically small rural northern communities).

Grande Prairie, Alberta

(Also includes data from their two satellite locations in the Peace County – Fort McMurray and Peace River)

What I Love about my Job:

Working with so many other people and it is 'neat'. I have this team and then I am a part of so many other teams.

Developing trusting relationships.

The privilege of being a part of someone's life and then allowing me to walk with them in their most vulnerable moments.

We get to talk about sex and drugs all da

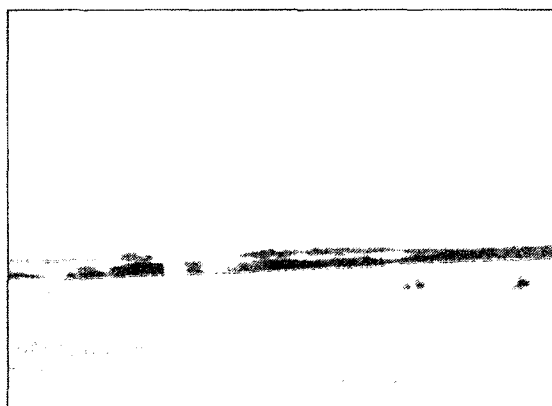
Love the freedom and autonomy I have with my job.

I love the population that we serve. I care deeply about them.

Focus group participants, 2012



Picture of Grande Prairie, AB (Aerial view) used with permission from Grande Prairie Regional Tourism Association, 2013

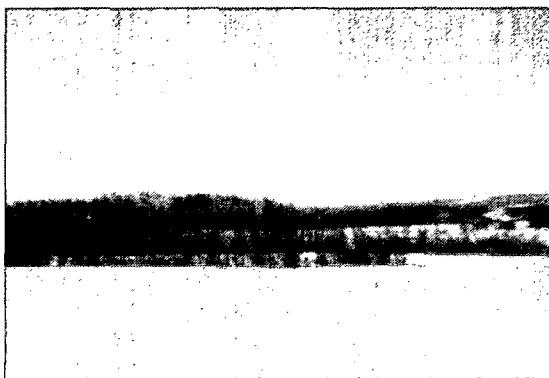


Picture of Grande Prairie, AB used with permission. Courtesy of Jamie Poirier, 2013.

Grande Prairie, also known as the Home of the Trumpeter Swan, has a population of approximately 55,000 people (Wikipedia, Grande Prairie, 2013). It is the largest city north of Edmonton, Alberta (the capital city of Alberta). It was incorporated as a city in 1958. The land area of Grande Prairie is 72.80 square kilometers and sits at an elevation of 669 meters. The economic landscape includes oil and gas, forestry, agriculture, retail and tourism (City of Grande Prairie, 2012). The above pictures were taken outside of Grande Prairie; however, the landscape for the entire Alberta Peace County is similar in nature. Much of the land consists of prairie 'as far as the eye can see'.

Fort McMurray has a population of approximately 76,000 people (Regional Municipality of Wood Buffalo, 2013). It

is not incorporated, thus is known as the largest unincorporated city in Alberta,



Prairie country found throughout the entire peace county. Used with permission. Courtesy of Jamie Poirier, 2013.

Canada (Fort McMurray Tourism, 2013). Fort McMurray is an urban service area in the Regional Municipality of Wood Buffalo in Alberta, Canada. The land area of Fort McMurray is 59.89 square kilometers and sits at an elevation of 370 meters. It is considered a major hub in oil production in Canada. The economic landscape includes the oil sands, natural gas, oil pipelines, forestry and tourism (Wikipedia, Fort McMurray, 2013).

The town Peace River was founded in 1914 (Wikipedia, Peace River, 2013). It straddles the banks of the Peace River and has a population of approximately 6,700 people (Town of Peace River Alberta, 2010). The land area of Peace River is 25.92 square kilometers and sits at an elevation of 325 meters. The economic landscape includes oil and gas, forestry, and agriculture (Wikipedia, Peace River, 2013).

Focus Group Demographical Questions

The focus group took place at HIV North in Grande Prairie. Parallel to Whitehorse, it was a small group consisting of three staff from the organization. Two participants were physically present while the other participant working at a satellite location in Fort McMurray was Skyped in. It is important to note that HIV North also has an office in Peace River. Statistics from that location will be included in this research. Two participants identified Grande Prairie as both northern and rural. One participant noted that Grande Prairie could be considered urban if left separate from north of the province. The one participant from Fort McMurray felt that Fort McMurray was most definitely both northern and rural. The region HIV North covers includes the North West Territory border to the Saskatchewan border to the British Columbia border and finally to Grande Cache and Fox Creek. The figure below highlights (in

red) the area in Alberta, Canada that this one organization covers within their mandate.



