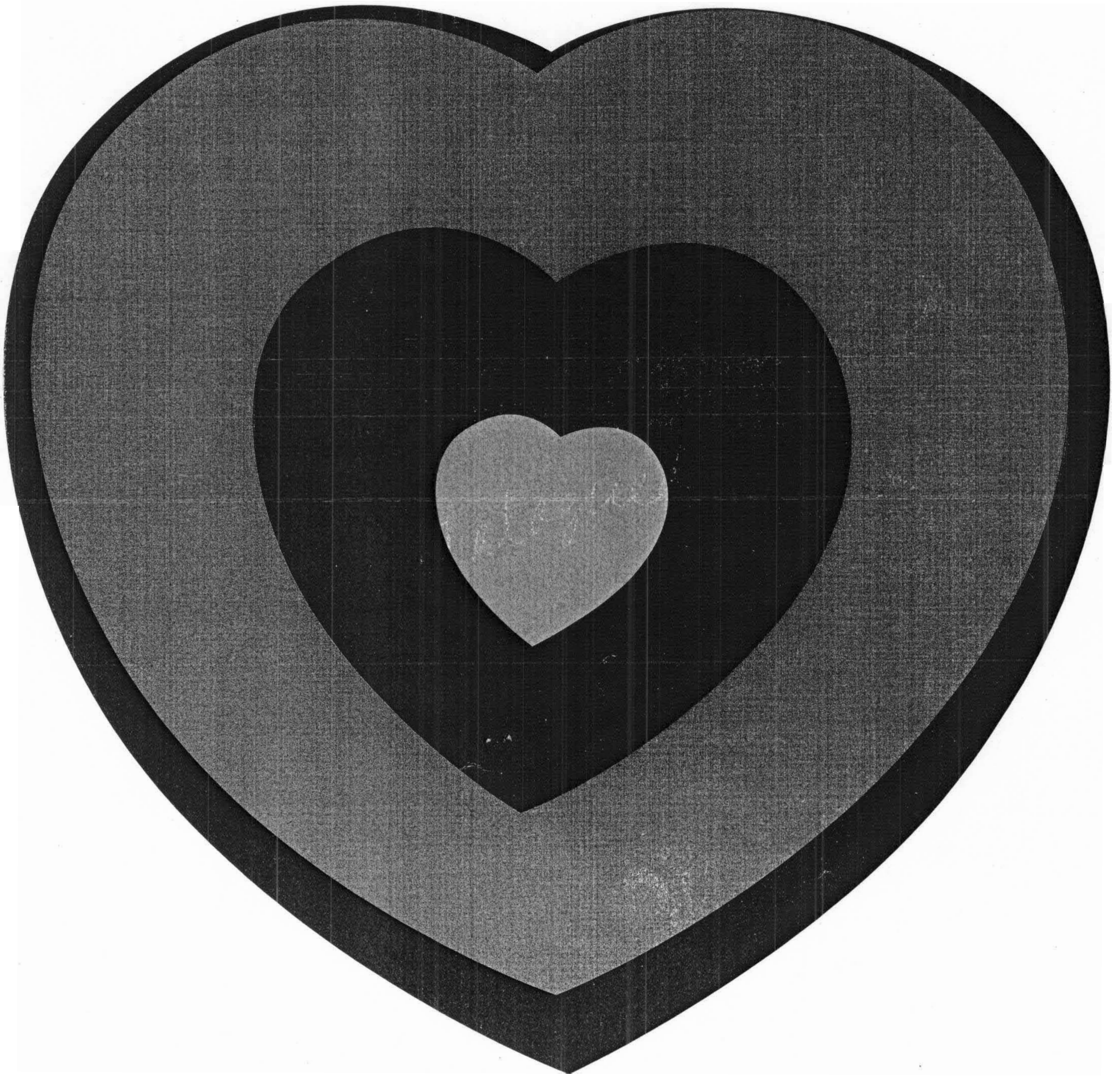
LIVING & SERVING

Persons with HIV in the Canadian AIDS Movement

CHARLES M. ROY, D.S.W.



LIVING & SERVING

Persons with HIV in the Canadian AIDS Movement

(COMPLETE VERSION)

CHARLES M. ROY, D.S.W.

ACKNOWLEDGMENTS

This research would not have been possible without the co-operation of the Canadian AIDS Society, its member organizations, Boards of Directors and staff. A special note of thanks to Grant McNeil, Joan Anderson, Glen Brown, Eric Dow and the Toronto PWA Foundation for their ongoing support.

Thanks to Health Canada who funded my education for three years, between 1989 and 1992, through a National Welfare Fellowship.

Thanks to AA Bronson for permission to reproduce the magnificent art of General Idea on the cover of this publication.

Thanks to Harold Weissman, George Getzel and Gary Anderson from Hunter College and Roy Cain from McMaster University for their support.

Over the past six years, Irwin Epstein has been my professor, academic advisor, chair of my examining committee and friend. Irwin supported and inspired me through times of great discouragement and adversity. His lessons will continue to serve me throughout the rest of my life.

Finally, I would like to thank all the People Living With HIV and AIDS (PHAs) who participated in this research study. Your stories have enriched this study with a powerful truth. Many of you sought reassurance that I would complete this study and that your words would be heard. I hope this report does justice to your experience and brings honor to the memory of those who are no longer with us.

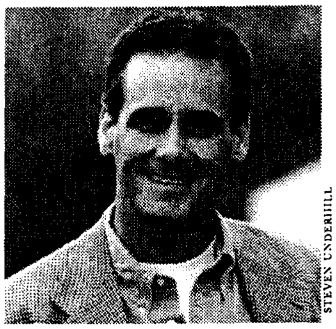
COVER ART

General Idea, *Infected Coeur Volant,* 1993

The three artists of General Idea – AA Bronson, Felix Partz and Jorge Zontal – lived and worked together in Toronto and New York for twenty-seven years. Canada's most infamous artists, they exhibited at museums and galleries all over the world, representing Canada at virtually every major international exhibition, including the Venice Biennale, the Paris Biennale, and the Sydney Biennale. In 1987 they first exhibited their AIDS logo – based on Robert Indiana's famous LOVE painting of 1967 – and began a long series of AIDS-related projects, including poster projects in New York, San Francisco, Toronto, and Berlin; placards on trams in Seattle and Amsterdam; an AIDS animation on the Spectacolor Board in Times Square, New York; a monumental AIDS sculpture in downtown Hamburg; a cover design for the Journal of the American Medical Association; and over forty other AIDS-related projects. Their major installation, *One Year of AZT/One Day of AZT,* has been exhibited internationally, and is now in the collection of the National Gallery of Canada. And other AIDS-related works are in collections of the Art Gallery of Ontario, the Musée des Beaux Arts (Montréal), the Museum of Modern Art (New York), the San Francisco Museum of Modern Art, and the Vancouver Art Gallery.

The image on the cover reproduces their work *Coeurs Volants,* a painting which reproduces a work by Marcel Duchamp from the twenties, but 'infects' the original red and blue design with additional green. It is, nonetheless, an optimistic work: it was one of the last works they were to produce together.

Both Felix Partz and Jorge Zontal died of AIDS-related causes in 1994. AA Bronson continues to live and work in Toronto.



ABOUT THE AUTHOR

Charles Roy is currently Executive Director at the AIDS Committee of Toronto, Canada's largest AIDS service organization. He is a member of the Toronto People With AIDS Foundation and AIDS ACTION NOW! Previously, he served on the Board of Directors of the Canadian AIDS Society where he was the founding chair of the People Living With HIV/AIDS Committee and vice chair of the Board. He has also served as vice chair on the Board of the AIDS Committee of Ottawa. In 1985, he worked for the Montreal AIDS Resource Centre, where he organized the city's first support group for People With AIDS. Other AIDS-related work includes: the Canadian Hemophilia Society, the Canadian Hospital Association, and the Montreal Children's Hospital. In 1986 he served as national president of Dignity Canada, an organization for gay and lesbian Catholics.

Charles graduated from the University of Ottawa in 1984 (B.A., Philosophy) and McGill University in 1985 (B.S.W.) and in 1987 (M.S.W.). He tested HIV positive in 1987, while completing his masters thesis at McGill University in Montreal. Two years later, he moved to Manhattan to enroll in the doctor of social welfare program at Hunter College School of Social Work of the City University of New York. On July 25, 1995, less than two months before the completion of this doctoral dissertation, Charles lost his life-partner, Alan Cornwall, to AIDS.

In memory of

Eric Commerford

1954 - 1993

and

Alan Cornwall

1961 - 1995

Contents

List of Tables

List of Charts

ORDER FORM

Living & Serving: Persons with HIV in the Canadian AIDS Movement.
Written by Charles M. Roy, D.S.W., Executive Director of the AIDS Committee of Toronto and published by the Canadian AIDS Society in 1996. This resource document will help your AIDS organization become more welcoming and accessible to the participation of people living with HIV/AIDS.

Please send me ___ copies of
Living & Serving: Persons with HIV in the Canadian AIDS Movement
(Complete version - English only). Maximum 2 copies.

Please send me ___ copies of
Living & Serving: Persons with HIV in the Canadian AIDS Movement
(Summary - English). Maximum 5 copies.

Please send me ___ copies of
La participation des personnes ayant le VIH au mouvement canadien de lutte contre le sida - Une contribution vitale
(Summary - French). Maximum 5 copies.

- Permission is granted for non-commercial reproduction for educational purposes.
- Free to Canadian individuals and organizations.
- Cost: organizations and individuals outside of Canada, $20.00 U.S. complete version and $10.00 U.S. summary versions.
- Please make cheque or money order payable to the Canadian Public Health Association.
- Payments by VISA account should include account number, expiry date and signature of cardholder.

Name
Organization
Address City
Province/State Country Postal Code
Tel. Fax
VISA Acc't# Expiry Date
Signature

Send to: **National AIDS Clearinghouse,** Canadian Public Health Association
400-1565 Carling Avenue, Ottawa, Ontario CANADA K1Z 8R1
Tel: (613) 725-3434 Fax (613) 725-9826 e-mail: aidssida @ cpha.ca
web site: www.cpha.ca

A Publication of the Canadian AIDS Society

Research Assistants: James Gillett, Catherine Worthington
Design: BrysonDesign

LIST OF ABBREVIATIONS

(Any abbreviation in the text that is not found here is probably an acronym for a member organization of the Canadian AIDS Society. Please see Appendix 4 for full name of organization).

AGM	annual general meeting
AIDS	acquired immune deficiency syndrome
AMFAR	American Foundation for AIDS Research
AAN	Atlantic AIDS Network
ASO	AIDS service organization
CAHR	Canadian Association for HIV Research
CANFAR	Canadian Foundation for AIDS Research
CAS	Canadian AIDS Society
CHS	Canadian Hemophilia Society
COCQ-SIDA	Coalition des organismes communautaires québécois de lutte contre le sida
CPHA	Canadian Public Health Association
GRID	gay related immune disorder
GSO	general service organization
GSO-L	general service organization in large city (population over 200,000)
GSO-S	general service organization in small city (population under 200,000)
HIV	human immunodeficiency virus
KS	Kaposi's sarcoma
OAN	Ontario AIDS Network
OI	opportunistic infections
PAR	participatory action research
PCP	pneumocystis carninii pneumonia
PHA or PLWHIV/AIDS	person living with HIV and/or AIDS
PLWHIV	person living with HIV
POC	people of color
PWA	person living with AIDS or an organization run by and for PHAs
PYLL	potential years of lost life
SC	organization serving a specific community (e.g. distinct cultural group, women, etc.)
SS	organization which provides one specific type of service (e.g. support, education, advocacy, etc.)

PREFACE

As the principal researcher in this study, I am not an entirely objective outsider. My involvement in AIDS has been both personal and professional. I have worked as a hospital social worker in an AIDS clinic and for a family service agency where I specialized in AIDS. My personal and professional involvement in the community-based AIDS movement, in which this research is based, is extensive. I have been on the board of local AIDS organizations as well as the Canadian AIDS Society where I was the first chairperson of the People Living With HIV/AIDS Committee. I am currently Executive Director at the AIDS Committee of Toronto, Canada's largest community-based AIDS service organization.

My first experience of AIDS came in 1985 when, as a recent graduate of the McGill University School of Social Work, I took on a summer job organizing the first support group for people with AIDS in Montreal. I saw first hand that AIDS was as much a social and political phenomenon as it was a medical reality. The following year, Eric, my partner, who has since died, was diagnosed with HIV. In the next year, I tested positive. In the years to follow, my world was filled with friends and lovers who were living with, and dying of, AIDS.

In 1993, while working on this dissertation, I met Alan. For the next two years he was my lover and friend. Alan was an inspired leader within the community-based AIDS movement. For more than four years he was the chair of the board for the Community AIDS Treatment Information Exchange (CATIE) and an active member of AIDS ACTION NOW! He was always supportive of this research and my involvement in the AIDS movement.
On the eve of my completing this dissertation, Alan died of AIDS.

In only ten short years my experience went from a young, curious, idealistic, social-work student to a grass-roots AIDS activist engaged in the battle of, and for, a lifetime. This research is rooted in more than just sound principles and theory. It is rooted in passion.

Because of the direct and severe impact this subject matter has on my life, I have chosen to write much of my doctoral dissertation in the first person. I hope this serves to remind the reader that AIDS is not an illness that only affects the uneducated, powerless, or disenfranchised. I am none of those things now, nor will I ever let this illness render me to such a state. The more powerful force to overcome, however, is the ignorance of others. It is my hope that this work will contribute to fighting the forces of ignorance that exist not only within the Canadian AIDS movement but throughout society.

Dr. Charles M. Roy
May 1996

Nobody should think that they can ignore AIDS or that they're above it or that it is something that they should be ashamed of talking about.

Alan Cornwall,
Lawyer, Person Living With AIDS, and Co-chair,
Community AIDS Treatment Information Exchange (CATIE)
Law Times, 29 May 1995

INTRODUCTION

This introduction provides an historical context for the medical, social, and political phenomenon we now call AIDS. It traces the evolving language we use to describe the illness and the Canadian landscape which the research documents.

Understanding the Illness

Historically, other terms have been used to describe the medical phenomenon most commonly referred to as AIDS. Anecdotal reports of this illness first surfaced in 1979 and doctors noted one commonality with the diseased group; the original cases, in New York, Los Angeles, and San Francisco, were all gay men. Consequently, researchers began calling this new disease Gay Related Immune Disorder, or GRID. The term is believed to have created a false sense of security among those not gay identified, as well as to further stigmatize the gay community. GRID is a term no longer used.

In 1982, reflecting the emerging scientific understanding of this illness, the term Acquired Immune Deficiency Syndrome, or AIDS, was coined, and a clinical definition for the disease was established. AIDS refers to a somewhat arbitrary list of opportunistic infections that have been redefined through the years.

Later that same year, AIDS-Related Complex, or ARC, was added as a second diagnostic category used to describe people who had developed serious health problems as a result of the same underlying immune disorder but who did not meet the established definition for AIDS.

Our ability to understand and describe this illness grew exponentially in 1983, when scientists isolated the human immunodeficiency virus, or HIV, the virus commonly believed to cause AIDS. Two years later, a test to identify persons infected with HIV was developed (Weitz, 1991). Today, we refer to various stages of HIV illness to describe people with HIV who do not have an AIDS-defining illness. The term ARC has since been abandoned.

Simply stated, HIV is a virus that can infect humans and damage their immune system. Once people become infected with HIV and develop a weakened immune system, they become vulnerable to a host of opportunistic infections (OIs). In the past, people diagnosed with AIDS would become ill and die quite quickly. Today, due to more knowledge, earlier diagnosis and better treatments, many people live with HIV longer and healthier. In fact, some HIV-positive people are known to live as long as fourteen years with HIV without ever showing any signs of illness (Whitehead & Patterson, 1993).

Clearly, this shift towards a longer and healthier life has enabled HIV-positive people to acquire organizational skills, become more politicized, and generally gain greater experience, so that they can play a more effective role within the community-based AIDS movement.

PHAs and the Language of AIDS

Many feel it is more useful to describe stages of HIV infection and abandon the somewhat arbitrary distinction between HIV and AIDS. I prefer to link them with the term People Living With HIV/AIDS, or simply PHA. I believe separating the two promotes a false distinction between HIV and AIDS and tells us very little about the state of a person's health. Additionally, the distinction provides some people living with HIV with a false sense of security, but gives others with

AIDS a false sense of despair. Language can feed into a denial about our health, which can be dangerous both to ourselves and others.

Some HIV-positive people who are asymptomatic believe, because they do not have AIDS, that they cannot infect others or that they need not consider any form of treatment. People with AIDS, on the other hand, may believe that treatment is senseless or that, since death is imminent, they do not need to take responsibility for their own lives, and therefore behave irresponsibly. Both of these beliefs are erroneous and dangerous.

Other than a few isolated and unexplainable exceptions, all people living with AIDS have HIV. Therefore, some authors are using the term People Living With HIV (PLWHIV) inclusively to describe all people with HIV disease regardless of their current or past history of illness. However, people with significant illness have a different experience of living with HIV than those who are infected but do not yet have any symptoms of illness. Illness, as well as the awareness of one's infection, brings about serious physical and emotional consequences. To make people living with significant illness invisible would be to render a terrible injustice and lack of respect for their experience. This is why an increasing number of researchers are choosing to use the terms HIV/AIDS to describe the infection and/or illness, and in Ontario the term PHA has been coined to describe the people with the infection and/or illness.

AIDS used to be thought of as a life-long diagnosis that, once imposed, was there regardless of the person's improved health. AIDS, more than any other illness, is loaded with stigmas that have serious consequences to even the most informed. Only through accelerated educational programs will the misleading and harmful rumors and misinformation attached to HIV/AIDS disappear.

At times it will be useful and important to talk about the experience of PHAs based on the degree of illness they are experiencing. At such times, the distinction between those with and without an AIDS diagnosis will be clear. I have also retained the distinction among HIV, ARC and AIDS in quotations and citations to be true to my sources.

AIDS in Canada

AIDS in Canada has reached epidemic proportions. According to Health and Welfare Canada, the federal government department responsible for the reporting of AIDS cases in this country, 11,573 people were either living or have died of AIDS in Canada (Quarterly surveillance update: AIDS in Canada, April 1993). This statistic alone, however, doesn't even begin to address the full scope of this country's problem. It is estimated that between 30,000 – 50,000 Canadians are currently living with HIV (Garmaise, 1993).

Canada has the sixth highest rate of AIDS among industrialized countries – 5.7 of every 100,000 Canadians have AIDS. Since the first known case in 1979, the number of new cases reported has increased each year. In 1992, it is estimated that over 2,000 Canadians were newly diagnosed with AIDS (Garmaise, 1993).

Another measurement of the impact of AIDS is the Potential Years of Lost Life (PYLL). AIDS is the only major disease to have a rapidly rising level of PYLL in Canada. AIDS has surpassed a number of other diseases, including kidney disease and diabetes, in terms of PYLL (Canadian AIDS Society, 1993a).

Although much has been discussed about AIDS not being a gay disease, homosexual and bisexual activity still accounts for over 80% of reported cases of AIDS in this country. Men account for over 94% of reported cases and 89% of these men are between the ages of twenty and forty-nine (Quarterly surveillance update: AIDS in Canada, April 1993).

A sign of the changing face of AIDS in Canada appears when the HIV demographics are examined. Since public health is a provincial responsibility, statistics from provinces, especially those that have implemented anonymous testing sites, are more reliable than federal government estimates. In the province of Ontario for example, the proportion of people testing positive for HIV who are women has risen from 1.3% in 1985 to 9.1% in 1991. In the provinces of Alberta and British Columbia, the proportion of people testing positive for HIV who are women is now close to 10% (Garmaise, 1993). This shift is tragic reminder that AIDS does not discriminat and that the educational messages are not effectively reaching all of our communities.

Although AIDS has penetrated every part of our country, it has been particularly devastating in large metropolitan areas. Eighty-nine (89) percent of all known cases of AIDS in Canada are found in Ontario, Quebec, and British Columbia. Toronto, Montreal and Vancouver are these provinces' largest cities and are Canada's only three cities with populations over one million. Provincial statistics confirm that the overwhelming majority of AIDS cases in Canada are within these three cities. Studies have shown that in Vancouver, which has a much higher incidence of HIV than the national average, HIV infection has surpassed heart disease and all cancers combined as a reason for PYLL among men. This is probably also true of Toronto and Montreal (Canadian AIDS Society, 1993a).

Medical Realities of HIV/AIDS

To truly understand HIV/AIDS, one needs to examine both the medical and social dimensions of the illness. Medically, HIV illness is devastating. The virus attacks a person's immune system rendering him/her increasingly defenceless to an ever-growing list of opportunistic infections. Many of these infections appear minor, such as fungal infections, but the body's compromised immune system prevents, or inhibits, the effectiveness of conventional treatments. Minor infections therefore can become persistent and often develop into more serious ailments.

More serious to PHAs are concerns around major opportunistic infections. In Canada, Pneumocystis Carninii Pneumonia (PCP), Kaposi's Sarcoma (KS), a once rare form of cancer now prevalent among PHAs, HIV Wasting Syndrome, and HIV Encephalopathy are the most common diseases among People Living With AIDS. These, as well as numerous other infections, can be both debilitating and life threatening.

The actual state of a person's physical health will play a large part in determining what role he/she can play and wants to play in the community-based movement to fight AIDS.

Social Dimensions of HIV/AIDS

Because gay men were the first to be identified with the illness, the community response to fighting AIDS throughout the Western world, including Canada, grew largely out of the gay and lesbian community. Many PHAs remain afraid to disclose their health status for fear of discrimination caused by a society's fear and ignorance of both homosexuality and life-threatening illness.

Today we know that AIDS affects all segments of society, yet the stigma persists. Unlike any other illness, men and women with HIV/AIDS, regardless of sexual orientation, race or class, remain fearful of society's response to them. Most remain secretive, and many forego the opportunity for education and proper medical treatment, in order to hide their illness from those most able to provide them with support.

For PHAs who keep their diagnosis 'closeted', the opportunities for community activism are limited. Some 'closeted' PHAs will volunteer in AIDS organization under the guise of responding to a need within a community in which they identify. For those 'closeted' as being both gay and a PHA, involvement in an AIDS organization would be treated with great suspicion, and most would not be able to come forward.

Fear created by stigma, as well as the deterioration of one's health, are significant barriers for PHAs to overcome in order to actively participate in their care and the organizations providing this care. Ongoing medical research and large-scale public education campaigns will be needed before many PHAs will be able to embrace the 'self-help', activist nature of the AIDS movement.

This research acknowledges these larger societal barriers facing many PHAs, but specifically focuses on how community-based AIDS organizations inadvertently create their own, additional barriers. This research also focuses on how organizations can work toward creating an environment that facilitates greater and more meaningful participation of PHAs.

CHAPTER 1

The Principles of Self-Help within the Canadian AIDS Movement

The AIDS movement has challenged the popular view of health care and the traditional relationship between those providing and those receiving this care. AIDS has helped move the medical model – from where the caregiver is the expert and the patient the beneficiary of this knowledge – to a place where the patient plays a much more vital role in decisions that affect his or her life. In the introduction to his book, The Fragile Coalition, Dr. Robert Wachter (1991) writes,

> *Having our patients or research subjects ask – or demand – to have an active voice in what we do and how we do it may be challenging, time consuming, and even unpleasant. It is also undeniably right.*

Wachter believes that the AIDS movement brought with it a new generation of activism that has altered how medicine is practiced.

> *In the history of medicine there has never been a politically savvy, unified group that found itself at risk for a deadly disease. (. . .) gays, already politically mobilized from their gay rights experience in the 1970s, were organized and prepared to do battle (p. 65).*

PHAs – people infected with the human immunodeficiency virus (HIV) as well as those who are ill with acquired immunodeficiency syndrome (AIDS) – have worked, with others affected by HIV and AIDS, to forge a new, progressive model of fighting illness. PHAs have a unique and important role to play within this self-help model of health care. Many PHAs see doctors, psychotherapists and other professional caregivers as simply partners in their care. Others see themselves as the real decision-makers in their own care, with professionals being consultants on whom they rely for certain information. This new attitude not only challenges the way in which medical professionals relate to PHAs, but also how social services and all forms of care are provided. This research examines the role of PHAs in the context of the community-based AIDS movement in Canada.

Canadian AIDS Society (CAS)

The Canadian AIDS Society is a rapidly growing national coalition of community-based organizations involved in the fight against AIDS. CAS now (1995) comprises over 100 organizations. CAS is generally regarded world-wide as a successful model for community organizing. Although CAS is not the only national AIDS coalition, it is the largest, most successful and most representative of the various communities affected by AIDS in Canada. The overwhelming majority of community-based AIDS organizations in Canada have membership within CAS which holds self-help as one of its guiding principles:

> *Our principles include the empowerment of people living with HIV/AIDS (PLWHIV) by ensuring their direct involvement in the decisions that affect their lives and in the organizations that serve their needs. (Canadian AIDS Society, 1991a).*

Other national AIDS organizations include: the Canadian Hemophilia Society (CHS), representing the interests of people with hemophilia, including those with HIV or AIDS; the Canadian Public Health Association (CPHA), involved in various health concerns and which established a national advisory committee on AIDS; the Canadian Association for HIV Research (CAHR), an organization of researchers, primarily medical doctors; the Canadian Foundation for AIDS Research (CanFAR), which was modelled after AmFAR, the American AIDS organization made famous by Elizabeth Taylor for their fund raising on behalf of AIDS research; and finally, the National Organization for People Living With HIV/AIDS (Network), a struggling, loosely defined collection of PWA organizations from different parts of the country.

CAS was founded in 1986 by a group of people, primarily gay men and lesbians, from sixteen cities across Canada. Each of the sixteen founding organizations provided a full range of services under three broad categories: education, support, and advocacy. These organizations served the general community as well as provided specific services to a more homogeneous, or target, group. The focus in the early years of this movement was almost exclusively on the gay community, the group most affected.

Self-Help

Self-help has always played an important role in the development of the community-based AIDS movement in Canada. Gay men and lesbians were at the forefront of this movement, responding to the critical needs of their own community. Later, as the epidemic spread so did the self-help nature of the AIDS movement. Community-based AIDS groups have emerged out of various ethno-cultural communities. People of color, including Canada's aboriginal people, have established numerous AIDS organizations to respond to the needs of their own communities. Women, youth, prostitutes and prisoners have also established AIDS organizations, signalling specific needs which they believe a self-help approach could address better than a general service organization.

Not only were community groups being formed based on geography and identity, but also activity. Organizations specializing in a specific service area such as treatment information, housing or advocacy now form a significant part of the national coalition.

The largest growth of self-help groups within the AIDS movement has been among PHAs. People With AIDS (PWA) organizations, as they are historically referred to, grew largely out of a frustration that general service organizations were not being sufficiently attentive or responsive to their needs. PWA groups were established to provide peer support and advocacy specifically for, and by, PHAs. It was commonly believed that very few PHAs were actually being involved in the operation of general service organizations, either at a staff or board level. This, despite the fact that many of these organizations were created by PHAs.

The community-based AIDS movement being studied is therefore defined not only by geography, but by identity, interest, and condition.

Outline of Study

The purpose of the research was threefold: first, to assess the degree and nature of the current involvement PHAs have within the community-based AIDS movement in Canada; second, to determine what barriers are present as well as what strategies are being utilized which affect the participation of PHAs within this movement; and finally, to assist in the development of new strategies and recommend policy changes that will help groups overcome barriers being faced by PHAs.

Chapter 2 will attempt to place this study in a broader context. Literature on self-help and volunteer organizations, especially those involved in the health field, will be examined. This review will help us understand the extent to which other organizations have made use of the individuals they intend to serve. PHAs may find that others have journeyed on a similar path in an attempt to involve themselves in organizations that serve their needs.

Chapter 3 describes the research methods used in this study, and Chapter 4 outlines how national coalitions have influenced the participation of PHAs within the community-based AIDS movement in Canada.

The next three chapters look at specific research findings in this study. Chapter 5 gives an overview of these findings. Descriptive data provides information about the degree and nature of PHA involvement throughout the membership of the Canadian AIDS Society. Five independent variables – type and size of the organization, size of the city, as well as region of the country in which the organization is located, and finally the length of time the organization has been established – will be highlighted to see if any clues exist to why some organizations have a higher degree of PHA participation than others. Each of these variables will be measured against the level of

PHA participation on both the staff and the board of directors of these organizations.

Chapter 6 examines the perceived advantages of involving PHAs in the life of AIDS organizations. Chapter 7 focuses on the perceived barriers PHAs experience that prevent greater or more meaningful involvement. Both the organization's and PHAs' perspectives will be documented.

Chapter 8 summarizes the research findings as well as provides recommendations for change.

CHAPTER 2

Literature Review

Over the last decade, much has been written about HIV and AIDS. As a result, reviewing the literature requires a clear purpose to serve as a guide through the volumes of articles, books, reports and anthologies on the complexities of the disease, and the response of communities to HIV and AIDS. This chapter has two purposes. First, it provides the social context for the current involvement of PHAs in AIDS organizing, by tracing the social and political development of the community-based response to HIV and AIDS. Second, it compares the struggle of PHAs to participate in the AIDS movement with other social movements in health which use a self-help model of organizing.

Even with the extensive literature on HIV and AIDS, there are gaps that limit the scope of this chapter. First, little has been written on the history of the PWA movement and its impact on HIV and AIDS. Indeed, one of the purposes of this report is to address the lack of documented discussion in this specific area of HIV research; however, this means that there is little previous work on which to draw.

A second issue, identified by Cain (1993), is that "despite their importance in the Canadian response to the HIV epidemic, AIDS service organizations have been the subject of relatively little systematic study" (p. 1). Most of the literature on community-based AIDS organizing is written from an American perspective (Stoddard, 1989). This focus is understandable considering, as Bayer & Kirp (1992) note, that "the United States has been most influential in shaping social attitudes and policy responses to AIDS" (p. 7). There is, however, an emerging interest in examining the community response to HIV and AIDS outside of the United States. With the global impact of this disease becoming more apparent, there have been recent works which compare AIDS organizing in industrialized democracies (Bayor & Kirp, 1992), across cultures (Herdt & Lindenbaum, 1992), and in developing nations (Altman, 1993; Carter & Watney, 1989).

There are similarities between the Canadian and American response to the AIDS epidemic. However, it is important to recognize the unique aspects of the Canadian community-based AIDS movement, especially when looking at the experiences and involvement of PHAs in the diverse range of ASOs (AIDS Service Organizations) in communities across Canada. This chapter, then, draws on Canadian resources as much as possible, including literature published by community-based ASOs, and uses American and other international sources when necessary.

The Social Context of Community-Based Organizing

The community-based response to HIV and AIDS has been crucial to the struggle against the epidemic, and continues to be at the forefront of AIDS activism, prevention, and care (Clausson, 1989; McGuire, 1989; Jonsen & Stryker, 1993). Sears (1991) describes the community-based AIDS movement as a

> *diverse set of responses to the AIDS crisis counterposed from the onset to that of public health and other state agencies. . . . These organizations range from relatively large staffed agencies following a conventional social service model, to People With Aids (PWA) groups based on philosophies of self-help, to*

> *activist groups committed to mobilization for social change . . . (p. 43).*

This section traces three broad phases in the community-based AIDS movement. First, the early organizing efforts of lesbian and gay communities. Second, the development of AIDS service organizations, what has been referred to as the AIDS service industry (Patton, 1990). And lastly, the formation of a PWA movement, and its impact on the community-based response to HIV and AIDS.

Dividing the history of community-based AIDS organizing into three phases follows the work of Weeks (1989). These phases have been modified because of the focus on community-based ASOs, where as Weeks's work centers on the social responses to HIV and AIDS. This chapter is not intended to represent the only history of AIDS organizing. In fact, there are numerous ways in which this history can be organized and conceptualized, depending on the purpose of the written project (see Berridge, 1992). In addition, there has been considerable interest in the history of the HIV epidemic (see especially Fee & Fox's two anthologies AIDS: The Burdens of History (1989), and AIDS: The Making of a Chronic Disease, (1992) as well as the British anthologies AIDS and Contemporary History by Berridge & Strong (1993) and The Time of AIDS by Herdt & Lindenbaum (1992).

Continuity of activism

The community-based response to AIDS emerged out of organized lesbian and gay communities within large urban centers (Cain, 1993). This relationship – between the gay and lesbian political movement and AIDS organizing – has been addressed in several texts on the early history of the epidemic (Altman, 1986; Patton, 1985; Padgug & Oppenheimer, 1992; Kayal, 1993). This literature is useful as it documents the 'prehistory' of AIDS organizing (Berridge, 1992). Of particular significance is the lineage between the political organizing of lesbian and gay communities in the 1970s and the development of a community-based AIDS movement.

Patton (1990: pp. 139-140) argues that Shilts's (1987) And the Band Played On, as well as other writings on the early history of the AIDS crisis (see "Facing AIDS" issue of Radical America, vol. 20, no. 6, 1987), have down-played the role of political organizing by lesbian and gay communities in responding to the epidemic and laying the foundation for the broader AIDS movement.

The Stonewall riot in New York in 1969 is considered to be the catalyst for a broad-based political consciousness around issues of sexual liberation and civil liberties within lesbian and gay communities (Adam, 1987). The resulting gay and lesbian political movement used the ideological aims and tactics of earlier civil rights and feminist movements as a means of struggling toward, as Padgug & Oppenheimer (1992) write, eliminating

> *discrimination and persecution by the organs of the state, church, the police and the medical and psychiatric professions; removing the stigma associated with homosexuality; and achieving public recognition of the legitimacy of homosexuality and the homosexual community (p. 250).*

This activism during the 1970s led to the formation of a political ideology based on a gay liberationist critique of oppressive social institutions, especially the medical establishment (Kinsman, 1987; Pawluch et al., 1994). Part of the politics included the development of local and national organizations as well as public spaces for gay cultural institutions such as bars, bathhouses, social groups, and gay and lesbian publications (Adam, 1987; Kinsman, 1987; Patton, 1985). For more information on the political history of the gay and lesbian movement, see Adam (1987) on the rise of the movement, and Teal (1971) and Marotta (1981) on the activism and political tactics of gay and lesbian groups in the 1970s.

By the early 1980s, there was an organized gay and lesbian community in most large cities in North America (Altman, 1982; Kinsman, 1987). When the first incidents of AIDS were reported, gay men and lesbians had the organizational and ideological means to develop educational programs and outreach services for those who were most severely affected by the disease.

While the interests of gay men and lesbians to some extent coalesced in the post-Stonewall era, there continued to be tensions, especially around issues of sexuality (Patton 1990). This can be seen in the involvement of lesbians in the politics of women's health, and the rise of an independent lesbian/feminist critique of the medical establishment in the 1980s (Winnow, 1992; Cain, 1993). The activism of gay men, in contrast, focused more on issues of sexual liberation, and, as

Altman (1986) writes, despite considerable health problems " . . . most gay men, even most activists, failed to incorporate health issues into any overall political analysis . . . " (p. 93).

The rapidity and success of early AIDS organizing efforts, however, did come about because of the knowledge and expertise that gay men and lesbians brought from previous organizing and activism. In particular, lesbians brought to this early response a feminist critique of health care and a model of organizing around health issues which emphasized self-empowerment, peer support, and peer education (Dreifus, 1970; Banzhaf et al., 1990). In addition, the mobilization of volunteers, mostly from gay and lesbian communities, made early attempts at AIDS organizing possible (Kobasa, 1991; Chambre, 1991; Kayal, 1993).

In American cities the outreach services directed at gay men were successful; however, early community-based efforts to reach ethnic communities affected by AIDS, especially Haitians, faced opposition because of cultural differences and homophobia (Altman, 1986; Patton, 1990). AIDS services in ethnic communities tended to develop out of existing social services (Porter, 1988; Delgado & Delgado, 1982). In Canada, however, there appears to have been less tension between gay/lesbian groups and ethnic groups in the early response to AIDS, especially in Toronto and Montreal (Cain, 1993; Schecter, 1990).

In AIDS in the Mind of America, Altman (1986) sketches the development of the first two AIDS service organizations to emerge from this early response, the Gay Men's Health Crisis (GMHC) in New York, and the Shanti Project in San Francisco. Several studies have been written on the early development of these two organizations (Arno & Hughes, 1989); in particular, there have been several studies on the mobilization and use of volunteers at the GMHC (Kayal, 1993; Chambre, 1991), and on the model of care and community-based service provision developed by the Shanti Project (Arno, 1986).

In contrast, less attention has been spent studying the development of ASOs in Canada. An exception is Cain's (1993; 1994) work on comparing AIDS service organizations in Ontario. In the case of the AIDS Committee of Toronto, Cain writes (1993) that,

> *In the early 1980s, Toronto had a wide range of gay and lesbian organizations, and these pre-existing institutions were used to organize a quick and co-ordinated response. Education forums organized by The Body Politic Collective, Gays in Health Care, and the Hassle Free Clinic lead to the establishment of the AIDS Committee of Toronto (p. 21).*

Cain argues that gay and lesbian communities were crucial in the early response to AIDS and the establishment of community-based ASOs, in all three Ontario cities studied – Toronto, Hamilton, and Thunder Bay.

This literature demonstrates that the presence of gay and feminist organizations, and responsive lesbian and gay communities, led to the development of the community-based AIDS movement (Kawata, 1989). The implication of this lineage is that the aims and structures of early AIDS service organizations were, as Kinsman (1991) writes, "informed by gay movement politics and by the feminist health movement's emphasis on empowerment."(p. 216).

The oppositional politics of early social movements would become an important part of the community-based AIDS movement's response to the epidemic. Patton (1990) suggests that the AIDS crisis provided an opportunity for gay men, many from higher social positions, to become involved politically in gay and lesbian organizations. The result was that there was a large pool of volunteers who wanted to be involved in AIDS organizations, but many of whom had little previous history of political organizing.

It is also interesting to note that governments in countries where there is more tolerance of the gay and lesbian movement reacted much faster with funding and support for the community-based response to HIV and AIDS (Patton, 1990; Kirp & Bayer, 1992).

Community-based AIDS service organizations (ASOs)

The need to develop and maintain AIDS service organizations in the early 1980s transformed the gay and lesbian movement. Padgug & Oppenheimer (1992) provide a detailed discussion of the long-term effects of the AIDS crisis on the gay and lesbian movement.

Winnow (1989), writing as an activist, claims that the AIDS/ARC crisis and its ensuing organizations became the lesbian/gay movement, and nearly all other issues took second stage.

> *At the same time as the AIDS crisis devastated those affected by the disease, and divided gay activists on issues of sexuality, it brought communities together in unprecedented ways to face the challenges of the epidemic. (p. 69).*

Gay and lesbian identities tend to be very diverse, cutting across lines of gender, race, class, and sexuality (D'Emilio, 1989). The AIDS crisis brought these communities together in organizing efforts (Patton, 1985). The issue of diversity, however, continues to be an ongoing source of tension in AIDS organizing, especially as HIV begins to infect communities other than gay men, such as women and injection drug users (Cain, 1993).