<http://sportfisherman.net/sportfish/alberta/maps/map-overview.html>

According to the participants, HIV North provides services to thirty-two HIV positive people living within their catchment: four in Fort McMurray, twenty-seven in Grande Prairie, and one in Peace River. The following demographics are based on PHA disclosure.

Grande Prairie

Of the twenty-seven PHA's accessing services, forty percent of them are Aboriginal, thirty percent are Caucasian, and thirty percent are other ethnicities. Seventy percent are women and thirty percent are men. They do not have any HIV positive clients that identify as being transgendered. All but one PHA are

heterosexual. Approximately half of the PHA's accessing services are active drug users.

Fort McMurray

This satellite location initially opened March of 2012. They predict a growth in PHA's accessing services by the end of the first year. Of the four PHA's accessing services are from other ethnicities. All of them identify as women originating from endemic communities. The participant sharing these demographics said that she was not sure if they were all heterosexual; however, they did all identify as having sexual relations with men. None of them have disclosed active drug use.

Peace River

The office in Peace River runs out of the Sagitawa Friendship Centre. The one client accessing services in Peace River identifies as a heterosexual Aboriginal woman who is not an active drug user. Though there is only one client, this does not mean that this is the only HIV+ person living in that community. It just means that this person is the only one who had the courage to disclose their status.

WHAT ARE OUR SERVICES?

Education (schools, prisons, agencies, nursing, practicum placements, LPN program, social work program)

Outreach (soup kitchen, street, rotary house shelter)

Harm reduction (out of office and pharmacies)

Referrals

HEP C programming (outreach, peer mentorship, support)

Building relationships

Advocacy and lay support

Medicine delivery

Pre and post-test counselling

Women's drop-in (sex trade workers)

(HIV North, 2012)

Qualitative Questions

The participants see GIPA as being really important. It is not just about involvement, it is about meaningful involvement. To them it is about volunteerism and being involved in governance, program development, service delivery, and

<hr/> <p><i>I would say that anytime we do a research project there is an opportunity there to explain how they can be more involved in the agency</i></p> <hr/> <p><i>Focus group participant, 2012</i></p>	<p>activism. The participants stated that the organization struggles with implementing GIPA. Currently there are only a handful of people who they see being potentially involved (due to life circumstances). According to the participants there</p>
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is no PHA representation on the board of directors (as far as they know there have been no disclosures around positive HIV status). They fault the intimidation of the governance model for this. The absence of PHA involvement is not from lack of trying. The organization tries to implement it whenever and however they can through invites, word of mouth, emails and events.

The staff at the organization has had good experiences working with volunteers at events. According to one participant, "Socialization and culture are a big part of it" (HIV North participant, personal communication, August 20, 2012). An important part of GIPA for them is PHA's sharing personal experiences through education. "It has meaningfulness to it and provides a positive impact" (HIV North participant, personal communication, August 20, 2012).

All of the participants agree that PHA involvement is important. It ensures that the needs of rural people are a priority and guarantees that services are provided in a meaningful way. Most of the existing research deals with urban individuals living with HIV.

This creates a barrier for accessing information on successful GIPA implementation. They, as

service providers, struggle with the underlying fear that the general population in Grande Prairie has in regards to HIV/AIDS. HIV does not have a face and does not discriminate. This perpetuates fear. If there is a chance to involve PHA's in a non-discriminatory manner, it is beneficial to all. Some of the benefits that came from focus group participants included:

"Even discrimination looks different here. One year ago I was having a conversation with a person who had been volunteering for a while. He talked about how here the discrimination he experienced was mostly within his own demographic. The conversation was more around homophobia but there were implications of HIV as well"

Focus group participant, 2012

Benefits of GIPA

- a) Greater positive peer mentorship;
- b) Young people being diagnosed are building relationships with service providers. It would be so cool to be able to hook up young people with someone who has been living with HIV for many years (for mentorship);
- c) Education (positive impact coming from positive people); and,
- d) Potential benefit to the individual (learning opportunity, seeing things through the eyes of service providers, emotional benefits).

When asked about the challenges that the Peace region faces when working with PHA's they stated that they are not currently working with any PHA's in their

organization. This is not from lack of trying on their part, but rather barriers such as: fear of disclosure; capacity (i.e. mental health, addictions, skill base, economic); apathy (PHA's show no interest in activism/volunteerism); stigma; transportation; seasonal weather; and, conflicting schedules for working PHA's.

This particular focus group had two categories in regards to capacity and skill building. First they discussed this in terms of a volunteer perspective, and second they had discussions based on a work perspective. Volunteerism is unpaid work. The work perspective focused on paid work (employment positions).

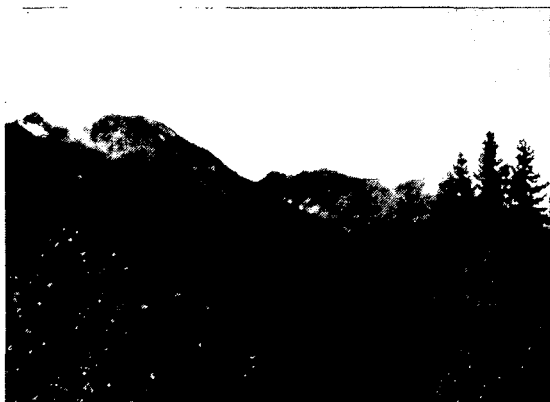
When looking at the volunteer perspective, participants noted that if PHA's had the means or willingness for this, skills and capacity would not be an issue. There are ways that the organization could assist them in attaining the skills. With volunteerism, not a lot of skills are required. It would depend on what the PHA wanted to do within the organization. There are things for people at all skill levels.

When looking at the work perspective, the organization is requesting a certain skill set required to do the work. The PHA would need skills specific to the job including, but not limited to effective communication, computer and academic education completion based on the job description. Not everyone, within this population, has these skills.

When asked what kind of assistance they think AIDS service organizations need in order to help promote and implement GIPA, their answer was very specific.

"From our experience in working at HIV North, PHA's do not have a desire to become involved in the organization. This is a town based in economic growth and people want to make money. Others have barriers that they experience which prevent them from becoming involved" (HIV North participant, personal communication, August 20, 2012).

Smithers, British Columbia



Used with permission. Courtesy of Shelly Lebreton-Mercer, 2013.



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Smithers has a population of approximately 6000 people. It is situated in the Bulkley Valley about halfway between Prince George and Prince Rupert. It is the service centre for the Bulkley-Nechako Region (approximately 20,000 people). Smithers was founded in 1913 and incorporated as a town in 1967 (Tourism Smithers, 2013). The land area of Smithers is 15.27 square kilometers (Wikipedia, Smithers, 2013) and sits at an elevation of 494 meters (Tourism Smithers, 2013). The economic landscape is based on logging, saw-milling, agriculture and mining (Relocation BC, 2013).

Focus Group Demographical Questions

The focus group took place via teleconference at Positive Living North in Prince George BC. The local AIDS service organization in Smithers is Positive living North West. It is managed through Positive Living North in Prince George. The focus group consisted of four participants (staff from the organization). All four participants identified Smithers as both a northern and rural community. According to the

participants, Positive Living North West provides services to twenty HIV positive people living in Smithers.

Of the twenty PHA's accessing services, eighteen of them are Aboriginal and two are Caucasian. Eight are women and twelve are men. They do not have any HIV positive clients that identify as being transgendered. All of the PHA's accessing services identify as heterosexual. Seventy percent or fourteen people are active drug users.

Qualitative Questions

When I first asked about the participants being aware of the GIPA principle, some stated that they were not aware of it. Through further discussion I was able to conclude that they recognized the definition of GIPA but they were not familiar with the term/acronym GIPA. I was astonished considering the importance that the organization placed on PHA involvement. What I came to understand was

that had I asked if they knew what the Greater Involvement of People living with HIV/AIDS was, they would have said yes. As mentioned in the beginning of this

If you are not listening to people who use the program then why bother running them?

Focus group participant, 2012

paper, acronyms can be deceiving. The participants narrowed down their understanding of

GIPA by concluding that GIPA was "full participation and equal participation" (Prince George focus group, personal

WHAT ARE OUR SERVICES?

Drop in
General support
Advocacy
Harm reduction
Life skills
Employment assistance
Housing assistance
Computer
Educational workshops
Cultural activities
Referrals
Outreach
Hugs

(Positive Living North West,
2012)

communication, September 18, 2012). Furthermore, they specified the importance of PHA involvement in program development and service delivery. One participant noted that feedback during the program cycle was important for sustainability.

The participants stated that the organization implements GIPA in the following ways:

- a) Surveys (services are member driven);
- b) Frontline warriors program;
- c) Education in the community;
- d) Volunteering through the organization;
- e) Asking for input (from PHA's) before bringing services to outlying communities; and,
- f) Asking PHA's what they want and what is effective for them.