Literature on the community-based response to AIDS has identified a number of social and political factors which have influenced the development of ASOs. One of the most significant changes, especially for PHAs, is the increasing formalization and depoliticization of ASOs over the past decade. The main force contributing to this shift is the increasing involvement of the state and health professionals in the community-based response to HIV and AIDS. Cain (1993), drawing on the work of Smith (1977), notes that "involvement with the state and the receipt of regular funding contribute to the formalization and bureaucratization of community organizations" (p. 666).

This institutionalization has occurred in a range of community organizations when they collaborate with the state, including women's groups (Rodriguez, 1988; Schechter, 1982; Staggenborg, 1988), Black political organizations (Marger, 1984), farm workers (Swartz et al., 1981), anti-poverty groups (Piven & Cloward, 1977), and native groups (Pearl & Riessman, 1965).

Early in the AIDS epidemic, especially with the American and Canadian political climates shifting to the right, state structures and public health were initially unresponsive to HIV and AIDS (Sears, 1991; Rayside & Lindquist, 1992). Combined with a strong attack on the gay and lesbian community from the right, the early years of the epidemic saw AIDS organizations receive little support from the left and liberal social movements, despite a common history in oppositional politics. As Patton (1985) notes, "no broad coalition effort has materialized, as neither the left pursues the AIDS issue nor do the primarily lesbian/gay organizations pursue leftist support" (p. 154).

This meant that gay and lesbian communities were isolated in their early efforts at AIDS organizing, with the exception of some allies in the health professions and community services. (Winnow, 1992; Patton, 1990; Alperin & Richie, 1989; Cain, 1993). This isolation was further compounded by the media and general public, who reacted to AIDS, and those communities infected and affected by HIV and AIDS, with fear and hostility, intensifying the stigma associated with the disease (Weeks, 1989; Crimp & Rolston, 1990).

By the mid-1980s, pressure from AIDS activists and the growing perception of AIDS as a public-health threat meant that governments in most industrialized democracies began to respond to the epidemic (Kirp & Bayer, 1992). The perception of AIDS as a public-health threat, which was reinforced and reproduced in the representation of HIV and AIDS in the media, greatly influenced the response to HIV and AIDS by public health and the state (Crimp, 1988). Consequently, AIDS activism has focused on responding to forms of discrimination against gay men and PHAs, and also demanding state funding to community-based efforts to provide support and services to those communities already affected and infected by HIV (Epstein, 1991; Kinsman, 1991).

Integrated into this response was a commitment to support community-based AIDS organizations. A network of AIDS organizations was in place, and the health-care policy of most industrialized democracies already viewed community health services as a cost-efficient and effective means of providing support and education (Rayside & Lindquist, 1992; Sears, 1991; Cain, 1992b).

In Inventing AIDS, Patton (1990) argues that this government funding and involvement in ASOs led to the professionalization of AIDS service organizations in America. MacLachlan (1992) also notes that the community-based response to AIDS in the United Kingdom, while initially focusing on self-help and group empowerment, has given "rise to more formally constituted organizations, usually modelled on conventional, hierarchical structures" (p. 434).

In both cases, the institutionalization of ASOs is criticized because it contradicts the earlier, more political form of AIDS organizing, based on gay liberation politics, community building and self-empowerment (Segal, 1989).
This trend toward formalization and depoliticalization is also evident in community-based AIDS organizations in Canada (Cain, forthcoming; Sears, 1991). At the end of the 1980s, after years of limited support to groups responding to the AIDS epidemic, the federal government in Canada formulated Phase I of its National AIDS Strategy. While AIDS organizers and activists were involved in this process, Sears (1991), following the work of Kinsman (1991), argues that,

> *the Canadian government's AIDS strategy has tried to develop a "partnership" with community-based groups, with the state providing the funding and receiving relatively cheap services. This partnership includes "guidance," so that an increasing degree of state regulation comes along with funding and a consultative process (p. 45).*

The rhetoric of community partnerships expressed in the federal government's AIDS strategy created a situation were ASOs had little choice but to serve the interests of the state and public health, at the expense of the communities they were intended to represent. The state involvement at the level of consultation and guidance meant that funding would be allocated to AIDS education and prevention, and less time and energy would be spent on programs and services designed to empower communities infected and affected by HIV and AIDS, and political activism directed at issues which impacted the lives of PHAs (Kinsman, 1991; Rayside & Lindquist, 1992). See Rayside & Lindquist (1992) for a discussion of the relations between community-based AIDS groups and government policy in three cities in Canada – Toronto, Vancouver, and Montreal – during the 1980s until the development of a federal AIDS strategy in 1989.

In Phase II of the National AIDS Strategy, while prevention, education, and research were still priorities, Health and Welfare Canada also recognized the need for more funding initiatives around care, treatment and support for persons living with HIV/AIDS. This response to the need for programs that focus on care, treatment, and support does not indicate an increase in funding from the federal government, but a shift in emphasis from education and prevention to support and care. In relation to partnerships between government and community-based AIDS organizations, Phase II of the National AIDS Strategy (1993) states that the AIDS Community Action Program (ACAP)

> *will continue efforts to assist community-based organizations to identify local and national issues and to help mobilize a community response to HIV disease and AIDS. ACAP will also seek to enhance participation of people living with HIV disease and AIDS in ACAP efforts (p. 18).*

The acknowledgement by Health and Welfare Canada of the role of PHAs in the community-based response to HIV/AIDS, and the importance of funding for support and care, indicates the inroads that have been made by PHAs and the PWA movement over the past decade. However, the 'partnerships' between the state and community-based organizations articulated in Phase I and Phase II of the strategy still largely reflect the interests of government rather than the needs and concerns of communities living with HIV and AIDS.

This form of state management encourages ASOs to adopt a model of service provision that contradicts the initial aims of the community-based AIDS movement. As ASOs become more like traditional voluntary health organizations, they are less able to address political and social issues such as homophobia, racism, sexism, and access to treatments (Smith, 1988; Cain, 1993b). The organizational changes in ASOs correspond to a general trend toward the 'degaying' and normalization of AIDS as the spread of the disease remains primarily in marginalized communities and is perceived to be a chronic, but manageable, rather than a terminal condition (Cain, 1993a; Fee & Fox, 1992).

Furthermore, this organizational model encourages professionalism in service provision, reinforcing the division between 'expert' and 'client.' The presence of this professional ideology inhibits the extent to which PHAs are able to participate meaningfully in community-based AIDS organizations (Cain, 1993b). Thus, increased relations with the government meant that ASOs were able to secure funding, but in doing so have become less accountable and responsive to the communities most affected by HIV and AIDS (Kinsman, 1991).

Most literature on the development of community-based AIDS organizations is based on the experience of large U.S. cities. Recently, there is more interest in the development of specific community-based AIDS organizations in cities and communities other than Los Angeles, New York, and San Francisco. See, for instance, Altman (1986) on the development of ASOs in smaller American cities, Carpenter (1988) and Kessler et al. (1988) on the development of the AIDS Committee of Massachusetts, Cain (1993a; 1993b; 1994) on the organizational management and changes of ASOs in Canada, and MacLachlan (1992) and Aggleton et. al. (1993) on the evolution of ASOs in the United Kingdom.

Striving and thriving with AIDS

The disregard shown by the state, public health, and the media toward communities infected and affected by HIV and AIDS, combined with the institutionalization of ASOs, served as a catalyst for the emergence of a politicized PWA movement, and the expansion of PWA organizations (Crimp, 1988; Crimp & Rolsten, 1990; Callen, 1990). As Patton (1990) argues:

> *the [PWA] movement was initially a self help movement which ran parallel to the emergent ASOs, but quickly grew into a coalition of local groups which were dissatisfied with the increasing bureaucratization of the AIDS service organizations. . . (p. 10).*

The PWA movement provided an opportunity for PHAs to address collectively the material and symbolic issues which affected their ability to live with HIV and AIDS, such as demanding access to treatments, and fighting against the stigmas associated with HIV and AIDS (Adam, 1992; Weitz, 1991). The literature on the PWA movement is useful as it traces the development of a political ideology that has encouraged PHAs to become more involved politically in all levels of the community-based AIDS movement.

Unfortunately, the role of the PWA movement in the community-based response to AIDS has received little attention from historians or social scientists. (For research on the experience of living with HIV and AIDS see O'Brien [1992] and Weitz [1991]). The history of the PWA movement, however, has been written by PHAs, primarily in two self-help volumes entitled Striving and Thriving with AIDS.

Despite attempts at diversity, for the most part the two volumes represent the voices of gay men. A similar text has been produced by women, entitled Women, AIDS and Activism and was produced by the ACT UP New York Women and AIDS Book Group (1990). In Canada, Andrea Rudd and Darien Taylor (1992) edited a related anthology, Positive Women: Voices of Women Living With AIDS, which is an international collection of narratives by women living with HIV and AIDS.

A section of Striving and Thriving with AIDS chronicles the history of the movement because, according to Callen & Turner (1988),

> *those of us left standing feel a responsibility to explain to those generations of people with AIDS who will follow how a PWA self-empowerment movement was born based on the breathtakingly obvious concept that people with AIDS ought to participate in those processes where decisions are made which directly affect our lives. (p. 288).*

The two anthologies urged PHAs to empower themselves by rejecting the 'victim' label associated with AIDS, taking control over their health, and fighting for their civil rights.

This political ideology was initially formulated in 1983, when a contingent of PHAs from New York and San Francisco met at the Second National AIDS Forum in Denver. This group of PHAs wanted to represent themselves at a major AIDS conference. By participating in a conference entitled "Health Pioneering in the Eighties" they asserted themselves as 'experts' in the area of AIDS, rather than passive 'victims'. The conference led to "the Denver Principles," a series of recommendations to health-care professionals, the general public, and other PHAs, which emphasized the rights and abilities of PHAs to make decisions about health care and other issues that affect their lives (Callen, 1987). In 1989, AIDS ACTION NOW!/Toronto, Réaction Sida/Montreal and ACT UP/New York combined to write the

Montréal Manifesto.[1] This work builds on the issues outlined in the Denver Principles, and declares the universal rights and needs of people living with HIV and AIDS. AIDS activists presented the document during their demonstration at the opening ceremonies of the Fifth International AIDS Conference in Montreal (TPA News, 1989).

These principles soon led to the development of autonomous PWA organizations in San Francisco and New York. Soon afterward, PWA organizations emerged in cities across North America and the National Association of People with AIDS was formed. In Canada, the first PWA group was formed out of a sub-committee at AIDS Vancouver in 1986. A similar group developed in Toronto in 1987 with the assistance of the AIDS Committee of Toronto, and in 1988 became the Toronto PWA Foundation (Rayside & Lindquist, 1992).

PWA organizations have focused on providing PHAs with practical support, such as financial assistance, treatment information and affordable alternative therapies, as well as on creating a supportive environment for PHAs to empower themselves by becoming involved in support groups and other self-help programs. This mandate makes sense given the model of organizing developed by many PWA groups. Patton (1990) describes this form of organizing as,

> *a hybrid between a gay liberation/identity model and the lobby/self-help model of such health-related groups as the Multiple Sclerosis Society . . . , which similarly create micro-cultures of diverse people sharing a common medically-related experience. (p. 10).*

As part of the PWA movement, self-help organizations enable PHAs to develop a cultural and political identity and community by sharing their common experiences of struggling to live with HIV and AIDS.

With the development of AIDS activist groups such as ACT UP and AIDS ACTION NOW!, PWA self-help organizations have devoted less energy to political advocacy. AIDS activist groups are independent of PWA organizations; however, they have nonetheless been shaped by the political ideology of the PWA movement. The activism of ACT UP, for instance, targets governmental, medical, and pharmaceutical policies that block access to treatments and other resources which would help PHAs live longer (Carter, 1992). For discussion of the debate regarding anonymous testing between public-health officials and AIDS activists see Bayer (1989) and Carter and Watney, (1989).

One of the issues that the PWA movement has faced is the diversity of people living with AIDS. This diversity has made PHAs become more aware of the needs and concerns that bind them together as a community. At the same time, the issue has also highlighted how homophobia, sexism, and racism impact different communities affected by HIV and AIDS. In terms of the PWA movement, the fact that HIV and AIDS has affected communities from all sectors of society has provided an opportunity for groups of PHAs to build coalitions. The advantage of this type of collaboration is that groups of PHAs are able to share resources, work collectively toward common goals such as funding programs and access to treatment information, generate more public awareness about HIV and AIDS and, as a result, reduce the social stigma.

While diversity has been a source of strength for the PWA movement, it has also created tensions. As Cain (1993) has noted, efforts by community-based organizations to recognize issues of gender, race and sexuality can complicate efforts to organize around the common needs and concerns of PHAs. In addition, as is the case with other identity movements (also referred to as new social movements), not all HIV-positive women, people of color, gay men and lesbians, heterosexuals and people from different social classes are able to embrace HIV and AIDS as a collective social identity, or feel comfortable as a part of the HIV and AIDS community.

Despite the tensions created by diversity, the empowerment ideology of the PWA movement has helped PHAs gain access to treatments, develop strategies for living longer, and become more involved in AIDS organizing (Cain, 1993a).

---

[1] TPA News (1989) reports that the authors of the Montréal Manifesto were ACT UP/Toronto and ACT UP/New York. The authors of the Montréal Manifesto were in fact AIDS ACTION NOW!/Toronto, ACT UP/New York and Réaction Sida/ Montreal. Tim McCaskell, past chair of AIDS ACTION NOW!/Toronto, verified this information. ACT UP has never had a chapter in Toronto, and the Montreal chapter was not yet formed in 1989.

It is becoming evident that this involvement is having an impact on the community-based AIDS movement. For instance, especially in larger cities in Canada, new forms of PWA organizing have emerged which either offer specialized services to PHAs, or direct their services toward a specific community of PHAs. One of these groups is Voices of Positive Women in Toronto. This group was developed by and for HIV-positive women:

> *We would like women living with HIV and AIDS to work together and build a strong voice. "Voices of Positive Women" hopes to build an organization which reflects the way women live, work, and respond to the challenge of serious illness (CASN, 1992, p. 5).*

In the case of women and AIDS, there is also an expanding international network of PWA organizations by and for women who are HIV positive (O'Sullivan & Thomson, 1992).

In addition to forming new AIDS groups, PHAs are also becoming more politically involved in broader AIDS organizing. As Rector (1991) argues, PHAs involved in large ASOs are beginning to assert that

> *the health potential of persons with HIV/AIDS has not been maximized. In part this is because our voice has not been heard with equal respect within the current structures established in the field of AIDS. Since the beginning, we have identified and articulated our role as active participants in designing, implementing and evaluating HIV/AIDS programmes, services and policies (pp. 3-4).*

In his study of ASOs in Ontario, Cain (1993a) notes that,

> *people living with HIV and AIDS have . . . pushed to increase the numbers of PHAs who are hired in influential positions in the organization to help ensure sensitivity to their needs and issues (p. 44).*

This political involvement has forced ASOs to reconsider their aims and structures, including hiring and employment policies, the availability of wellness programs and other services, and the traditional separation of education and support departments (Cain, 1993a). The recent interest by ASOs in health promotion and the health needs of PHAs is an example of the political impact of PHAs in community-based AIDS movement (Trussler & Marchand, 1993).

Community-Based Organizing and the Politics of Health

Dennis Altman (1993) recently argued that community-based AIDS organizing is subversive because "it challenges the 'expert' control of knowledge and the state's control of policy" (p. 1). The challenges that Altman refers to stem from a still-contested politics of living with HIV and AIDS which emphasizes the empowerment of PHAs and the importance of their involvement at all levels of AIDS organizing. Many PHAs see themselves as the 'new experts' in managing their own health, with professionals playing the role of consultants. In this sense, the AIDS movement shares a common history with other social movements in health which emphasize the role of self-help within community organizing.

Since the 1970s, a number of community-based movements have emerged, as Sears (1991) writes, "out of the intersection of a health crisis ... with a struggle against oppression" (p. 42).

The twinning of health issues with social-structural inequalities around gender, sexuality, class, race and social stigma creates a common ground among the women's health movement, the independent living movement, and the community-based AIDS movement (Bayer, 1986; Sears, 1991). Each of these movements emerged as a response to the inactivity of the state and insensitivity of the medical establishment to the health and social needs of communities who are marginalized and/or stigmatized. The community organizing within these movements has gained legitimacy as a result of their political activism, and also as state health policies began to recognize the value of community health promotion and prevention initiatives (Clarke, 1994).

This next section briefly looks at the women's health movement and the independent living movement as examples of community organizing around health, which, like the community-based AIDS movement, have challenged the state and the medical establishment by empowering and involving the communities they provide services to, and claim to represent.

The women's health movement

The first wave of feminism corresponds to the activism by women during the late 19th and the 20th centuries for equal rights, in particular the suffrage movement. Achieving the right to vote as citizens was followed by a second wave of feminism in the late 1960s and 1970s when women struggled collectively toward civil liberation from oppressive patriarchal institutions. The women's health movement developed out of this second wave of feminism. With increasing medicalization, women began to realize the need to regain control over their bodies and lives from state structures and the medical profession (Gillett Fruchter et al., 1977). As a result, much of the early community organizing and activism in the women's health movement was directed at fighting for women's reproductive rights, and the right to abortion. Since these early efforts, women's groups, centers and collectives have struggled to empower women, provide health-related services and change existing health and social institutions (Dreifus, 1977).

At the level of personal empowerment, women's groups have developed a variety of self-help programs and techniques, ranging from consciousness-raising groups to programs which teach women to conduct their own gynecological examinations. There is also a strong emphasis on self-help and deprofessionalization within women's organizations. As Gillett Fruchter (1977) has noted,

> *[health clinics] uniformly have women, often nonprofessionals, doing the bulk of the medical services; their emphasis, always, is on the patient involvement in diagnosis and treatment, on deprofessionalization of service (p. 274).*

As a part of the feminist movement, women's health activists have also engaged in political activism directed at medical and social institutions which are unresponsive to women's health issues, and at the state, for more consistent funding to community initiatives (Dreifus, 1977).

With the recent rise of conservatism, community organizing around women's health lost the momentum that it gained in the 1970s, though women's groups and organizations still continued (Winnow, 1992). Recently, however, there has been a rise in community-based organizing around the politics of women living with breast cancer. There is an absence of community groups designed to provide resources, support and advocacy for women with cancer, but this is slowly changing. As the number of women with breast cancer increases, women are responding by developing resource centers and support service organizations (Wilkinson & Kitzinger, 1993).

There are several parallels between PHA involvement in AIDS organizing and women with breast cancer. The most evident similarity is the importance of empowering those who are affected by the disease so that they can have a voice in community organizing and influence the state's control of policy. As Winnow (1992) argues,

> *cancer, like AIDS, is about living. It is about living with a life-threatening disease, in whatever state, in whatever condition. We desperately needed a resource, support, and advocacy centre where women with cancer could be empowered to make their own choices and be supported by other women – a centre controlled by women with cancer. I knew this vision was possible because the models had already been built for AIDS, as well as in the women's community (p. 71).*

The Women's Cancer Resource Center in the United States, which Winnow (1992) describes, as well as the Burlington Support Services for women with cancer in Canada, which Clarke (1994) describes, are examples of community-based organizations by and for women with cancer.