Benefits of GIPA

- a) They [PHA's] are the experts;
- b) It [GIPA] makes the organization successful;
- c) Involving PHA's keeps programming relative;
- d) PHA's skillset across the board can be great;
- e) Gives them a sense of ownership;
- f) Helps them to take pride in something;
- g) Gives credibility to the organization and the work everyone does;
- h) Gives [the PHA] a sense of positive and knowledge that they are doing something good;
- i) Provides hope;
- j) It pushes PHA's in a healthier direction in their recovery (from addiction);
- k) Leads to more volunteering and employment;
- l) Reduces marginalization; and,
- m) Better outcomes for both the PHA and the organization.

When I look at the above examples of the benefits of GIPA, I feel that the response from the organization is accurate when it comes to generalizing. On the other hand, I can definitely see how newer organizations are more hopeful and have not yet had a

whole lot of experience implementing the GIPA principles. When asked about the challenges that Positive Living North West faces when working with PHA's they stated that they are not currently working with any PHA's in their organization. This is not from lack of trying on their part.

Barriers to PHA involvement in AIDS service organizations:

- a) Confidentiality;
- b) Transportation and/or a lack of effective transportation;
- c) Stigma;
- d) Drug use;
- e) Anonymity;
- f) Conflict with inter-relationships;
- g) Advocating;
- h) Meeting people where they are at (what is comfortable for them); and,
- i) Working around the members (PHA's) schedule.

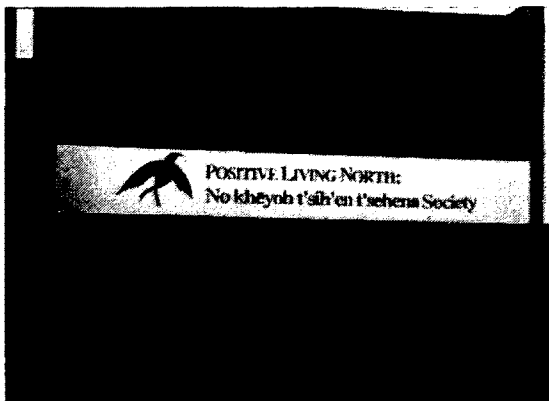
Talking about the challenges and barriers is an important part of the process for accommodating the needs of clients. The participants shared their struggles around engaging with PHA's who were able to be in a place to commit to wanting to engage in GIPA. They felt that the capacity and skill level of people living with HIV/AIDS was not an issue unless it refers to actual paid work. In regards to employing PHA's, it is their experience (from within their own community) that PHA's lack the skills specific to a staffed position, as often it requires specific academic education. They work with the strengths of the PHA and accommodate for volunteer positions. The assistance that organizations need in order to implement GIPA is housing, access to

When I look at this building (Positive Living North) I see..."a place where people can come and access whatever services they need. Whether it be a cup of coffee or a support meeting. I see a place where someone who is living with HIV does not have to hide it or be ashamed of it. They can take the knowledge that they have gained and share it so somebody else knows how to protect themselves against HIV".

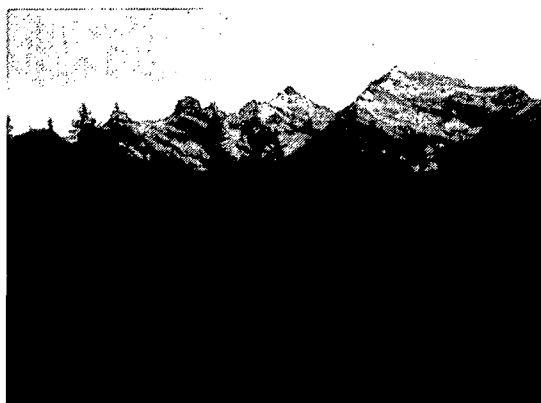
Focus group participant, 2012

telephones, dedicated paid staff, increased funding, and addiction supports.

Prince George, British Columbia



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Prince George, also known as the northern capital of British Columbia, has a population of approximately 76,000 people (City of Prince George, 2011). It is situated at the junction of the Fraser and Nechako rivers. Founded in 1807 and incorporated as a town in 1915, the land area of Prince George is 318.26 square kilometers (Wikipedia, Prince George, 2013). The city sits at an elevation of 575 meters (2013). The economic landscape is based on the service industry, education, forestry, mining, prospecting, transportation and government (2013).

WHAT ARE OUR SERVICES?