This form of empowerment within cancer organizations fosters a politics of health that argues that those who are living with the disease should have a voice in the policies that impact their lives. While the breast cancer movement is still forming, it is growing and slowly influencing the state control of funding to community groups, the medical profession and cancer research, and the structures of the current cancer institutions in North America (Winnow, 1992; Kushner, 1984).

The independent living movement

The independent living movement, which includes all forms of organizing around physical and mental disability, has passed through three stages of political development (Zola, 1987). In the first stage the problem of disability was demystified, and people with disabilities were informed of their treatment options and the facilities they could turn to for assistance. This initial effort led to the development of self-help programs, in which people with disabilities participated collectively in support groups and other forms of empowerment (Withorn, 1980).

The second stage of development is represented by the establishment of community organizations, sometimes referred to as independent living centers, that are located outside of the medical establishment, and encourage people with disabilities to become more integrated into the general community (Dejong, 1979). In the 1970s, state health-care policies embraced the struggle of many persons with disabilities to be more involved as citizens by participating in independent living centers. This community organizing around disability, as Zola writes (1987), "spawned national coalitions and advocacy groups such as Disability in Action, American Coalition of Citizens with Disabilities, and Disabled Rights Education and Defense Fund" (p. 33).

Throughout the 1980s, though, this shift toward community integration became a means for the state to cut funding and support to community groups designed to help persons with a wide range of disabilities empower themselves (Leonardis & Mauri, 1992). While this deinstitutionalization devastated many people with disabilities, it also spurred a third stage in the development of the independent living movement. This third stage is represented by the several community-based responses by persons with disabilities to this lack of government support. An example of this form of community-based organizing is the self-help advocacy movement. Rhoades et al. (1986) describe this movement as, "an international network of voluntary organizations run by and for people with mental disabilities who are speaking for themselves and demanding that they be recognized as valuable and contributing citizens " (p. 2).

This movement enables persons with disabilities to collectively address the stigma and prejudice associated with disabilities, and struggle for broad social change. In this sense, the struggles of persons with disability are similar to those of PHAs within the community-based AIDS movement. For instance, this form of community organizing by and for persons with disabilities has enabled them to speak as 'experts' within the existing disability organizations and institutions, and help ensure that their needs are being addressed. In the 1980s, these organizations have successfully lobbied for government funding, and representatives from the movement were invited to participate in national disability conferences (Rhoades, 1986).

Health from below

In each of the social movements in health described above, the communities who are most affected by disease and disability have found the means to empower themselves and articulate a politic of health in the struggle to have their needs recognized and met by the welfare state. This political activism for health and the elimination of oppression is what Sears (1991) refers to as "health from below":

> *the politics of health from below often starts with concerns about the coercive aspects of state control. [It is] a struggle through which those most affected by specific health threats take power over the resources, knowledge and conditions of life necessary to procure well-being (p. 32).*

In each of the social movements, the communities most affected have challenged the expertise of health professionals and state officials, and demanded that health be treated not exclusively as a physiological condition, but as a social and political issue that must be addressed.

The community-based response to AIDS emerged in order to make this "health from below" ideology a reality. However, the increasing management of AIDS organizing by the state and public health limits the extent to which community-based AIDS organizations can subvert the state's control of AIDS policy and articulate alternatives. The politics of living with HIV and AIDS that has emerged within AIDS organizing over the past decade offers one way in which the community-based response to AIDS can retain its emphasis on "health from below." Certainly this will be an important issue in the chapters to follow. They examine the ways in which PHAs have become involved in AIDS organizations and the impact of this involvement on the community-based AIDS movement in Canada.

CHAPTER 3

Research Methodology

Chapter 3 describes the research methods employed in this project. The research had three phases, using both quantitative and qualitative methods.

First, a comprehensive survey was mailed to all seventy (70) member and associate groups of the Canadian AIDS Society. The survey asked questions ranging from numbers of PHAs on staff and on boards to more descriptive data such as strategies that help PHAs become more involved in the organization and obstacles they believe discouraged this type of involvement (see Appendix 1). In most cases (66%) the person completing this survey was either the executive director or the chairperson of the Board of Directors. In either case it was assumed that PHAs would have minimal input at this phase of the study. Therefore, the second phase of this research consisted of focus groups of PHAs involved in a variety of roles within fifteen CAS member organizations. Through these focus groups, PHAs were given the opportunity to discuss what has helped facilitate their involvement in a community-based AIDS organization, as well as pinpoint the specific barriers they have experienced to obtaining greater or more meaningful involvement.

During the 1993 Canadian AIDS Society Annual General Meeting (AGM) in Montreal in May, a one-hour plenary session presentation was held explaining some of the preliminary findings in the first phase of the research. Specifically, the strategies and barriers for greater PHA participation were presented. After this session, participants were invited to meet in smaller groups to discuss further strategies. Each group was asked to submit a summary of its discussions on both organizational strategies and individual strategies to overcome barriers (Appendix 3). Thirteen discussion groups, each comprising approximately ten people from various organizations, reported on their discussions. These reports, representing Phase 3 of this research project, will be summarized in Chapter 8 – Summary and Recommendations.

PARTICIPATORY ACTION RESEARCH

The research method which best describes this project is Participatory Action Research (PAR). This form of research has three main characteristics.

Social research

First, it is social research. Social researchers believe that we can pursue scientific truth and solutions to practical questions simultaneously. In social research, science should lead to improved practice. The research method employed in this project sought not only to measure the degree and nature of PHA participation in the community-based AIDS movement, but also to document practical ways to help groups across Canada bring about greater and more meaningful involvement of PHAs.

A second feature of social research is that for major organizational change to take place, the subjects of the research need to be directly involved with the social researchers. This research was not commissioned by the Canadian AIDS Society to outside researchers. The need for this research was identified by PHAs on the Board of Directors of CAS. It was this group who determined which questions were going to be asked and how the research would be conducted. One of the most striking participatory features of this research was that a PHA on the Board of Directors of both CAS and of a member organization being studied was the principle researcher. 'Outsiders' did not play a leadership role in this research project.

The third feature of social research methodology is that key informants actively participate in the research. In this project, community-based AIDS organizations actively participated through surveys (Phase 1) and PHAs through focus groups (Phase 2). After the research was collected, representatives of member organizations had an opportunity to comment on the findings and propose solutions to problems through discussion groups at the CAS Annual General Meeting (Phase 3).

In his book Participatory Action Research, W.F. Whyte (1991) writes,

> *some of the people in the organization or community under study participate actively with the professional researcher throughout the research process from the initial design to the final presentation of results and discussion of their action implications. PAR thus contrasts sharply with the conventional model of pure research, in which members of organizations and communities are treated as passive subjects, with some of them participating only to the extent of authorizing the project, being its subjects, and receiving the results (p. 20).*

Participation of frontline workers

Besides being social research, another characteristic of PAR is the participation in decision making by low ranking organizational members. In addition to the leaders of the community-based AIDS movement who were consulted in Phase 1, PHAs, whose lack of involvement in leadership positions was the subject of this research, were involved through Phase 2 focus groups. Like farmers' participation in agricultural research, PHAs could lend invaluable hands-on knowledge to research in the AIDS movement, which otherwise would not be accessible through simple observation by scientists.

Sociotechnical framework

Finally, PAR is characterized by the sociotechnical framework in which it is built. The community-based AIDS movement is not merely a social system. Technological factors that impact on the running of a business need to be considered and integrated. Examples of this range from medical knowledge that serves to understand the physical limitations of a person with AIDS to understanding the insurance industry, which prevents AIDS organizations from offering disability insurance to PHAs.

As we explore the various phases of the research, it will be clearly illustrated how PAR is utilized throughout this project.

PHASE 1:
NATIONAL SURVEY

An important feature of this research was my role as researcher and author as well as a leader in the Canadian community-based AIDS movement, which was being studied. During the period of time that the research was being conducted, I served on the CAS Board of Directors and was the founding chairperson of the Persons Living With HIV/AIDS Committee of the board. In establishing the mandate for this new committee, PHAs on the board determined that enhancing the environment in member organizations so that PHAs throughout the country could better participate in the life of their local AIDS organization needed to be a priority. This committee then determined the need to conduct research on the barriers that PHAs experience in becoming involved in the community-based AIDS movement. Anecdotal reports suggested that PHAs were finding it difficult to gain access to decision-making within community-based AIDS organizations. AIDS organizations, on the other hand, reported difficulty interesting PHAs in the life of their organizations.

The CAS board's PLWHIV/AIDS Committee first discussed survey questions at a meeting in October 1991 in Calgary. Committee members appeared to have vastly different opinions about the current level and nature of PHA involvement in our member groups from coast to coast. The committee therefore agreed that the first issue the survey needed to address was to determine the level and nature of PHA involvement. Secondly, the committee members had a variety of ideas about what constituted an 'appropriate' level of involvement, as well as the proper remedies. These differences appeared to be based on regional differences, rural or urban experiences, culture, age etc. It was decided that each group needed to have an opportunity to discuss the problems that it experienced in trying to involve PHAs as well as share the strategies it used to overcome existing barriers. The survey, therefore, would not only provide a quantitative profile of PHA participation within community-based AIDS organizations across Canada, but would provide a comprehensive list of barriers that groups were experiencing as well as successful and unsuccessful strategies used to overcome these barriers.

In November, 1991, four representatives of the Canadian AIDS Society met with four representatives of a new and struggling coalition, the National Network of Organizations for PLWHIV/AIDS [2] (see Chapter 4). Among the issues discussed were obstacles PHAs were facing in community-based AIDS organizations across Canada. Accessibility, group insurance and flexible hours were some of the issues raised (Canadian AIDS Society, 1991c). The design of the survey questions needed to be capable of describing these types of problems and their potential solutions.

In January, 1992, a draft of the survey was sent to ten people deeply involved in the community-based AIDS movement in Canada, who had agreed to serve as reviewers. Experience of the reviewers included those living in small to large cities; those with varying degrees of involvement in local, regional and national organizations; and volunteers as well as employees of community-based AIDS organizations. Six of the ten reviewers were PHAs. Nonetheless, upon reflection, their experiences were too narrow. Most were either executive directors of agencies or chairs of the Boards of Directors. Also, nine of the ten were gay, white men. The remaining reviewer was a woman.

Seven of ten reviewers had replied with their comments by the end-of-the-month deadline. Two were unable to reply due to illness and were contacted by phone. The tenth person had teamed up with another reviewer and they combined their comments on the one response form.

In February, 1992, the CAS PLWHIV/AIDS Board Committee met at Lac Supériere, Quebec. Included on the agenda was another opportunity for committee members to comment on the draft survey. Comments and suggestions from reviewers and committee members were analyzed and integrated into the survey instrument. Many of the reviewers, particularly those who were not HIV positive, perceived the questions as threatening. They perceived a trap being set. They feared being punished for their honest responses or that they would need to sacrifice truthfulness for 'political correctness'. The questionnaire was revised with more questions that allowed the respondents flexibility in providing answers that reflected the reality of their agencies and validated that reality. A revised covering letter also provided additional assurance that the information would not be used in a punitive manner. By the end of February, 1992, a revised draft was mailed to all reviewers and committee members for final comments.

The Board of Directors of the Canadian AIDS Society was updated on the progress of the survey during a board meeting at the end of February, in Ottawa. As a result of this discussion another important change was made. The board was sensitive to ensuring that member and associate groups viewed the survey as a way of helping them move forward and not a vehicle by which the new and influential PLWHIV/AIDS Committee of CAS could monitor their activities and 'punish' them for their inadequacies. In order to address this important concern, it was agreed that the survey would be mailed out on behalf of the entire board, and not just the PLWHIV/AIDS Committee. It was believed that this would reinforce the view that the board would be realistic in its expectations of its members, who would not be left at the mercy of its 'radical' PHA board members. The ownership of the survey by the entire board made the process less threatening, thereby permitting a higher degree of candor. The covering letter, which accompanied the survey, was signed by the chair of board .

Test sites

Six organizations were selected as test sites for the survey and each was contacted by phone. Selection of the test sites considered the importance of input from each region, both linguistic groups, small as well as large cities and a variety of organizational types.

---

[2] CAS representatives were Joan Anderson, Charles Roy, René Raymond, and Richard Burzynski. Network representatives were Doug Wilson, Darien Taylor, Pei Lim, and Kurt McGifford.

TABLE 1

NATIONAL SURVEY TEST SITES / TYPE / REGION / LANGUAGE

ORGANIZATION	TYPE	REGION	LANGUAGE
Vancouver PWA Society	PWA	Pacific	English
AIDS Calgary	GSO-L	Prairie	English
AIDS Housing Group of Ottawa	SS	Ontario	Bilingual
MIEL Québec	GSO-L	Quebec	French
Nova Scotia PWA Coalition	PWA	Atlantic	English
AIDS New Brunswick	GSO-S	Atlantic	Bilingual

GSO-L = General Services Organization in a large city
GSO-S = General Services Organization in a small city
PWA = Organization of Persons Living With HIV/AIDS
SS = Organization which provides one specific type of service (*e.g. support, education or advocacy)*

At least one group was selected from each region, three groups were predominantly English speaking, one French speaking, and two groups functioned in both official languages. Three groups were general service organizations (GSOs), two were PWA organizations, and the sixth provided a specific support service (housing). Of the forty-two cities where CAS groups exist, the six test sites include cities that range from Vancouver, one of the largest cities in Canada, to Fredericton, one of the smallest (see Appendix 4).

It was only at this point that the survey was translated into French. In addition to the one French-speaking group and two bilingual groups selected as test sites, the three francophone members of the board were asked to comment on the translation of the survey. The final draft of the survey was mailed to the test sites in March, 1992, and completed and returned by mid-April.

The main difficulty groups had in completing the survey was in giving total numbers of PHAs involved in the various locations in their organizations. Some groups provided numbers of self-disclosed PHAs while others provided totals based on otherwise confidential information. It was clear that the survey questions would need to be clarified if we hoped to gain valid and reliable statistics. Some groups provided qualitative descriptions, or generalizations, where numbers were being requested (e.g. many, most, all, dozens, hundreds). Also, both PWA groups found some questions more difficult to answer than GSOs. For example, when asked to list the various programs their organization offered specifically for PHAs, GSOs took the time to determine which programs offered support, advocacy, and education specifically for PHAs and which ones were for a broader community. The two PWA groups simply indicated that "all" of their programs were for PHAs and did not see the value of providing a list of programs.

Questions which appeared confusing or redundant were modified. When we asked for numbers of PHAs, we specified "self-disclosed." Although it promoted conservative estimates of actual PHA involvement, it provided us with consistent statistics on this vital piece of information. It also provided us with the same information that was generally available in the community. In addition to the covering letter by Joan Anderson, chair of the CAS Board of Directors, an instruction sheet was attached addressing some of the problems encountered in the testing phase.

Survey distribution

The final version of the survey was distributed to the seventy member and associate groups of CAS. Completed surveys were returned over an eight-month period from mid-April to mid-December, 1992 (Appendix 1).

By the May, 1992, CAS AGM, which took place in Halifax, approximately one-third of the groups had returned their completed surveys. The AGM provided the first opportunity to discuss the survey with the entire membership. Although no one would publicly express opposition to completing the survey, privately many organizations remained concerned that the results would be used to 'attack' individuals and organizations who had not been successful in involving PHAs in key positions. This fear represented a larger concern in the AIDS movement; many gay men and women who were not infected, but highly affected by and committed to the fight against AIDS, felt that the value of their contribution was being diminished by the movement to empower PHAs.

In order to allay any fears members may have had, the presentation of the survey was made primarily by the chair of the board and not by a PHA. An atmosphere of trust was further promoted when Mark Mees, executive director of AIDS Vancouver, stated that the questions alone had already assisted his organization in implementing changes they had not previously considered. Such a clear endorsement of the survey by a highly respected member of the community could have only increased the chances of success.

By the end of the summer forty (40) of the seventy (70) groups had responded (57% response rate). Early in the fall of 1992, two research assistants were hired to contact the thirty (30) groups who had not yet responded. Eric Dow (Toronto) and Hélène Spénard (Quebec City) contacted the English- and French-speaking groups, respectively. They began by establishing a contact person by phone, then mailed each group another copy of the survey. Approximately two weeks later they again followed up by phone. If the surveys had not yet been completed and returned, a time was scheduled for a phone interview where the statistical information could be obtained, if not the more time-consuming descriptive data.

Most English-speaking groups that had not responded were in Ontario. Dow took advantage of the fact that he would be seeing representatives of these groups at an Ottawa meeting of the Ontario AIDS Network in December. Many of the groups submitted their surveys at that time or he met with them during breaks to collect the data he needed. By the end of the year, all but five organizations had completed the survey, bringing the final response rate to 93%.

CAS organizes its membership within five regions. All of the groups in the Atlantic (7), Ontario (26), and Pacific (6) regions completed the survey. In Quebec, thirteen of the fifteen groups (13/15) responded, and in the Prairies all but three (13/16) responded. Four of the five groups that did not complete the survey came from cities with populations under 80,000, and all five groups were classified as General Service Organizations (GSOs). One possible explanation for the homogeneity of this group is that organizations in smaller cities often try to duplicate the services of GSOs in larger cities which have greater funding bases and therefore, more staff and volunteer support. The survey, therefore, may have become one more task that these organizations could not reasonably accomplish.

TABLE 2

CANADIAN AIDS SOCIETY REGIONS / NUMBER OF GROUPS / PROVINCES & TERRITORIES

REGION	TOTAL # of GROUPS (# responding to survey)	PROVINCES & TERRITORIES
Atlantic	7 (7)	Newfoundland & Labrador Nova Scotia Prince Edward Island New Brunswick
Quebec	15 (13)	Quebec
Ontario	26 (26)	Ontario
Prairie	16 (13)	Manitoba Saskatchewan Alberta Northwest Territories
Pacific	6 (6)	British Columbia Yukon

PHASE 2: FOCUS GROUPS

It was decided that the best and most efficient way to capture the experience of PHAs was to visit each region of the country and interview groups of PHAs who were associated with a variety of CAS member organizations. The purpose of the focus groups was to ask PHAs who were currently involved in a community-based AIDS organization how they were encouraged to participate in the life of the AIDS organization. They were also asked to share any experiences they had or were having that were barriers to greater or more meaningful involvement. Finally, the participants were asked if they had any friends who were PHAs but were not involved in any AIDS organizations. This final question was intended to serve two purposes. First, it gave us access to the views of a group of PHAs we would otherwise not hear from. Second, it gave the participants permission to speak freely of any negative experiences they might have had, or were currently having, without being labelled by their peers as whiners or complainers. It was through this question that we expected to get the unedited truth about the PHA's experience of an organization.

Because the working assumption of the study was that PHAs did not have significant involvement in these organizations, and that organizational barriers did exist, it was essential to broaden the study to include PHAs directly. Without them, the study would have relied solely on the information provided by those already in positions of power within AIDS organizations, thereby perpetuating the status quo.

Testing

Before the final sites were selected and the interview guide completed, focus groups were conducted. In December, 1992, the PHA Caucus of the Ontario AIDS Network (OAN) met in Ottawa prior to a regular quarterly meeting of the OAN. Thirty PHAs attended this meeting, and organizers had agreed to set aside a two-hour period to test our focus groups. The thirty participants were organized into three groups. One group comprised participants from Toronto, the second group consisted of participants from cities in central and southern Ontario (other than Metro Toronto) and a third group was made up of those from Northern Ontario, where communities are more isolated and therefore their experience, possibly, different.

The two hours were spent in the following way: the first half hour comprised an overview of the entire project and the purpose of the focus groups. It was also used to field any questions participants had in regards to confidentiality. Many participants were concerned that if they were candid, it would be reported to the executive director of their agency and that they would somehow be reprimanded. Confidentiality, therefore, was a central concern for those participating. One hour was then set aside for the focus group, and the final half hour was used for each of the three focus groups to report back to the larger group on its discussions.

Each of the three groups had a facilitator. The Toronto group was facilitated by myself, the project coordinator. The other two groups were facilitated by Peter McGuire of the AIDS Committee of Ottawa and Glen Pelshea of the AIDS Committee of Toronto. They each had been provided with a Facilitator's Guide , and a brief meeting was held with them at an earlier time. Each of the three sessions was audio recorded so that the final design of the interview guide could consider the experiences of all three groups. It became evident that concerns about anonymity and confidentiality appeared to be inversely proportionate to the size of the city. Few people from Toronto expressed this as a concern, yet many from Northern Ontario saw this as the primary barrier.

Another characteristic of the focus groups was that the size of the group seemed to affect group process. The larger the group, the more participants interacted with each other and not just with the facilitator. Also, the one hour set aside for the focus group was not nearly enough time for the group. The testing helped determine that we would strive to have as many as 10 participants in each group. The larger-sized group would provide a greater sense of anonymity for participants, thereby allowing more candor with their observations. The larger group also meant that two hours would be needed for each focus group. The pre-testing also helped to anticipate that experiences would be broad, largely based on the geographic location of the groups. If more than one AIDS-related organization existed in a particular area, participants often had some degree of involvement in more than one group. Questions therefore attempted to capture the overall experience of the PHA, and not restrict it to his or her involvement with the organization hosting the focus group. Finally, the pre-testing demonstrated that experiences can vary in different parts of the country, thereby establishing the need to hold focus groups in a variety of locations throughout the country.

Site selection

Because of the delay in receiving the completed Phase 1 surveys, site selection and design for the focus groups began before all the surveys were received. Initial decisions in selection and design were therefore based on preliminary findings and pre-existing hypotheses.

Twelve organizations representing a cross-section of CAS member groups were originally selected. Six were GSOs, three were PWA organizations and three were community specific. Later, once this research generated a new typology for CAS organizations, three organizations which were described as service specific were invited to join the Phase 2 process.[3]

It is commonly believed that groups in smaller cities face greater obstacles. Comparisons among experiences of PHAs in cities of different sizes would therefore be necessary. Of the six GSOs selected, three came from Canada's largest cities (Toronto, Montreal and Vancouver) and three came from cities with populations under 200,000 (Saskatoon, St. John's and Fredericton).

Another commonly held belief is that PWA groups enjoy greater success in attracting PHAs than do GSOs. As most of the PWA groups are in the larger cities,[4] the PWA groups in the three largest

---

[3] To expedite the completion of this report, the process was modified at this late stage to provide personal interviews with one key PHA member of each of these three organizations.

[4] Five of the seven PWA groups are in one of Canada's seven largest cities.

cities were chosen. This would facilitate comparison between the GSO and PWA groups in the three largest centers.

An additional commonly held belief is that groups serving already marginalized populations experience greater and more complex problems in their attempts to involve PHAs. Three groups – serving women, people of color (POC), and Canada's aboriginal people – were selected.

TABLE 3

FOCUS GROUP PARTICIPANTS

GROUP / DATE	REGION	CITY & POPULATION	LANGUAGE	TYPE
Nfld. & Lab. (Mar. 8.1993)	Atlantic	St. John's 96,215	English	GSO-S
AIDS N.B. (Mar.13.1993)	Atlantic	Fredericton 44,722	Bilingual	GSO-S
C-SAM (Feb.23.1993)	Quebec	Montreal 1,775,871	French	GSO-L
CPAVIH (Feb.22.1993)	Quebec	Montreal 1,775,871	French	PWA
ACCM (Aug.30.1994)	Quebec	Montreal 1,775,871	English	SS
ACT (Feb.17.1993)	Ontario	Toronto 2,275,771	English	GSO-L
Toronto PWA Fdn (Feb.17.1993)	Ontario	Toronto 2,275,771	English	PWA
Black-CAP (Feb.16.1993)	Ontario	Toronto 2,275,771	English	SC
Casey House (Aug.30.1994)	Ontario	Toronto 2,275,771	English	SS
AIDS ACTION NOW! (Sep.13.1994)	Ontario	Toronto 2,275,771	English	SS
AIDS Saskatoon (Jan.11.1993)	Prairie	Saskatoon 186,058	English	GSO-S
Feather of Hope (Jan.13.1993)	Prairie	Edmonton 618,195	English	SC
AIDS Vancouver (Jan.19.1993)	Pacific	Vancouver 1,542,744	English	GSO-L
Van. PWA Society (Jan.20.1993)	Pacific	Vancouver 1,542,744	English	PWA
Positive Women's Network (Jan.19.1993)	Pacific	Vancouver 1,542,744	English	SC

GSO-L = General Services Organization in a large city
GSO-S = General Services Organization in a small city
PWA = Organization of Persons Living With HIV/AIDS
SC = Organization which serves one specific community (*e.g. distinct cultural group, women*)
SS = Organization which provides one specific type of service (*e.g. support, education or advocacy*)

TABLE 4

CANADIAN AIDS SOCIETY GROUPS BY CATEGORY / NUMBER & NUMBER OF FOCUS GROUPS

CATEGORIES	NUMBER of CAS GROUPS	NUMBER of FOCUS GROUPS HELD
Category 1: GSO-L (cities>200,000)	16	3
Category 2: GSO-S (cities<200,000)	26	3
Category 3: PWA Organizations	7	3
Category 4: SC Groups Serving Specific Communities	10	3
Category 5: SS Groups Providing Specific Services	11	3
TOTAL	70	15

Finally, three groups providing a specific services – hospice care, buddy/support group programs, and treatment advocacy – were consulted.

The sampling plan for the focus groups therefore provides for possible comparison in the experience among PHAs in each of the five regions and between five distinct grouping: GSOs in large cities (3 groups), GSOs in small cities (3 groups), PWA organizations (3 groups), community specific (3 groups), and service specific (3 groups).

Design

Once the organizations agreed to host a focus group, they were mailed (or faxed) two supporting documents. One document was addressed to the coordinators of the focus groups, thanking them for assuming this role and outlining the responsibilities as well as the purpose of the groups. The letter specifically provided instructions for the selection of focus group participants. They were asked to select participants that represented the diverse nature of their group as well as the diverse way in which PHAs participate in their organization.

The letter also attempted to overcome two obstacles that could prevent PHAs from participating in the focus group. First, travel expenses for those too ill to take public transportation, as well as those who lived out of town, would be reimbursed. Second, child care would be provided for those, usually women, who might not be able to attend otherwise. It was stated that if the local group could not make provisions for these people, CAS would provide financial assistance. It was important that if the focus groups were to adequately discuss obstacles to involvement, those experiencing the greatest obstacles should be able to attend and express their concerns directly.

The second supporting document sent to all groups was an invitation that the coordinator could duplicate and give to potential participants. The invitation gave a brief history of the project as well as the goals of the focus group. It also outlined five questions that the participants should take a few minutes to consider before attending the group.

The back of the invitation addressed concerns that we anticipated participants might have: confidentiality, audio recording and a brief profile of the facilitator's credentials. Finally, the invitation provided the details of the focus group (time, date, location, local contact person) and thanked participants for agreeing to attend.

Several follow-up phone calls were made to local coordinators prior to each meeting. In cities where CAS board members lived (Saskatoon, Vancouver, Toronto, Montreal, Fredericton), they were asked to assist with the local organizing.

Since this research was not part of the regular work plan of the Canadian AIDS Society, the board could only approve a small budget. Scheduling of the focus groups therefore was largely determined by economic factors. Since the facilitator of the focus groups was also chair of the CAS PLWHIV/AIDS Committee and on the CAS Board of Directors, focus groups were scheduled around pre-existing meetings.

The five focus groups in the Prairie and Pacific Regions took place between January 11 and 20, 1993, scheduled to coincide with a Vancouver meeting of the CAS PLWHIV/AIDS Board Committee. The three Ontario focus groups took place February 16 and 17, 1993 in Toronto, where the facilitator lived. The Quebec groups took place in Montreal on February 22 and 23, 1993, immediately prior to a meeting of the CAS Board of Directors in nearby Ottawa. The only region that required special funding was the Atlantic Region were no board or committee meetings had been previously scheduled. These focus groups took place between March 8 and 13, 1993. Interviews conducted with PHAs from service specific organizations took place in August and September, 1994.

The ten focus groups that were held in English were facilitated by myself. The two Montreal focus groups were held in French and were co-facilitated with Daniel Bégin, the Montreal-based member of the CAS Board of Directors. Both documents were translated into French for these two groups.

TABLE 5

TOTAL FOCUS GROUP PARTICIPANTS BY TYPE OF ORGANIZATION

ORGANIZATION	TOTAL # of PARTICIPANTS
AIDS Vancouver	7
AIDS Committee of Toronto	7
Comité sida aide Montréal	3
GSOs - large cities (total)	17 (24%)
AIDS Saskatoon	6
AIDS New Brunswick	7
Newfoundland and Labrador AIDS Committee	3
GSOs - small cities (total)	16 (23%)
Vancouver AIDS Society	5
Toronto PWA Foundation	6
Comité des personnes atteintes du VIH	8
PWA Organizations (total)	19 (27%)
Positive Women's Network	6
Feather of Hope	6
Black Coalition for AIDS Prevention	3
Specific Community (total)	15 (21%)
AIDS Community Care of Montréal (ACCM)	1
Casey House	1
AIDS ACTION NOW!	1
Specific Services [5] (total)	3 (4%)
Total Focus Group Participants	70 (99%) [6]

All focus group participants were asked to fill in a brief fact sheet (Appendix 2). In total, twelve focus groups were conducted between January and March, 1993, and an additional three organizations consulted in August and September, 1994, for a total of fifteen organizations. A total of seventy (70) PHAs participated -- an average of almost five per organization.

---

[5] Organizations which provide a specific service did not participate in the original focus groups. One PHA in a leadership position in each of three organizations of this type was consulted in August or September, 1994.

[6] Not 100% due to rounding of percentages.

Profile of focus-group participants

Geographical Distribution: As Tables 3 and 4 indicate, focus groups were held in all regions of the country and in cities of varying sizes. Atlantic Canada had the fewest participants, with ten people in two focus groups. Ontario and Pacific Regions had the most participants, with eighteen each.

Nature of Involvement: More than half of the participants indicated that they were clients of the agencies (57.1%), while just under half (48.6%) said they were volunteers. Fifteen of the participants (21.4%) indicated they were employed by the agencies and twelve (17.1%) were Board members.[7]

Frequency of Involvement: When asked how often they are at the agency, over forty percent (40.9%) of the respondents indicated that their participation was daily. Another third (33.3%) indicated that they participated in an agency activity at least weekly. Only nine participants (13.6%) said their activity was monthly, and eight indicated that their participation was less than once a month.

Length of Involvement: Almost half of those who responded (48.5%) indicated that they had been involved with the organization for more than one year, but fewer than three. Eight participants (11.8%) had become involved within the past month. Fifteen (22.1%) had been involved for more than a month but less than one year. Twelve participants had participated in the organization for more than three years.

Current Health of Participants: Almost a third of the respondents (30.9%) indicated that they had an AIDS-defining illness; however, none of the participants were "very ill" at the time of the focus group. Five participants (7.4%) described themselves as not having an AIDS defining illness but being currently ill. All other participants (61.8%) indicated they were HIV positive but either did not currently have symptoms or never had symptoms.

Age of Participants: Participants ranged in age from 19 to 60 years. The vast majority (71.1%) were between the ages of 20 and 49. The mean age of participants was 36.1 years.

Gender: Fifty-eight (82.9%) of participants were male. The remaining twelve (17.1%) were female.

Sexual Orientation: The majority of respondents (68.7%) indicated that they were gay. Another 13.4% identified as being bisexual, and the remaining 17.9% were heterosexual.

Education: All of the seventy participants indicated that they completed high school. More than half (55.9%) indicated that they completed a community college diploma or university undergraduate degree. Almost one-fifth (19.1%) indicated that they completed graduate school.

Employment Status: Twenty-nine participants (43.3%) indicated that they were currently employed. The majority (56.7%) were unemployed. This group included those on government assistance as well as those on private disability insurance.

Occupational Background: When asked to indicate the nature of their last job, one-third (33.3%) indicated a professional or semi-professional job. Another third (33.3%) indicated some type of office job (clerical or managerial). Eighteen participants (27.3%) listed service industry. Only four respondents indicated a blue-collar job (technical/industrial).

Cultural Background: Sixteen of the seventy participants (22.8%) indicated that they had a distinct cultural background. Seven participants (10%) were aboriginal while four identified as people of color. Five participants stated they were from distinct cultural communities but did not identify with the categories provided. Of these, two stated they were Acadian, one Jewish, one Anglo-Québecois and one a French immigrant.

Distance of Travel: Most of the participants (69.2%) indicated that they lived within ten kilometers of the agency. Another fifteen participants (23.1%) lived between ten and thirty kilometers away while five participants (7.7%) lived more than thirty kilometers away.

Mode of Transportation: One-third of the respondents (33.3%) walked or cycled to the agency. Another third (33.3%) took public transportation. A quarter (25.8%) of the respondents took their own vehicles, while the remaining five respondents either had to take taxis or rely on friends or relatives for drives.

---

[7] Participants could check as many of the categories as applicable. This is why the figures do not add up to 100%.

Agency Rating: The vast majority of respondents thought quite favorably of their agencies (20.6% responded "excellent", while 58.8% responded "good"). Another eleven participants (16.2%) rated their agencies as "fair". Only three participants indicated they believed their agencies were doing a "poor" job and no one rated his or her agency as "terrible".

These statistics indicate that Phase 2 of this study reached a cross-section of PHAs throughout Canada. The group appeared diverse in region, age, gender, sexual orientation, cultural background, health status and type, and frequency and length of involvement. Notable within the profile of participants is that the group was relatively well educated and came from white-collar backgrounds.

It is a concern that the study was unable to involve people with significant illness, children, the poorly educated and those who had strong negative feelings towards their local AIDS organization. After each focus group, participants were given a comments sheet that they could take home. If they thought of anything they would like to add, or if they withheld information they didn't want to share in a group, they could mail in their comments anonymously. Only one participant submitted additional comments, which suggests that focus group participants were comfortable expressing their opinions within the groups themselves.

PHASE 3:
STRATEGY GROUPS

After completion of the focus groups, I was invited to present the preliminary findings of this study at a plenary session of the 1993 Canadian AIDS Society AGM in Montreal. Approximately 250 participants, representing the entire membership of the national coalition, were in attendance. My one-hour presentation focused on some of the major themes that organizations highlighted in Phase 1 of the study. Both barriers to and advantages of greater PHA involvement were discussed. After the plenary session, participants were invited to attend small group discussions where they were asked to reflect on what was needed to bring down some of the barriers that existed for PHAs.

Approximately 150 of those attending the plenary voluntarily moved into a discussion group. Thirteen groups were formed – three were French-speaking and ten English-speaking. Each group self-selected a facilitator and a recorder. The various strategies that were discussed in the group were recorded on a form provided (Appendix 3) and collected at the completion of the session. These strategies are included in Chapter 8: Summary and Recommendations.

SUMMARY

The goals of the research were: (1) to describe the current level of participation by PHAs within the community-based AIDS movement, as seen through the Canadian AIDS Society; (2) to determine the nature of this involvement; (3) to identify the strategies organizations are utilizing that help facilitate greater and more meaningful PHA involvement; and (4) to identify the barriers PHAs are experiencing and to develop strategies as to how these barriers can be brought down.

Three inter-related phases of research were utilized in this project. First, a detailed survey was completed by 93% of all organizations within the Canadian AIDS Society. Second, personal interviews and focus groups were held with PHAs across Canada. Finally, delegates at the CAS AGM were told of some of the barriers PHAs were confronting, and were given the opportunity to develop strategies as to how they could remove these barriers within their own organizations.

The participatory action research design captured the experiences of many constituents within the community-based AIDS movement in Canada. Phase 1 sought the experience of those in leadership positions. It was the assumption of this research that executive directors and chairs of boards were often not PHAs. Phase 2 was an opportunity for PHAs themselves to provide input into the research. Phase 3 provided a mix of those infected and affected by HIV/AIDS to work together to seek solutions to identified problems.

Chapter 4 will provide an overview of the community-based AIDS movement in Canada, focusing specifically on how national coalitions have historically involved themselves in addressing the question of PHA involvement in the community-based AIDS movement.

CHAPTER 4

The Participation of PHAs in the National Community-based AIDS Movement

This chapter traces the development of PHA participation within the national community-based AIDS movement in Canada, and it may, at times, read like a history of PHA participation within CAS. Other organizations have either had little interest in this subject matter, or limited organizational development. In fact, the entire study focuses on CAS member groups. Although each member organization of CAS has its own history of PHA involvement, this chapter attempts only to describe the extent and character of PHA participation at the national level. Nonetheless, this will help explain the historic development that was occurring not only nationally, but in local organizations throughout the country as well. This chapter also helps set the stage for the research findings in Chapter 5, which looks at PHA involvement in each of the CAS member groups.

Specifically, this chapter looks at four aspects of PHA involvement: i) the degree of involvement on the CAS Board of Directors and staff; ii) how the membership of CAS changed throughout the years, reflecting a changing role for PHAs within the coalition; iii) how PHAs organized to secure a stronger voice throughout the national coalition; and iv) the relationship between the increased involvement of PHAs and the emerging issues being discussed within CAS.

Minutes of the CAS annual general meetings as well as anecdotal accounts from some of the major participants in the movement were the primary data sources.

PHA Participation on the CAS Board of Directors and Staff

In May, 1985, the First Canadian Conference on AIDS was held in Montreal. Representatives from community-based organizations, professional groups and government agencies concerned about AIDS were in attendance. Community representatives used this opportunity to meet informally during the evenings. It was here that the idea for a national umbrella organization for community-based AIDS groups was first envisioned (Burzynski, 1992).

A three-member steering committee was appointed to continue the organizing effort. Although no one on the steering committee was known to be a PWA, it is important to remember the historical context. The test to identify persons living with HIV was not yet available; therefore, the reference here only pertains to people with

TABLE 6

PHAs ON THE BOARD OF DIRECTORS OF THE CANADIAN AIDS SOCIETY BY ANNUAL GENERAL MEETING

YEAR	CITY	PHAs/TOTAL # of BOARD MEMBERS	COMMENTS
1985	Montreal	0 / 3	Founding Meeting
1986	Toronto	0 / 8	1st General Meeting
1987	Ottawa	0 / 8	2nd General Meeting
1988	Toronto	1 / 9	1 designated PWA Seat
1989	Quebec City	2 / 9	1 designated PWA Seat plus 1 others elected
1990	Winnipeg	4 / 9	1 designated PWA Seat plus 3 others elected
1991	Ottawa	7 / 12	5 designated PWA Seats plus 2 others elected
1992	Halifax	6 / 12	5 designated PWA Seats plus 1 other elected
1993	Montreal	7 / 12	5 designated PWA Seats plus 2 others elected
1994	Toronto	9 / 12	5 designated PWA Seats plus 4 others elected
1995	Edmonton	7 / 12	5 designated PWA Seats plus 2 others elected

AIDS. PWAs were very reluctant to come forward because of the degree of fear and prejudice that existed throughout society. A second factor was that, without a test to isolate HIV, only those with significant illness could be identified. The debilitating effects of the illness at a time when few or no treatments were available usually meant a quick and painful death, with little time left for any unfinished projects, let alone new ones. The historical context lends some clarity to why PWAs were omitted from this initial stage of development.