Education sessions (schools, corrections, detox, community organizations)
 Provide information
 Referrals
 Visit outlying communities (Port Simpson-Fort Nelson-Dawson Creek-Williams Lake)
 Outreach
 Fundraising
 Advocacy
 Meals
 Food program
 Nutritional information
 Hampers
 Member support meetings
 Hospital visits
 Medical appointments
 Outings
 AIDS Walk

(Positive Living North, 2012)

Focus Group Demographical Questions

The focus group took place at Positive Living North in Prince George BC. There was eight staff participating. Seven participants identified Prince George as a northern community. One participant considered Prince George to be both rural and northern. According to the participants, Positive Living North West provides services to eighty-nine HIV positive people living in Prince George. Of the eighty-nine PHA's accessing services, approximately 80% of them are Aboriginal and 15% are Caucasian. Five percent come from other populations. The split between women and men is approximately 50% with one person identifying as transgendered. About 97% of the PHA's accessing services identify as heterosexual, leaving three people who identify as homosexual (gay men or men who have sex with men (MSM)). Approximately 85 of the 89 PHA's are active drug users.

"The power of presentations with someone living with HIV is beyond words"

"There is a great amount of wisdom in the collective"

"It {working together} does not come from a position of power...it comes from a position of equality"

"I wouldn't know about HIV if it wasn't for the people working here and the people living with HIV"

"It gives members a chance to be a part of the solution, to give back"

"I [staff member] become better educated"

Qualitative Questions

Similar to Smithers, when I first asked about the participants being aware of the GIPA principle, seven out of eight participants stated that they were not aware of it. I expect that some of this influence was in part due to the two focus groups being held together. However, once we started discussing GIPA in greater detail, it was obvious to me that they had a good understanding of the principle. The participants narrowed down their understanding of GIPA by concluding

*Focus group participants,
2012*

that GIPA was “people living with HIV/AIDS having involvement with what the organization is moving forward with. Their voice being heard” (Prince George focus group, personal communication, September 18, 2012).

I should note that Positive Living North has two program locations in Prince George. One being their main location, and the other being a cultural drop-in centre where the primary focus is addressing the root causes of the HIV epidemic. The majority of the participants stated that the organization implements GIPA in the following ways:

- a) Frontline warriors (PHA's involved in the education program);
- b) Board of Directors;
- c) Help with food hampers;
- d) Volunteering;
- e) PHA feedback on programming;
- f) Peer Support Worker; and,
- g) Sharing circles that incorporate culture.

The importance and benefits of involving people living with HIV/AIDS:

- a) Promotes learning;
- b) It gives the PHA's an opportunity to contribute and be involved in something;
- c) It helps an agency set priorities;
- d) Allocates the best way to spend money;
- e) To inform youth;
- f) To help avoid a new infection by sharing;
- g) “It gives members a chance to be a part of the solution, to give back.” (focus group participant, 2012);
- h) Encourages other PHA's;
- i) Alleviates stigma; and,
- j) Increases self-esteem.

Barriers to PHA involvement in AIDS service organizations:

- a) Addictions
- b) Mental health
- c) Anger (personal state they are in in their lives on a daily basis)
- d) Health (physical limitations for PHA's)
- e) Funding
- f) Poverty
- g) Self-imposed stigmas
- h) Oppression/repression
- i) Education
- j) Living in a northern community
- k) They can't remove themselves from HIV when they work in an HIV organization

Challenges of working with people living with HIV/AIDS:

- a) "They don't feel like I am one of them" (focus group participant, 2012)
- b) Lack of school education
- c) Working with the skills they [PHA's] have
- d) "As a staff I feel that I can't please everyone" (focus group participant, 2012)
- e) Miscommunications
- f) Assumptions
- g) Accommodating health needs
- h) Poverty
- i) Being a non-aboriginal staff when majority of clients are aboriginal
- j) Staff turn-over
- k) Methadone [clients who are taking this as a prescribed medication]
- l) Medical needs
- m) Lack of driver's license and vehicle

There was discussion around solutions to the challenges and barriers. Most of the participants agreed that a starting point was talking about it and having further discussion. The participants felt that they promoted GIPA the best that they were

able to. They try to provide opportunities for PHA involvement whenever and wherever they can. Most of the barriers come from outside systems that they are unable to change. Some of these barriers include poverty, addiction, funding, stigma and health.

The participants at Positive Living North in Prince George felt that the capacity and skill level of people living with HIV/AIDS was an issue but that the organization had a responsibility to work around the available skills and capacities of the clients. . Participants agreed that it is the systemic barriers that create the most challenges around implementing GIPA. The assistance that organizations need is increased funding and more staff to train PHA's in skill development (including basic life skills).

A Study Analysis

Using a thematic approach, I have provided an analysis of the similarities and differences between all four communities. The analysis includes data gathered through the qualitative process. The findings are as follows:

Importance of GIPA

All of the communities acknowledged the importance of the GIPA principle. Not all communities actively use GIPA. This is mostly due to reasons beyond their control. They find it difficult to engage with PHA's who may not be in a place to be actively involved in an agency. They base the importance of GIPA for many reasons; however, the reasons more frequently noted were:

1. It provided an opportunity for PHA's to be invested in their community.
2. It facilitates meaningful involvement between the PHA and the community.