The Canadian AIDS Society was officially founded in 1986. An eight-person board of directors was elected with no provision for ensuring the participation of PHAs on this decision-making body (Canadian AIDS Society, 1986).

It wasn't until 1988 that the membership agreed to a bylaw change which created a ninth board seat specifically designated for a person with AIDS. It is important to note that this seat was for someone with AIDS and not open to anyone with only HIV infection. Because the seat was created for someone with significant illness, the term of the position was one year, unlike all other positions which were two years in duration.

Kevin Brown, representing the Vancouver PWA Society, was unanimously acclaimed as the first to hold a PWA-designated seat on the CAS Board of Directors. Brown was an outspoken AIDS treatment activist who was known to the entire AIDS movement in Canada. In the mid-1980s, Brown was one of the first in Canada to be 'out' publicly in the media as a PWA.

Additionally, a motion was put forth at the 1988 AGM to establish a task force on representation within CAS to review board structure and to ensure fair representation based on language, region, gender, and HIV status (Canadian AIDS Society, 1988).

At each annual general meeting, the participation of PHAs grew not only in numbers but in awareness and organization. Each year an informal caucus was reconstituted, and developed an agenda which it would discuss at a specifically designated time at each AGM. In 1989 the PHA Caucus put forward a motion that committed the board to consider a bylaw change expanding PWA representation to at least two directors.

Meanwhile, Don DeGagné of the Vancouver PWA Society replaced his longtime friend and colleague, Kevin Brown, as the PWA designate on the board due to Brown's failing health. Brown died shortly after. DeGagné went on to become the first PWA to hold an executive position on the board when he was appointed vice-chairperson (Canadian AIDS Society, 1989).

For many, however, it was the 1990 Annual General Meeting in Winnipeg that stands out as the most significant turning point within the Canadian AIDS Society, where PHAs began to claim ownership of the movement. As instructed at the previous AGM, the Board of Directors came prepared to create a second seat for PWAs. However, PHAs had an additional year of organizing behind them and came prepared with a more demanding proposal. Under the leadership of Peter Wood (Newfoundland and Labrador AIDS Committee), Michael Smith (AAN!, Toronto), Alex Kowalski (Vancouver PWA Society), and dozens of other PHAs from across Canada, the caucus proposed a restructuring of the board that would guarantee a minimum of five PHAs on the CAS board. The outgoing Board of Directors unanimously supported the resolution; however, the new formula could not be implemented until the following year. Smith and Kowalski were among those who died before the next AGM.

The old formula, which guaranteed only one position for a PWA, was used for a final time in 1990. Four PHAs were elected to the Board of Directors that year, indicating a strong commitment by CAS members to the principles of a self-help movement (Canadian AIDS Society, 1990).

Don DeGagné, vice-chairperson of the CAS board, who had been holding the only PWA-designated seat, ran for one of the eight non-designated positions. DeGagné won his seat, and Peter Wood replaced him in the PWA-designated position. Don Walker, a PHA representing the AIDS Committee of Ottawa, also won a seat on the board. A fourth PHA, René Raymond from Mouvement d'information, d'education et d'entraide dans la lutte contre le sida (MIELS), a Quebec City group, continued in the second year of his term. Raymond, however, would not make his HIV positive status known for another year.

During the subsequent year, not only would PHAs hold four of the nine seats on the Board of Directors but they would also hold three of the four influential seats on the Executive Committee (DeGagné, vice-chairperson; Raymond, treasurer;

and Walker, secretary). Walker died before the completion of his first year on the board.

Later that same year Chris Cockrill was hired as treatment officer, thereby becoming the first PHA employed by the Canadian AIDS Society. Cockrill had been the chairperson of the Comité des personnes atteintes du VIH (CPAVIH), a PWA coalition in Montreal. His hiring was seen as an acknowledgement that PHAs had a unique contribution to make within the movement, especially in areas that directly impacted on our lives, such as treatment.

The following year, the new formula for electing the CAS Board of Directors was implemented. The new structure had twelve seats. Member organizations of CAS were divided into five regions. Two people from each region were elected to the board. One of the two seats in each region was designated for a PHA. The final two seats were at-large positions, and open to anyone regardless of region or HIV status. This structure guaranteed that a minimum five of twelve seats on the CAS Board of Directors would be filled by PHAs. The new formula opened the designated seats to any self-disclosed person with HIV infection and did not limit it to people with AIDS. Although the changes dealt with representation based on region and health status, they did nothing to address gender or language. French-speaking board members were generally limited to the two representatives from Quebec. No women occupied designated PHA seats, leaving the board dominated by men.

In 1991, the board elections saw ten nominees for the five regional seats designated for PHAs. Additionally, two other self-disclosed PHAs, DeGagné and Raymond, were elected to non-designated positions. For the first time in its seven-year history, PHAs represented a majority on the governing body of CAS (Canadian AIDS Society, 1991b).

The following year, six of the seven PHA board members returned. Because of a bylaw restricting directors to two consecutive terms, DeGagné could not seek re-election (Canadian AIDS Society, 1992b). This is significant because he became the first PHA to leave the CAS Board of Directors for a reason other than illness or death. This, perhaps, signalled a new era, where PHAs lived longer and healthier lives thereby creating better opportunities for more meaningful contributions to the community-based AIDS movement in Canada.

The 1993 AGM was another significant year for PHA participation on the CAS Board of Directors. Raymond was the only PHA to seek re-election to the board. Four of the five left to pursuit other interests, (Michael McDonald, Charles Roy, Drew Ferrari, and Arn Schilder) while the fifth, Michel Bégin of Montreal, had died earlier in the year.

Raymond's re-election to the board was significant. Months earlier, the outgoing board had made him the first PHA to chair the CAS Board of Directors. In order to continue to serve, he needed to be re-elected to a third term. The board recommended a bylaw change allowing this to be possible, and the membership eagerly accepted it (Canadian AIDS Society, 1993b).

A total of seven PHAs were elected to the board that year, once again restoring a majority status. Previously, the only PHAs on the CAS board were gay, white, middle-aged men. The new PHA membership on the board signalled a change to the face of AIDS in Canada. Two women, two youths (under 25 years of age), and one person of color were elected.

While the CAS Board of Directors was experiencing a transformation in PHA participation, staff was not going through the same metamorphosis. Cockrill had become too ill to participate in the 1993 Forum or AGM. It was around this time that he went onto long-term disability. In the fall of 1993 he died. During this time, only one other PHA had joined the staff, in a relatively junior programming position. PHAs had been overlooked for all three of the four management positions that had changed hands during that year.

Two significant events regarding PHA participation occurred at the 1994 AGM in Toronto. Once again, a small group of PHAs indicated a desire to change the CAS bylaws to ensure that the majority of board members were PHAs. For the third year in a row, the discussion generated little support from either the members of the PHA Forum or the general assembly. A move to restrict CAS membership to those organizations that guarantee majority PHA representation on their governing bodies was made and later withdrawn after debate clearly signalled lack of support for the motion. Secondly, the membership elected an unprecedented nine PHAs to the twelve-member board (Canadian AIDS Society, 1994). This indicated that PHAs, given the encouragement and opportunity, are willing to serve in leadership positions within the movement.

The message many received from this sequence of events was that CAS, and the community-based AIDS movement in Canada, is more than a group of PHAs. Many non-infected people are deeply committed to the fight against AIDS and have made extraordinary contributions to the cause. We therefore need not relegate them to a second-class status within the movement. Very few non-infected people would actually debate the issue on the floor; however, when some PHAs spoke against the motion, it clearly gave permission for others to vote against the motion. Many PHAs voiced concern that their empowerment within the movement was not contingent on the diminishing or devaluing of someone else's contribution. The second message was that the membership clearly recognized the important contribution PHAs have made and can continue to make within the movement.

Changing Membership within CAS

The sixteen (16) founding members of the Canadian AIDS Society were all what would be described today as General Service Organizations (GSOs). It wasn't until 1986 that the Toronto PWA Foundation became the first PWA organization to join the national coalition (Canadian AIDS Society, 1986).

TABLE 7

PWA ORGANIZATIONS BY YEAR THEY JOINED THE CANADIAN AIDS SOCIETY (CAS) [8]

YEAR	ORGANIZATION
1986	• Toronto PWA Foundation
1987	• Vancouver PWA Society
1988	• AIDS ACTION NOW! [9]
1989	• Nova Scotia PWA Coalition
	• PLWA Network of Saskatchewan
1990	• Body Positive Coalition of Manitoba
	• CPAVIH (Montreal)
	• Calgarians Living With AIDS Society [10]
	• Vancouver Island PLWA Coalition [11]
1991	• Edmonton Persons Living With HIV Society
1992	• Positive Women's Network [12]

In the years to follow, other PWA organizations joined the national coalition, ensuring that PHAs had a presence that some believed GSOs alone could not guarantee.

The popular belief is that PWA organizations differ from GSOs in that they are governed exclusively by PHAs. This is not the case. In Canada, only two organizations, Vancouver PWA Society and Montreal's CPAVIH, have policies guaranteeing that Boards of Directors are comprised exclusively of PHAs. Other organizations, such as Nova Scotia PWA Coalition (NSPWAC), began by maintaining this principle but eventually gave way to more pragmatic realities. Most PWA organizations have policies guaranteeing majority representation on their governing bodies. Today, most PWA organizations have both people infected and affected by HIV/AIDS on the boards of their organizations. Both the Vancouver and Montreal groups, while maintaining PHA boards, have few PHAs on staff. No organization has been able to operate exclusively by PHA participation.

One rationale as to why PWA organizations need to involve those not infected, either on the board or on staff, involves the question of continuity of leadership and skills. As Chapter 7 will illustrate, many organizations believe that PHAs lack the knowledge, skills, and health necessary to keep up with the demands of the work. Organizations who hire only PHAs may feel as though they are limiting the pool too much and are unable to attract someone with a particularly needed skill. One other justification for this decision is that, historically, PWAs did not live long, healthy lives. As a result, organizations needed to constantly train new staff to prevent the quick loss of skills and knowledge gained by the collective experience of the organization. Today, organizations may want to reconsider whether this is still true.

Unlike some PWA organizations that started out exclusively run by PHAs, AIDS ACTION NOW! (AAN!) introduced a new model to the Canadian AIDS Society when it became a member of the coalition in 1988. Although it does not fall into the conventional definition of a PWA group, AAN! membership in CAS has particular impor-

---

[8] Other PWA organizations, such as Voices of Positive Women, have since joined CAS. This chart is intended to note only the CAS member organizations during the time this research was being conducted.

[9] Not categorized as a PWA organization, but guarantees a majority of PHAs on its board/steering committee.

[10] No longer exists.

[11] Same as 10.

[12] Same as 9.

tance for the empowerment of PHAs. Unlike some AIDS advocacy groups such as ACT-UP, who take on a broad AIDS activist agenda, AAN! limits its role to advocacy for PHAs. It therefore follows that its structure provides for a majority of PHAs on its steering committee. In light of the enormous success this advocacy group has achieved, AAN! stands alone as an important model for other non-PWA groups who may doubt the abilities and achievements of PHAs (Canadian AIDS Society, 1988).

Until 1989, the only PWA organizations with PHA majorities on their governing bodies were in Toronto and Vancouver (CPAVIH in Montreal joined CAS in 1990). At this point in history, 90% of AIDS cases in Canada were found in Quebec, Ontario and British Columbia. The prevailing logic suggested that only the major cities (Montreal, Toronto and Vancouver) in these three provinces had the critical masses to sustain a PWA coalition. Beginning in 1989, PWA coalitions emerged in mid-sized cities such as Halifax, Winnipeg, Saskatoon, Calgary, Edmonton, and Victoria. Calgarians Living With AIDS Society and Vancouver Island Persons Living With AIDS Coalition both proved to be short-lived organizations. Other groups found ways to integrate the non-infected into their work. To date, no PWA organizations exist in small cities (under 100,000 population).

The Positive Women's Network (Vancouver) became a full member of CAS in 1992 (Canadian AIDS Society, 1992b). After exploring various organizational models, PWN eventually adopted the AAN! model that integrates those infected and affected, yet guarantees that PHAs have a majority voice on its governing body.

National Gatherings of PHAs

The first organized meeting for PWAs from across Canada was at the First Canadian Conference on AIDS held in Montreal in May 1985. The conference organizers announced a time and place where PWAs could meet one another. Minutes and attendance were not recorded. Each subsequent year at CAS AGMs, a workshop time was scheduled where PHAs could meet to develop and discuss a list of topics.

On March 2-4, 1990, a few months prior to the Canadian AIDS Society's Annual General Meeting, people from the various PWA organizations met in Vancouver. The meeting, sponsored by the Canadian AIDS Society, was designed to discuss the establishment of a Canadian network of PHAs. Although representatives of the Canadian AIDS Society were present, it was unclear what the relationship would be between the emerging PHA Network and CAS. The issue of an independent network created much tension among community activists. Some loyalists within the Canadian AIDS Society felt that a second national body would weaken the community response to AIDS. The advocates of an independent network however felt that "[e]mpowerment implies and demands a separate identity" (People With HIV Network Update, October, 1990).

Under the leadership of Doug Wilson of AIDS ACTION NOW! in Toronto, the Canadian Network of Organizations for PLWHIV/AIDS (Network) was formed. Without the benefit of any infrastructure, such as bylaws, constitution, staff, office, or a secure funding base, the Network held its founding meeting. Both organizations and support groups for PHAs were represented at the Montreal meeting, which took place in 1991, six years after CAS was conceived in the same city. The membership criterion for the Network was loosely defined as any support group or organization in which PHAs were guaranteed a majority on the governing body. Most organizations that were represented were either PWA groups already members of CAS or segments of existing CAS groups, such as PHA caucuses, which were emerging in GSOs. Support for the Network was mixed, with some being enthusiastic and others believing it would be more productive to focus all the energies of PHA activists on local organizations and influencing the directions of CAS.

Not coincidentally, at the same time that an independent Network was being born, issues of PHA involvement within CAS were a central focus. It was at the 1991 AGM in Ottawa where PHAs insisted that more time was needed for the purposes of organizing. The PHA Caucus was assigned a two-hour period at this AGM to organize and bring its resolutions forward to the general assembly. Daniel Clowes, president of AIDS New Brunswick, emerged as an important leader, and quickly organized the approximately forty people in attendance. The caucus developed a long list of items it wanted to discuss and planned a series of meetings throughout the AGM to address them. This meant working through meal breaks and into evenings, restricting the participation of some PHAs whose health would not permit such a rigorous schedule.

By the final day of the AGM the caucus emerged with five resolutions, all of which were passed by the general membership. The resolutions dealt with organizational issues such as the development of a two-day PHA Caucus meeting prior to the following year's AGM. One resolution, however, stands out as being particularly important for the future role of PHAs within CAS. The resolution stated that the membership criteria should be altered to "ensure significant and appropriate representation of PHAs in CAS member groups" (Canadian AIDS Society, 1991b, p. v).

As planned, a two-day PHA Forum was held prior to the 1992 Halifax AGM. Attending were seventy-five PHAs representing forty-two member organizations of the society. Not in attendance however, was Daniel Clowes, who, one year earlier, was so instrumental in ensuring that the forum became a reality. Clowes died one day before the opening of the forum.

The seven PHAs on the Board of Directors organized the meeting and reported on their activities over the past year. The group reported that they had formally been recognized by the board as a Standing Committee. They had drafted terms of reference for the committee and were presenting them to the caucus for their consideration. The founding chairperson of this committee, Charles Roy, now held a newly designated position on the Executive Committee. Also reported was the development of a survey on the role of PHAs within the member groups of the society (Appendix 1). The survey, which is the basis for this study, was approved by both the PHA Committee as well as the entire board for circulation to the general membership (Canadian AIDS Society, 1992a).

The 1992 AGM saw an unprecedented twenty-four (24) resolutions surface from the PHA Caucus. Clearly, the forum provided an important opportunity for PHAs to come together to share ideas and debate issues. Predictably, the forum experience was anecdotally reported to be of particular importance to people living outside of large metropolitan areas, where similar opportunities are not readily available. A review of the evaluations suggested that the forum was a more valuable experience to PHAs than was the AGM.

One important policy that was debated at the AGM was the revised membership criteria which included a statement on PHA participation (Canadian AIDS Society, 1992a). Instead of dictating what such a policy would include, each group was instructed to develop its own definition of significant and appropriate representation and submit a report to CAS on what its own local definition was, how it came to these conclusions, and how it managed to implement its policy. This strategy invited each community to grapple with this difficult issue and at the same time take ownership of the problem.

For CAS, this marked another important step forward in advocating for the rights of PHAs. Previously, CAS had been seen as advocating for an increased role for PHAs within its national structure and with outside organizations. Now, CAS appeared to be challenging each of its member groups in this regard. This would undoubtedly be the most difficult and, yet, important step. Previously, a relatively small and select group of PHAs participated at the national level. The seventy member-groups of CAS could provide a place for thousands of PHAs to become involved in the Canadian community-based AIDS movement. The difficult questions that remained were how best to channel and sustain this increased level of participation.

The Annual Forum for PLWHIV/AIDS, as it is called, has become an integral part of the Canadian AIDS Society's AGM. Prior to 1992, subsidies for member groups to send two representatives to the AGM were offered to each member without any conditions. In planning the AGM, at a board meeting in early 1992, the newly formed PLWHIV/AIDS Committee of the board advocated that the subsidies should be divided equally between the AGM and the forum. This new condition would all but guarantee equal participation by PHAs at the CAS AGM, which immediately followed the forum. If an organization did not send a representative to the PHA Forum they would lose one of their subsidies. This would force many member groups to assist PHAs within their local groups to become better informed so they could represent their organization at both of these national gatherings.

The debate over the allocation of subsidies was probably the most divisive issue the new board faced. PHAs and non-PHAs on the board took opposite points of view, and the debate was deferred to the executive of the board to bring back a detailed recommendation the next day. The executive was convened that same evening, and at 2 o'clock the next morning a compromise was reached. It was agreed that the subsidies would be divided equally between the AGM and forum; however, a provision was made for organizations who could not find a PHA to attend. It was expected very few organizations would find this condition unmanageable and the provision would be fazed out in a few years when it was reasonable to expect that all groups would have a PHA for at least one of its two delegates.

The following year, the Second Annual Forum for PHAs was also a success, attracting over 125 PHAs. The Network, meanwhile, had become stagnant and had failed to capture the interest of PHAs or potential funding sources. Both Doug Wilson, the founding chair of the Network, as well as Pei Lim from the Vancouver PWA Society and a key member of the Network Steering Committee, had died. Although the Steering Committee continued to meet, the lack of effective leadership, the federal government's decision not to provide ongoing funding, and the increased participation of PHAs within CAS all contributed to the demise of an independent Network.

PHAs and the New AIDS Agenda

The increased involvement of PHAs has greatly influenced the agenda of CAS. The feature plenary at the 1986 Second Canadian Conference on AIDS was a panel of PWAs (Canadian AIDS Society, 1986). It was, however, at the 1987 AGM that PWAs began to play a prominent role in the community-based AIDS movement in Canada. Kevin Brown (Vancouver PWA Coalition) and Jim St. James (Toronto PWA Foundation), both PWAs, emerged as leaders at this meeting. Brown and St. James, in a presentation on alternative therapies, promoted what was at the time a new philosophy for PWAs in Canada. Taking a chapter from the women's health movement, they advocated that PWAs take charge of their health by being more active in the decisions that affect their lives. Although they were speaking specifically of treatment options, the philosophy has lent itself to all types of community action. This was the first documented sign of PWA empowerment at a Canadian AIDS Society annual general meeting (Canadian AIDS Society, 1987).