3. It gives PHA's a sense of responsibility in implementing services that are relevant to them and their needs.
4. Allows for an opportunity for PHA's to show their skills and/or obtain new skills.

Benefits to PHA Involvement

There are many benefits to involving PHA's in local AIDS service organizations. Though some of the organizations do not currently use GIPA and others struggle with implementing it, they did have a clear understanding of the benefits of GIPA. The themes that stood out the most were:

1. Peer mentoring.
2. Skills/Capacity building
3. Gives value and credibility to the organization and what they provide to the community.

Challenges in working with PHA's

While GIPA appears to be an invaluable concept, it is not without challenges. Many of the challenges were similar in nature. One organization was not even able to answer this question due to their lack of GIPA implementation. The challenges that were more commonly noted include:

1. The lack of skills that PHA's bring to the agency.
2. Continuous drug and alcohol issues that prevent PHA involvement.
3. Lack of confidentiality and anonymity.
4. The agency needing to accommodate any health needs that the PHA's may have.

Barriers to PHA Involvement

Often, PHA's want to become involved in agencies; however, so many things prevent them from doing this. There were several barriers that participants noted during the focus groups. These barriers include:

1. Stigma and discrimination
2. Lack of anonymity
3. Transportation
4. Working around the schedules of potential PHA's who are interested in being involved.

Skills and Capacities

The skills and capacity level of clients was an issue that the organizations could not address without more support from government. On one hand the agencies felt that their staff was not able to assist in training due to unavailable staff and/or lack of monetary support to provide this. On the other hand they felt that it was their responsibility to work within the skill level that clients presented.

Assistance needed

In light of the assessment of the skills and capacity of both the clients as well as the organizations, the agencies felt that they needed three things in order to implement GIPA.

1. Supportive government
2. Increased funding opportunities
3. A way to share the experiences of GIPA among other rural and/or northern Canadian communities.

Finally we come to the conclusion. The following pages will summarize what we have already covered in this document. From learning about HIV and its' early beginning to the GIPA principle created by forty-two countries in 1994. It provides an overview of GIPA implementation in the northern context and how the social determinants of health play a key role in HIV/AIDS. Finally it will look at how my research was beneficial to western Canada and how it can be used to complement existing services in AIDS service organizations. All of this from my own voice; my own perspective.

CHAPTER SIX

Conclusion

This research project was something that I was very invested in. It may be finished in the sense of a written document, but it is far from being finished in its use. My passion and commitment are written in these pages. AIDS has been a heated enigma for the last thirty plus years in Northern America and it does not seem to be lessening any. What continues to give me hope is the ongoing research that tells us just how close they may be to finding a cure. I have to believe in this. It gives me a thread of hope to hang onto throughout the misery and death that surrounds this disease.

What has made this disease so unique is the AIDS movement tied to it. So many people have given their lives to advocating for millions of people around the world. GIPA was initially addressed as a way to empower people in a movement that holds so much purpose and meaning. We are a group of millions of people with so many skills and abilities. It would seem natural that we would be the ones to find the light within the shadows. If only people would understand the role that GIPA holds within our world today and just how important it is to the lives of so many.

We are all impacted in different ways; some of us through race, some of us through gender, and others through class. The effects may differ but the disease affects us all the same. Some of our bodies are stronger than others, but there is still no escape from the sickness that continues to ravish our existence. Some of us come from northern communities, while others dwell in the warmer southern climates. Some of us live in more isolated communities where services are non-existent. While

others live in metropolitan areas erupting with services. This is something that needs to change, but it will not if left in the hands of the government. We can only lay blame for so long before we ourselves begin to lend credence to the issues at hand that need to be addressed.

This is where the journey ends. Well, at least this part of it. I am amazed at the power of the written word and how it can transcend into something that has so much meaning. Using autoethnography gave me the opportunity to share with people a part of my life that does not get much notice. Living with HIV/AIDS is not something that I tend to shout to the rooftops. Through this medium I was able to educate and share information about a disease that has ravaged the world as well as my life. It was inspiring to be able to use Chang as an educational guide to share my experiences using autoethnography. Her insight on ethnography as a research method allowed me access to a tool that created a meaning narrative for my knowledge and shared experiences.

HIV/AIDS has been in the spotlight for more than three decades. It is a disease that has ravaged communities and decimated populations. What makes HIV/AIDS so different than other diseases? HIV/AIDS is just one of the many diseases that exist in our world today. Like any other, it is mediated by social determinants of health and mitigated by proper diagnosis and clinical care. As such, it deserves equitable allocation of resources, sympathy and concern that other diseases garner from the society at large.