Also in 1987, CAS took advantage of being in the nation's capital and invited guests from several federal government agencies to its meeting. Presentations were designed to educate government officials as to the differing needs among various types of community-based AIDS organizations. Representatives from GSOs in small, medium, and large cities, as well as a PWA organization, gave presentations. One of the ten key issues outlined was the "acceptance of PWA coalitions as credible groups" (Canadian AIDS Society, 1987, p. 3).

Although board structure dominated the agenda at the 1990 Winnipeg AGM, it was not the only sign of empowerment for the PHA community within CAS. One of the workshops offered at this AGM was titled "Interaction between Persons Living With HIV/AIDS and AIDS Service Organizations" (Canadian AIDS Society, 1990).

Also significant this year was the establishment of a National Therapies Committee. Since treatment information is so essential to the lives of PHAs, it was decided that the composition of this national committee would be designed to guarantee that a majority of its members were PHAs.

It was also this year that the Canadian AIDS Society saw itself advocating for the role of PHAs in other organizations. The Canadian Public Health Association (CPHA) had earlier established an AIDS Advisory Committee. This committee had a designated position for a community representative, but had made no provision for PHAs. At the Winnipeg AGM it was suggested that CAS initiate a letter-writing campaign to advocate for such a change (Canadian AIDS Society, 1990). This was a further sign that the society had not only seen the role of PHAs as an important one within its own organization, but it had integrated a philosophy that allowed it to see such a change as being vital throughout the entire AIDS movement in Canada. The recent structural changes to its board gave CAS the credibility it needed to champion the cause of PHA rights.

Since the development of the First Annual Forum for PHAs in 1992, a series of workshops and working groups were struck to discuss a broad range of issues of interest to PHAs. In addition to organizational development issues, it became clear that PHAs were primarily interested in treatment and research, income security, housing and hospice care, and health promotion strategies (Canadian AIDS Society, 1992a). These became the central issues in which PHAs believed CAS ought to be involved.

Today, the CAS Board of Directors and staff appear more focused on these issues, which are central to the lives of PHAs. In addition to the strong PHA presence on the Board of Directors and at the annual general meetings, CAS has implemented other policies that guarantee a strong PHA presence on committees. Moreover, on committees that have a direct impact on the lives of PHAs, such as the National Therapies Committee and the National Ad Hoc Committee on Income Security, PHAs are guaranteed a majority voice.

CONCLUSION

PHAs are becoming more influential, better organized, and leaders of a new AIDS agenda for community action. This chapter outlined the history of PHA participation within the Canadian AIDS Society. It focused on the PHA involvement within the national coalition but did not attempt to comment on each of the member groups of CAS. The following chapter will look at the member groups of CAS and the current level of participation of PHAs within the national membership.

CHAPTER 5

Research Findings

This chapter provides a quantitative profile of the current involvement of PHAs in the community-based AIDS movement in Canada. Five independent variables were chosen as a framework for describing and categorizing the organizational members of the Canadian AIDS Society. These five independent variables were: i) type of organization; ii) size of annual budget; iii) size of city; iv) region of the country; and v) founding year. These independent variables were cross-tabulated with two sets of dependent variables: i) the participation of PHAs on the Board of Directors; and ii) the staffing of PHAs, both (i and ii)within the membership of the Canadian AIDS Society. Both the actual number of PHAs participating and the proportion (#of PHAs/total board members and #of PHAs/total staff) are used in the analyses. It was anticipated that these comparisons would provide some insight into the involvement of PHAs within the membership of the Canadian AIDS Society.

Originally, it was hoped that the research would also capture the level of PHA participation as volunteers and service users. Organizations defined these volunteers and service users in many different ways. Some saw their entire donor and mailing lists as consumers of services and/or volunteers, while others had a much more limiting definition. In most cases, however, organizations reported that they did not document the HIV status of their volunteers or service users. Organizations were therefore reluctant to estimate the number of PHAs in either of these groups. This points to a significant limitation in the data regarding PHA involvement collected by most organizations. Moreover, an inability to determine if PHAs are already involved makes it difficult to determine if more are needed and to determine how to bring about greater or more meaningful involvement. Concerns about confidentiality represented another barrier to gathering PHA-relevant information about these groups. For these reasons, we have chosen to exclude quantitative information collected about volunteers and service users in these organizations. It is, however, important not to dismiss this type of involvement as unimportant or irrelevant. Involvement as volunteers and clients can provide much insight into an organization's attitude and success in involving PHAs. In this regard, qualitative data that the organizations provided relevant to PHA involvement as volunteers or service users will be included in Chapters 6 and 7. The final chapter (8) will also include recommendations regarding data gathering.

PHA INVOLVEMENT: BOARD AND STAFF MEMBERSHIP

Board membership

Table 8 shows the distribution of PHA board membership. For all CAS respondents, just over

TABLE 8

ORGANIZATION TYPE BY PHAs ON THE BOARD

COUNT ROW PCT.	0 PHAs	1 PHA	2 PHAs	3 PHAs or MORE	
GSO-L		4 26.7	3 20.0	8 53.3	
GSO-S	7 31.8	9 40.9	5 22.7	1 4.5	
PWA			1 16.7	5 83.3	
SC	3 30.0	3 30.0	2 20.0	2 20.0	
SS	2 18.2	2 18.2	1 9.1	6 54.5	
Column totals	12 18.8	18 28.1	12 18.8	22 34.4	64 100.0

four-fifths (81.3%) had at least one PHA board member. The remaining organizations (18.8%) had no PHAs on their boards at the time of the survey. The average PHA board membership level was 2.41, with a standard deviation of 2.63. Although PHA board membership tended to be low, a substantial minority (34.4%) of boards had three or more PHA members. Among this group, the majority had three or four PHA members, but one organization had eight, one had nine, and three had eleven PHAs.

The relative composition of a board is as important as the actual number of PHAs on a board. In order to determine the size of the voice that PHAs have on an organization's board, the proportion of board positions filled by PHAs was calculated. Board size ranged from three to twenty, with a mean of 11.73 (standard deviation 3.34). PHA representation on boards tended to be low. Approximately three quarters (76.6%) of organizations had boards with under 30% PHA membership. Of the minority (23.4%) with 30% to 100% PHA board representation, seven groups indicated that over 50% of their board members were PHAs. This represents 10.7% of all responding organizations. Therefore only one in every ten CAS member groups can report having a majority of PHAs on its governing body. On average, approximately one-fifth (21%) of board membership within CAS were PHAs.

Staff membership

Fewer PHAs participated in organizational functioning as staff members than they did as board members. Six of the responding organizations indicated that they had no staff. These six organizations are not included in the statistics that follow. Of those organizations which had staff, 62.7% had no PHA staff. Approximately one-quarter (25.4%) of those organizations with staff had one PHA staff member, and 11.9% had two or more PHA staff. The highest within this group were two organizations which had seven PHA staff members.

TABLE 9

ORGANIZATION TYPE BY PROPORTION OF PHAs ON STAFF

COUNT ROW PCT.	NO PHA STAFF	UNDER 30% PHA STAFF	30% AND OVER PHA STAFF	
GSO-L	6 40.0	9 60.0		
GSO-S	16 80.0	1 5.0	3 15.0	
PWA	4 66.7		2 33.3	
SC	8 80.0	1 10.0	1 10.0	
SS	3 37.5	3 37.5	2 25.0	
Column totals	37 62.7	14 23.7	8 13.6	59 100.0

The proportion of PHA staff to total staff members was calculated to determine the representation of PHAs on staff in CAS organizations. Total staff ranged from zero to fifty, with a mean of 6.7 (standard deviation 8.35). As Table 9 shows, of those organizations with PHA staff, most (14 of 22 or 63.6%) had less than 30% PHA staff members. Of those eight organizations with more than 30% PHA staff members, five indicated that their organizations had 50% or more PHA staff.

TYPOLOGY OF CAS ORGANIZATIONS

As the community-based network grew, newly formed organizations offered specific services and targeted particular constituencies. Many of these newer organizations indicated in Phase 1 of this research that they did not describe themselves within the conventional categories established years earlier. This research, therefore, provides the basis for a new typology for CAS groups. To begin with, all of the 16 founding organizations of CAS, as well as the majority of organizations within CAS today, can be described as General Service Organizations (GSO).

GSOs provide a range of services including: prevention education to the general community, as well as more specific target groups; support services to PHAs, their friends, and family members; and some advocacy. GSOs, therefore, are not specific to a particular segment of the community they serve or in the services they provide. Whether it is Toronto, with a population over two million, or Jasper with fewer than two thousand, one General Service Organization exists in each of the forty-two (42) communities in Canada where a CAS member group is found. Appendix 4 maps out the seventy groups of CAS and indicates in which category they belong. It distinguishes between GSOs in relatively large cities, that is those with populations over 200,000 (GSO-L), and GSOs in relatively small cities, those in cities smaller than 200,000 (GSO-S). Thus, two types of GSOs exist in CAS: those in relatively large cities and those in relatively small cities.

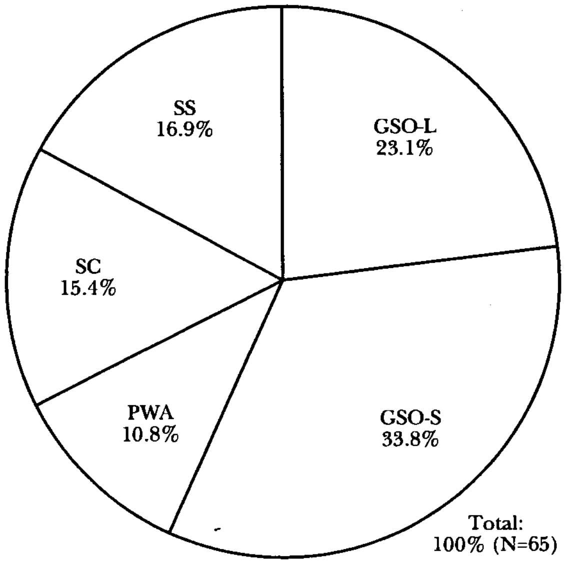
As most other types of CAS organizations exist only in relatively large cities, the GSO distinction will help determine whether any differences are based on actual organization type, or the size of the city.

A third type of CAS member is the PWA organization. For the most part, these organizations limit their activities to providing direct services to PHAs. These organizations were established by small groups of PHAs, often displeased with the work of their local GSO. PWA organizations were assumed to be run if not exclusively, then primarily, by PHAs. In Toronto, Montreal, Vancouver, Winnipeg, Edmonton, Saskatoon, and Halifax, PWA organizations have set up offices within blocks of existing GSOs.

A fourth organizational type can be best described as providing a range of services to a specific, targeted community (SC). Hence, ten (10) CAS organizations are specifically designed to serve such particular communities as women, prostitutes, people with pre-existing disabilities, as well as people from specific ethno-cultural communities. These organizations often provide both support services to PHAs and prevention education within their defined target communities.

CHART 1

THE PROPORTION OF RESPONDENTS WITHIN EACH TYPE OF CAS GROUP



Finally, a fifth type can be described as organizations that provide a specific type of service (SS) without necessarily identifying with a specific target community. Eleven (11) of the seventy (70) groups surveyed fit into this category. Five groups provide housing or hospice facilities, two provide other types of support activities, and three have a focus on treatment. One group is a provincial coalition providing an additional networking opportunity to its members.

When PHA board and staff involvement are related to typology, the data suggest that there are some interesting differences. As can be seen in Table 8, GSOs in large cities, PWA organizations, and SS organizations appear to have more PHAs on their boards than do GSOs in smaller communities or those organizations which serve special communities (SC). Table 10 collapses PWA, SS, and SC into one Special Category cell, allowing each category to be large enough to draw comparisons. Chi-square analysis indicates that there are significant differences among GSO-L, GSO-S, and this composite of the three other organizational types. GSO-S have fewer PHA board members, using categories of "low" (0 or 1 PHAs) and "high" (2 or more PHAs), than the other two groups (chi-square 9.41, d.f. 2, significant at the .01 level).

TABLE 10

ORGANIZATION TYPE BY PHAs ON THE BOARD
(PWA, SS, SC are collapsed into one category)

COUNT ROW PCT.	LOW 0 to 1	HIGH 2 or more	
GSO-L	4 26.7	11 73.3	
GSO-S	16 72.7	6 27.3	
Special Category	10 37.0	17 63.0	
Column Totals	30 46.9	34 53.1	64 100.0

The trend that appears is that PWA organizations, likely because of policy and mandate, have the highest number of PHAs on their boards. Organizations providing a specific service (SS) appear second highest. Of the eleven organizations that fit into this category (SS), nine are in Toronto or Montreal, the top two population centers in Canada. The other two organizations are in Ottawa and Winnipeg, the fifth and sixth largest cities, respectively. City population, as well as organizational type, might be a factor in determining PHA involvement.

GSOs in relatively large cities report similar statistics to SS organizations. Just over half (53.3%) of GSOs have three or more PHAs on their boards. The remaining half (46.7%) reported having one or two PHAs on the board. All GSOs in relatively large cities reported having at least one PHA on their boards (see Table 8).

Both organizations serving specialized communities (SC) and GSOs in relatively small communities lagged behind the other three organizational types. Over 70% (16 of 22) of GSOs in relatively small cities had only one or no PHAs on their boards. Perhaps more surprising is that organizations serving specialized communities find it difficult to involve PHAs in leadership roles within their organizations. Nine of the ten organizations in this category (SC) are in one of Canada's three largest cities. The tenth organization is in Edmonton, the seventh largest city. Yet, only two of the ten organizations within this category (SC) had three or more PHAs on their boards. Six of the ten organizations had only one or no PHAs on their boards. This finding, compared with the relative successes of other organizations in the same cities, suggest that something unique within the organizational type, Specialized Community (SC), is a barrier to PHA involvement.

Both specialized communities and GSO-S have two important common characteristics. First, both of these types of organizations serve small communities, whether geographical or ethno-cultural. Second, within each of these communities people are already marginalized. SCs often serve minority groups within large metropolitan areas. These communities are usually tight-knit. Members who are infected with HIV are often reluctant to come forth for fear of recrimination and ostracization within their communities. Similarly, GSO-S serve primarily gay men in relatively small, often rural, communities. These men do not have the protection and anonymity that urban centers, with large gay populations, offer. Barriers for PHA involvement in community groups will be more fully explored in Chapter 7.

TABLE 11

ORGANIZATION TYPE BY PROPORTION OF PHA BOARD MEMBERS

COUNT ROW PCT.	NO PHA BOARD MEMBERS	UNDER 30%	30% AND OVER	
GSO-L		11	4	
		73.3	26.7	
GSO-S	7	15		
	31.8	68.2		
PWA		1	5	
		16.7	83.3	
SC	3	5	2	
	30.0	50.0	20.0	
SS	2	5	4	
	18.2	45.5	36.4	
Column totals	12	37	15	64
	18.8	57.8	23.4	100.0

As Table 11 illustrates, when the proportion of PHA board members is related to organizational type, PWA organizations are the only ones with the majority (5 of 6 or 83.3%) with 30% or more PHA board representation.

TABLE 12

ORGANIZATION TYPE BY NUMBER OF PHA STAFF

COUNT ROW PCT.	NO PHA STAFF	1 PHA STAFF MEMBER	2 PHA OR MORE STAFF MEMBERS	
GSO-L	6	5	4	
	40.0	33.3	26.7	
GSO-S	16	3	1	
	80.0	15.0	5.0	
PWA	4	1	1	
	66.7	16.7	16.7	
SC	8	2		
	80.0	20.0		
SS	3	4	1	
	37.5	50.0	12.5	
Column totals	37	15	7	59
	62.7	25.4	11.9	100.0

PHA staff representation appears similar to PHA representation on boards. Results for PHA staff levels, however, are not as easy to interpret, given that the majority of organizations have no PHA staff. Of those organizations that have PHA staff,

TABLE 13

ORGANIZATION TYPE BY PROPORTION OF PHA STAFF

COUNT ROW PCT.	NO PHA STAFF	UNDER 30% PHA STAFF	30% AND MORE PHA STAFF	
GSO-L	6	9		
	40.0	60.0		
GSO-S	16	1	3	
	80.0	5.0	15.0	
PWA	4		2	
	66.7		33.3	
SC	8	1	1	
	80.0	10.0	10.0	
SS	3	3	2	
	37.5	37.5	25.0	
Column totals	37	14	8	59
	62.7	23.7	13.6	100.0

it appears that GSO-L, PWA, and SS have more PHAs, and the proportion of PHA staff in PWA organizations is greater than any other type of organization.

At first glance, Table 12 appears to show that GSOs in relatively large cities are more successful in hiring PHAs. This has to be compared to the findings in Table 13, which examines proportions. Over a quarter of GSO-Ls (26.7%) employ two or more PHAs. However, when looking at proportions, no GSO in relatively large cities has 30% or more PHAs on staff.

Perhaps the most striking finding in this analysis is that only one of the six PWA organizations surveyed has two or more PHAs on staff. One other PWA organization has one PHA on staff, while the other four who have staff have no PHAs employed.

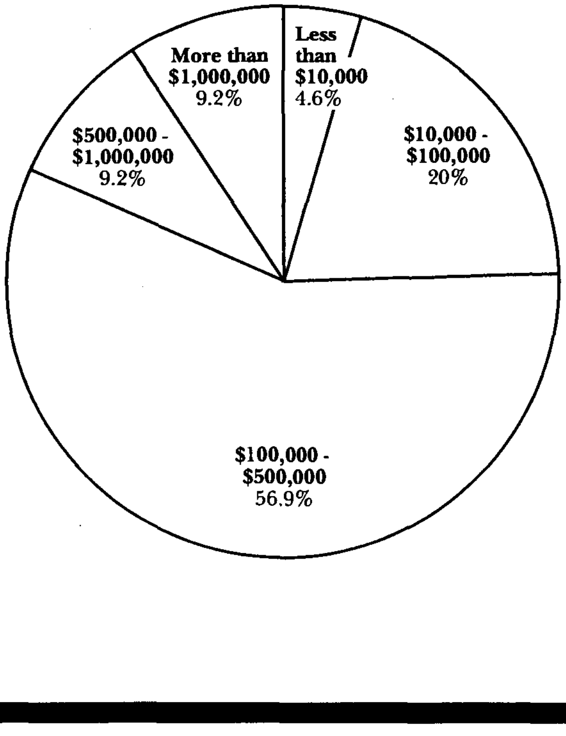
SIZE OF ANNUAL BUDGET

The size of an organization can be measured in a variety of ways: the number of people on staff, the number of programs and services offered, and the size or square footage of their place of business. For the purpose of this study, we asked organizations to reveal their annual budgets, which we used as an index of the size of the organizations.

Chart 2 displays the respondents' 1992 annual budgets as reported in the survey. Budgets ranged from $0 to $2.8 million, with a median of $200,000 and a mean of just under $340,000. Over 80% (81.5%) of reporting organizations had budgets under $500,000.

CHART 2

ANNUAL BUDGET OF CAS MEMBER ORGANIZATIONS



The size of an organization could potentially impact on the ability, or desire, to involve PHAs. Organizations with large budgets are often found in large cities, where more PHAs live. This increases the possibility of finding a PHA with the required skills. Larger organizations may also have more specialized positions, thereby allowing for the possibility to train a PHA for the specialized skills required, while at the same time having a larger support staff to assist PHAs in performing their tasks. Larger organizations with specialized positions can mean less need to find any one, 'perfect' candidate who is able to perform a multitude of tasks that a smaller organization may require of its one or two employees.