It is in the hands of the service providers to encourage people living with HIV/AIDS to be invested in providing services. Though one of key components in

doing this relies on monetary support from governments, this can no longer be used as a reason to delay the involvement of positive persons. There are many other ways to solicit funding. I encourage organizations to look to other sources because increased involvement means bettering the lives of many PHA's.

The truth is that there is so much fear attached to this enigma and society still will not accept that there is no shame in living with this disease. The shame comes from the ignorance that we, as a nation, are responsible for. There is no difference between cancers, Parkinson's disease, Multiple Sclerosis, heart disease, diabetes and HIV/AIDS. What will it take for society to see this?

While this disease does not discriminate, it still affects populations in different ways. Gay men are still the predominantly affected group; however, women, youth and Aboriginal peoples are close behind. The rates of infection among Aboriginal peoples have been compared to the rates of infection in some African countries. This is because of the unequal ratio of Aboriginal people to non-aboriginal people in Canada. Aboriginal people only make up 3.8% of the Canadian population, so when HIV runs rampant in their communities, it becomes a national concern and the responsibility of the government to address.

GIPA, the Greater Involvement of People living with HIV/AIDS, is a principle that has been endorsed through the United Nations. It seeks to empower not only PHA's but the organizations that work with them. When used correctly it exudes meaning for all parties involved. One thing that I have learned over the years is that there is nothing more powerful than the shared stories of those with lived experience.

Through studies done globally people have been able to look at the benefits and challenges of implementing this phenomenon in the work that they do both locally and internationally all around the globe. The next steps include appealing to government for assistance in carrying out this much needed principle. The work has already started through government acknowledgement in regards to the social determinants of health. We need to take it one step further and demand adequate supports in order to carry out the concept of GIPA within our local organizations. Poverty, addiction, funding, stigma and health continue to be barriers for meaningful involvement of people living with HIV/AIDS. To change this requires action from all invested participants.

We are in a global crisis right now and have been for years in regards to the AIDS epidemic. It is a proven fact that prevention is the answer for not only reducing infections but for long term cost saving when it comes to supporting people living with HIV/AIDS. It is about time that the government acknowledges this and accepts the wisdom of the people who have been working frontline for decades. We need to build a stronger, more inclusive movement for and by the people living with HIV. There are so many people out there living with HIV/AIDS who can offer great things to this movement, but they are not given the opportunity to do so. It is time for change. The lives of millions of people are dependent on this. This means that we

*Each time a man stands up
for an ideal or acts to
improve the lot of others, or
strikes out against injustice,
he sends forth a tiny ripple of
hope, and crossing each
other from a million different
centers of energy and
daring, those ripples build a
current that can sweep down
the mightiest walls of
oppression and resistance.
Robert F. Kennedy*

need to take the steps first because if we wait for government, we will be waiting for a long time.

I am proud of the research that I have accomplished. It can be a guide to help so many people expand on services for PHA's. It can also be a point of contact for those looking at comparing GIPA in Eastern Canada. My goal is to share this document with people across the nation so that they can use it to benefit people living with HIV/AIDS. It is so important for AIDS service organizations to implement the GIPA principle. This research tells us that it is not used to its full potential. Social work is a very important part of the work that we do with society. It is a profession with no bounds. We work with people from all walks of life and take on issues that create segregation, oppression and inequality. This project was a blessing to be involved in and I feel honoured to have met so many wonderful people that care so much about the clients they work with. I can only hope that this was a helpful step in the right direction for those living with HIV/AIDS and the organizations that they consider home.



This picture is that of a painting that my thesis supervisor, Dr. Si Transken, presented me with after attending one of her classes to discuss my research. She is not only a professor, but a creative artist and activist. She has been an inspiration to me throughout my educational journey and I look forward to learning more from her in the years ahead.

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APPENDIX A

Focus Group Research Questions

Demographics:

1. Which community do you identify with: northern, rural or both?
2. Approximately how many PHA's does your organization provide service for in your community?
3. How many of these people represent the Aboriginal population, Caucasian population and other ethnicities?
4. Approximately how many identify as women, men and transgendered?
5. What is the main population that accesses your organization: homosexual or heterosexual?
6. What percentage would you say identify as active drug users?

GIPA context:

7. Are you aware of the principle known as the Greater Involvement of People with HIV/AIDS (GIPA)? If so, what is your understanding of this principle?
8. Does your organization implement GIPA? If yes, how is GIPA implemented?
9. In your opinion, is it important to involve people with HIV/AIDS in your organization? If yes, why is it important?
10. In your opinion, are there benefits to involving people with HIV/AIDS in the HIV/AIDS in your organization? Please tell me what you think these benefits are?
11. What is it that you do within your organization? Please describe your experience of working with PLHAs in your organization.
12. Are there challenges for you in working with PLHAs in your organization? If yes, please describe what these challenges are and how you think they can be overcome? (Facilitator to note that this question is in regards to working with other PHA's involved in the organization)

13. Please describe what you consider to be the major barriers to involving people with HIV/AIDS in your organization. How do you think these barriers can be overcome?
14. (Facilitator to note that this question is about barriers involving people to participate in the organization)
15. How does capacity and skill level on the part of people with HIV/AIDS and PLHA organizations affect their ability to become involved in your organization?
 - i. For example, do you think that PLHAs have the necessary skills and capacities to take part in the different areas within your organization?
 - ii. If not, please can you describe what skills and capacities you consider PLHAs need to participate effectively?
16. What kind of assistance (for example technical advice or training) do you think service providers at AIDS service organizations, or other related service organizations, need in order to help promote and implement GIPA? Please list as many examples as you can.

Other:

1. What do you consider to be the highlight of your job? Please feel free to share a memorable moment you have had in regards to your work with HIV positive people.
2. Is there anything you would like to add on the involvement of PLHAs in service organizations, or about other issues that you feel are important?

APPENDIX B

Informed Consent to Participate in Research

Project title: Beyond the Horizon: The Implementation of GIPA in Northern Communities from the Perspective of Service Providers

Purpose & Goals: The objective of this research is to assess the involvement of people living with HIV/AIDS within service organizations in northern and rural communities across Canada. It will look at the barriers that people living with HIV/AIDS face in regards to their involvement, as well as how to address them within the global context of the definition of the GIPA (Greater Involvement of People Living with HIV/AIDS) principle. The project will help to assist not-for-profit organizations nationally to implement better practice around GIPA in their communities. It will be a way to facilitate meaningful dialogue around this issue with many participants across Canada.

All participants were pre-determined by the researcher based on geographical location and the target population to whom you provide services. All participants are service providers in northern/rural AIDS service organizations. No disclosure around HIV status is necessary or will be sought. Technology used in this research includes on-line surveys, computers, flash drives, tape recorders and written documents.

Participants will be asked to participate in a focus group at their AIDS service organization (place of work). The duration of the focus group will be 2 hours maximum. Ten questions will be asked during this time. The focus groups will be tape-recorded but no one else besides the researcher will be privy to access them. The researcher will be undertaking transcription of all tapes. Your anonymity is important to the researcher. Every participant will be given a number to replace their names in the transcription. The tapes will be permanently and physically destroyed by burning once transcribed. Transcriptions may be kept for future research; however, as previously mentioned, no names or locations will be identifiable. In stating this, you, the participant agree to the future use of this data in any further relevant studies that may include publications. These publications may include planning documents, academic articles for publishing, comparative analysis documents including other studies.

Your confidentiality is important and will be respected. No names or identifying information will be included in the research; however, your anonymity cannot be guaranteed. As the researcher, I cannot guarantee or control what other focus group participants do with the information they gather. As mentioned previously, all tapes will be permanently and physically destroyed by burning once transcribed.

After transcriptions are complete they will be forwarded to all participants for review to make necessary corrections or to add additional information. A final copy of the

research will be made available to you after it is completed. This information will be disseminated nationally and be made available globally.

Potential benefits to the study include:

- Gain a better understanding of the strengths and limitations of GIPA in organizations
- Increasing the capacity for GIPA in organizations; and,
- Local organization's voices heard in a broader national context

There are no known risks attached to this study, though this can be discussed in deeper context during the focus group if needed.

Your participation is voluntary and you have the right to withdraw at any time during the research process without repercussion. If this happens, all of your information will be withdrawn from the research.

If you have any questions, please do not hesitate to contact the researcher, Christal Capostinsky, at 250-612-2351 or caposti@unbc.ca

Copies of the final research results will be made available to you after completion. If you do not receive a copy, please contact the researcher. Any complaints about this project should be directed to the Office of Research at the University of Northern British Columbia reb@unbc.ca or 250-960-6735

I, _____, give my voluntary consent to participate in this project. I have read the above informed consent information in regards to the project and fully understand the nature of my consent to participate. If I have any questions, I will address them to the appropriate contacts listed in this agreement. I am aware that I can withdraw my consent at any time without repercussion, and that all my information will be struck from the research.

Participant

Date

Witness (another participant)

Date

Researcher (Christal Capostinsky)

Date