Some will argue that small organizations are often started by PHAs, thereby increasing the potential of employing PHAs. Others will point out that small organizations have very few staff and can't afford to hire PHAs who, one day, may need to go onto long-term disability, thereby bringing the operation of an agency to a stand-still.

TABLE 14

BUDGET BY NUMBER OF PHA BOARD MEMBERS

COUNT ROW PCT.	0 PHAs	1 PHA	2 PHAs	3 OR MORE PHAs	
under $100K	7 46.7	2 13.3	1 6.7	5 33.3	
$100K-$500K	5 13.5	13 35.1	9 24.3	10 27.0	
over $500K		3 25.0	2 16.7	7 58.3	
Column Totals	12 18.8	18 28.1	12 18.8	22 34.4	64 100.0

TABLE 15

BUDGET BY PROPORTION OF PHA BOARD MEMBERS

COUNT ROW PCT.	NO PHA BOARD MEMBERS	LESS THAN 30% PHAS ON BOARD	30% OR MORE PHAS ON BOARD	
under $100K	7 46.7	4 26.7	4 26.7	
$100K-$500K	5 13.5	26 70.3	6 16.2	
over $500K		7 58.3	5 41.7	
Column Totals	12 18.8	37 57.8	15 23.4	64 100.0

Size of organization (using budget as a measure) does appear to be related to PHA participation, although numbers are too small to produce significant chi-square statistics. As can be seen in Tables 14 and 15, those with larger budgets appear to have greater PHA representation on their boards, both in terms of actual PHAs and the proportion of PHAs on the board.

The same pattern holds for PHA staff. Table 16 indicates that those with larger budgets appear to have greater PHA staff levels. Larger organizations (measured by budget) have more staff; therefore, it is not surprising that they hire more PHAs. Correlation statistics computed for all four relationships suggest that there is a significant positive relationship between only budget and actual numbers of PHAs on staff (r=.43, significant at the .001 level). However, there is not a significant relationship between budget and staff proportion.

TABLE 16

BUDGET BY NUMBER OF PHAs ON STAFF

COUNT ROW PCT.	NO PHA STAFF	1 PHA ON STAFF	2 PHAs OR MORE ON STAFF	
under $100K	8 80.0	2 20.0		
$100K-$500K	26 70.3	9 24.3	2 5.4	
over $500K	3 25.0	4 33.3	5 41.7	
Column Totals	37 62.7	15 25.4	7 11.9	59 100.0

SIZE OF CITY

There is a direct relationship between the population of a Canadian city and the number of PHAs in that city. Toronto, Montreal, and Vancouver are the only three Canadian cities with populations over 1 million. Gay men still account for over 80% of reported AIDS cases in Canada. Not coincidentally, these three cities have both the highest populations of gay men and PHAs.

When examining the distribution of responding CAS organizations in small, medium, and large cities, three-quarters (75.4%) are in cities of over 100,000.

Tables 17 through 20 suggest that organizations located in larger cities have more PHA participa-

TABLE 17

CITY POPULATION BY NUMBER OF PHAs ON BOARDS

COUNT ROW PCT.	0 PHAs	1 PHA	2 PHAs	3 OR MORE PHAs	
under 100K	7 43.8	6 37.5	2 12.5	1 6.3	
100K-1M		7 29.2	8 33.3	9 37.5	
over 1M	5 20.8	5 20.8	2 8.3	12 50.0	
Column Totals	12 18.8	18 28.1	12 18.8	22 34.4	64 100.0

TABLE 18

CITY POPULATION BY PROPORTION OF PHA BOARD MEMBERS

COUNT ROW PCT.	NO PHA BOARD MEMBERS	UNDER 30%	30% AND OVER	
under 100K	7 43.8	9 56.3		
100K-1M		19 79.2	5 20.8	
over 1M	5 20.8	9 37.5	10 41.7	
Column Totals	12 18.8	37 57.8	15 23.4	64 100.0

TABLE 19

CITY POPULATION BY NUMBER OF PHA STAFF

COUNT ROW PCT.	NO PHA STAFF	1 PHA STAFF MEMBER	2 PHA OR MORE STAFF MEMBERS	
under 100K	11 78.6	2 14.3	1 7.1	
100K-1M	16 66.7	6 25.0	2 8.3	
over 1M	10 47.6	7 33.3	4 19.0	
Column Totals	37 62.7	15 25.4	7 11.9	59 100.0

TABLE 20

CITY POPULATION BY PROPORTION OF PHAs ON STAFF

COUNT ROW PCT.	NO PHA STAFF	UNDER 30%	30% AND OVER	
under 100K	11 78.6		3 21.4	
100K-1M	16 66.7	7 29.2	1 4.2	
over 1M	10 47.6	7 33.3	4 19.0	
Column Totals	37 62.7	14 23.7	8 13.6	59 100.0

tion than those in smaller centers. This relationship is clearer for PHA participation on boards (Tables 17 and 18) than for PHA staff (Tables 19 and 20), once again, because few organizations had PHA staff. It was not possible to compute valid chi-square statistics for these relationships. While there is some suggestion of a positive trend, no significant correlation exists between PHA participation and city size.

PHA participation variables were also examined by comparing participation in centers over one million (Toronto, Montreal, and Vancouver) with participation in all other centers. The three large centers have a larger proportion of PHAs on boards than those organizations in other centers (chi-square 8.27, d.f. 2, sig. at the .02 level). The difference between cities of over 1 million and smaller centers for number of PHAs on boards also approached significance. Tables 21 and 22 show these relationships.

TABLE 21

ORGANIZATIONS IN 3 LARGEST CITIES (Toronto, Montreal, Vancouver) VS. ORGANIZATIONS IN ALL OTHER CENTERS BY NUMBER OF PHAs ON BOARDS

COUNT ROW PCT.	NO PHA ON BOARD	1 OR 2 PHA ON BOARDS	3 OR MORE PHAs ON BOARDS	
Toronto, Montreal, Vancouver	5 20.8	7 29.2	12 50.0	
Other Centers	7 17.5	23 57.5	10 25.0	
Column Totals	12 18.8	30 46.9	22 34.4	64 100.0

TABLE 22

ORGANIZATIONS IN 3 LARGEST CITIES (Toronto, Montreal, Vancouver) VS ORGANIZATIONS IN ALL OTHER CENTERS BY PROPORTION OF PHAs ON BOARDS

COUNT ROW PCT.	NO PHA BOARD MEMBERS	UNDER 30%	30% AND OVER	
Toronto, Montreal, Vancouver	5 20.8	9 37.5	10 41.7	
Other Centers	7 17.5	28 70.0	5 12.5	
Column Totals	12 18.8	37 57.8	15 23.4	64 100.0

No significant relationship was found between staff participation in Toronto, Montreal and Vancouver and organizations in other centers.

REGIONS

Canada is made up of ten provinces and two territories, each with its own government. The delivery of health and social services is the responsibility of the provincial governments; therefore the development of community-based AIDS organizations is often influenced by the support they receive from these regional governments. In addition to the political and economic impact that these jurisdictions impose, Canada has unique cultural differences influenced by regional considerations that do not necessarily follow strict political boundaries. In the United States, when one speaks of middle-American, east-coast, and west-coast mentalities, they conjure up familiar images. Similarly, Canada has distinct cultural differences based on regions.

CAS, like many other Canadian institutions, organizes its membership into five distinct regions (see Table 2). The Atlantic Region comprises the four east-coast provinces. Each has a small, mostly rural population and is considered economically challenged. Each of these four provincial governments provides relatively low levels of government funding to community-based AIDS organizations. This has resulted in the development of only seven groups in four provinces. Groups in this region have a loosely defined coalition called the Atlantic AIDS Network (AAN). They meet formally once a year, and members of the organizations meet periodically throughout the year to collaborate and share information.

The province of Quebec is a region of its own. It is considered distinct culturally, based on being predominantly French-speaking. Although the population of Quebec is second only to the province of Ontario, it has also been historically characterized as one of Canada's economically challenged provinces. Fifteen (15) of the seventy (70) CAS member groups are in the province of Quebec, with over half (8) being in the city of Montreal. Among the Quebec-based CAS members is COCQ-SIDA, a provincial coalition of community-based AIDS organizations. COCQ-SIDA is a well-organized, provincially funded organization. It has full-time staff and permanent offices. They bring representatives of their membership together several times a year.

Although it has fallen on hard economic times of late, Ontario is Canada's largest province and its provincial government has historically been the most supportive of the community-based AIDS movement. Over one third (26) of all CAS members are spread throughout fourteen different Ontario communities. Twelve groups are located in Toronto alone. The Ontario AIDS Network (OAN) is the largest provincial AIDS coalition. Its staff coordinates quarterly meetings of the entire membership, as well as periodic meetings for representatives from various disciplines within the membership. Through the auspices of the OAN, the Ontario government sponsors quarterly meetings of PHAs from throughout Ontario. Once a year, the OAN hosts a three-day conference for PHAs, consisting of a series of skills-development and information-sharing workshops.

TABLE 23

NUMBER OF PHAs ON BOARDS BY REGION

COUNT ROW PCT.	0 PHAs	1 PHA	2 PHAs	3 OR MORE PHAs	
Atlantic	2 28.6		3 42.9	2 28.6	
Quebec	4 28.6	4 28.6	1 7.1	5 35.7	
Ontario	3 12.0	10 40.0	4 16.0	8 32.0	
Prairie	3 25.0	2 16.7	4 33.0	3 25.0	
Pacific		2 33.3		4 66.7	
Column Totals	12 18.8	18 28.1	12 18.8	22 34.4	64 100.0

The Prairie Region consists of three provinces and one territory. Oil-rich Alberta is the wealthiest of all Canadian provinces and is the only jurisdiction in the Prairies with a regional coalition. Nine (9) of the sixteen (16) CAS members in the Prairies are in Alberta.

Finally, the fifth region is the Pacific Region. With Vancouver at its center, this region is made up of the province of British Columbia and one Yukon Territory. This region has the smallest number of groups (6); however, four (4) of these groups are based in Vancouver and produce many of the national leaders of the community-based AIDS movement, including PHAs. The B.C. AIDS Network serves a coordinating function for British Columbia organizations.

Table 23 displays the number of PHAs on boards by region. The Pacific Region had the largest number of PHAs on boards (four of six organizations had three or more PHA board members). Approximately one-third of Quebec and Ontario organizations (35.7% and 32.0%, respectively) had three or more PHA board members. The Atlantic Region and the Prairie Region had fewer organizations with three or more PHAs (under 30%). The Quebec and the Pacific Regions had the largest proportion of organizations with 30% or greater PHA representation on just over a third of their boards (see Table 24).

TABLE 24

PROPORTION OF PHA BOARD MEMBERS BY REGION

COUNT ROW PCT.	NO PHA BOARD MEMBERS	UNDER 30%	30% AND OVER	
Atlantic	2 28.6	4 57.1	1 14.3	
Quebec	4 28.6	5 35.7	5 35.7	
Ontario	3 12.0	17 68.0	5 20.0	
Prairie	3 25.0	7 58.3	2 16.7	
Pacific		4 66.7	2 33.3	
Column Totals	12 18.8	37 57.8	15 23.4	64 100.0

There was no apparent relationship between region and PHA staff levels. Numbers of PHA staff were too small to clearly determine any trends.

Regional Differences when Controlling for Three Largest Cities

We previously determined that when we compare cities with populations of over 1 million (Toronto,

TABLE 25

NUMBER OF PHAs ON BOARDS BY REGION (excluding organizations in Toronto, Montreal and Vancouver)

COUNT ROW PCT.	0 PHAs	1 PHA	2 PHAs	3 OR MORE PHAs	
Atlantic	2 28.6		3 42.9	2 28.6	
Quebec	1 16.7	3 50.0		2 33.3	
Ontario	1 7.7	7 53.8	3 23.1	2 15.4	
Prairie	3 25.0	2 16.7	4 33.0	3 25.0	
Pacific		1 50.0		1 50.0	
Column Totals	7 17.5	13 32.5	10 25.0	10 25.0	40 100.0

Montreal and Vancouver) and all other centers, there is a notable difference in the number and proportion of PHAs on boards. Tables 25-28 remove the 24 CAS organizations in these three cities, then compare regions.

TABLE 26

PROPORTION OF PHAs ON BOARDS BY REGION
(excluding organizations in Toronto, Montreal and Vancouver)

COUNT ROW PCT.	NO PHA BOARD MEMBERS	UNDER 30%	30% AND OVER	
Atlantic	2 28.6	4 57.1	1 14.3	
Quebec	1 16.7	3 50.0	2 33.3	
Ontario	1 7.7	12 92.3		
Prairie	3 25.0	7 58.3	2 16.7	
Pacific		2 100.0		
Column Totals	7 17.5	28 70.0	5 12.5	40 100.0

TABLE 27

NUMBER OF PHA STAFF BY REGION
(excluding organizations in Toronto, Montreal and Vancouver)

COUNT ROW PCT.	NO PHA STAFF	1 PHA STAFF MEMBER	2 PHA OR MORE STAFF MEMBERS	
Atlantic	4 57.1	2 28.6	1 14.3	
Quebec	5 83.3	1 16.7		
Ontario	10 76.9	2 15.4	1 7.7	
Prairie	7 70.0	2 20.0	1 10.0	
Pacific	1 50.0	1 50.0		
Column Totals	27 71.1	8 21.1	3 7.9	38 100.0

TABLE 28

PROPORTION OF PHA STAFF BY REGION
(excluding organizations in Toronto, Montreal and Vancouver)

COUNT ROW PCT.	NO PHA STAFF	UNDER 30%	30% AND OVER	
Atlantic	4 57.1		3 42.9	
Quebec	5 83.3	1 16.7		
Ontario	10 76.9	3 23.1		
Prairie	7 70.0	2 20.0	1 10.0	
Pacific	1 50.0	1 50.0		
Column Totals	27 71.1	7 18.4	4 10.5	38 100.0

The most striking difference is between Canada's two largest provinces and regions, Ontario and Quebec. When we remove Toronto and Montreal, respectively, Quebec has 2/6 (33.3%) of its remaining organizations with three or more PHAs on their boards. Ontario, by contrast, has only 2/13 (15.4%) of its organizations that are not in Metropolitan Toronto with 3 or more PHAs on its boards.

Not only are the Ontario numbers low when compared to Quebec, they are low when compared to both the Atlantic and Prairie Regions. All but two organizations in the Pacific Region are in Vancouver, making it difficult to point to any trends on the west coast.

Proportions of PHA board members are also low in Ontario, when we exclude the Toronto groups. All Ontario groups outside of Toronto have less than 30% representation of PHAs on their boards. Although the numbers are too small to produce statistically significant findings, they do suggest that Ontario cities are lagging behind cities of similar size in other regions of the country in their PHA involvement.

Numbers of PHAs on staff are very small when we exclude Toronto, Montreal, and Vancouver. Although it is not statistically significant, it is worth noting that three of the seven (42.9%) Atlantic groups have 30% or more PHAs on staff. Although Atlantic Canada is made up of small, mostly rural communities, they have made an effort to hire PHAs with their limited resources.

FOUNDING YEAR

AIDS Vancouver and the AIDS Committee of Toronto were the first two community-based AIDS organizations to be founded. The year was 1983.[15] The mean founding year for CAS member groups was 1987.54. This longevity variable was considered to determine whether or not involvement of PHAs in the life of an organization is affected by the length of time an organization has existed.

Two schools of thought exist in this regard. First, some believe that organizations that have been around longer have established infrastructures and are no longer operating as though they were in crisis. As a result, they can turn their attention to secondary considerations such as the involvement of PHAs. Others believe that the opposite is true. They fear community-based organizations will turn away from their roots and become more professionalized, thereby limiting the possible involvement of PHAs over time.

No significant correlations, or even trends, were noted with respect to age of organization and PHA participation on either boards or staff.

CONCLUSION

This chapter explored the degree of PHA involvement within the organizational membership of the Canadian AIDS Society. Some organizations within CAS have been more successful than others in attracting PHAs to both board and staff positions. Overall, organizations were more successful in recruiting PHAs to voluntary board positions than they were to paid staff positions. Although most organizations (81.3%) had some PHA presence on their boards, the overwhelming majority (65.6%) had fewer than three. On the average, only one-fifth (21.9%) of board members within CAS member groups were PHAs. Similarly, only seven CAS member groups (10.9%) have a majority of PHAs on their governing bodies.

Significantly fewer PHAs participated in CAS organizations as staff members than they did as board members. Of those organizations with any staff, 62.7% reported having no PHA staff. Just under one in ten (9.6%) employees of CAS member groups were PHAs. Similarly, only five organizations (7.8%) had a majority of PHAs as staff.

Some types of organizations have more success than others in recruiting PHAs to both board and staff positions. Generally, PWA organizations had greater success in attracting PHAs to board positions but shared in the struggle to employ PHAs. Large organizations, particularly those in Toronto, Montreal, and Vancouver, had more success in involving PHAs than those in smaller organizations and in smaller communities, whether regional or ethno-cultural.

This chapter traced the participation of PHAs in the community-based AIDS movement by giving us a snapshot of the member organizations of the Canadian AIDS Society. Clearly, most organizations find it difficult to attract PHAs to active roles within their organizations. The next chapter (6) looks at the advantages of involving PHAs in the community-based AIDS movement, while Chapter 7 identifies the barriers PHAs face to greater or more meaningful participation.

CHAPTER 6

Advantages of PHA Participation

This chapter documents the important contribution that PHAs make to the community-based AIDS movement in Canada. Information in this chapter has been informed by both Phase 1 and Phase 2 of the research. In Phase 1, those in leadership positions completed comprehensive written surveys. Many of the questions invited narrative responses, giving the authors ample opportunity to document the experience of their organizations. A second source of information was Phase 2, where focus-group meetings of PHAs were audio recorded. Quotations have been extracted from both phases of the project.

Statements on the survey forms or during interviews – from PHAs, as well as from those not infected but in leadership positions in the AIDS movement – outline the advantages of involving PHAs. These advantages have been categorized under four broad headings (below): "Impact on the Agency," "Impact on Service Delivery," "Impact on Other Workers," and "Impact on Individual PHAs."

During the project, organizations as well as PHAs were promised that any information they disclosed about their agency would be presented anonymously. CAS member organizations agreed to participate in this study with the clear understanding that their organization and members could be candid, often critical, without any fear that the information they shared could be used against them. To protect privacy, only the following identifying information is disclosed: i) type of group (as categorized in Appendix 4), if the quote was extracted from the survey completed on behalf of a CAS member group; or ii) PHA, if the quote was attributable to one of the seventy PHAs who attended one of the fifteen focus groups; and iii) region of the country (as outlined in Table 2, Chapter 3). This will help with any comparisons of experiences within different sectors of the Canadian community-based AIDS movement and, at the same time, provide a degree of anonymity.

Before elaborating on the four "Impact" areas however, there are three broad "Issues" that PHAs bring to community-based AIDS organizations: PHA empowerment, skills and knowledge, and personal resources. Each of these, for each PHA and for each organization, has its own importance and dynamic. Any agency wishing to increase its involvement of PHAs must acknowledge these issues. By addressing them first, another perspective – and perhaps a better appreciation of the advantages of PHA participation – can be gained.

ISSUES

PHA empowerment

As PHAs became more mobilized throughout the Canadian community-based AIDS movement (see Chapter 4), we have demanded that we speak on our own behalf. Doctors, hospitals, as well as AIDS organizations with no serious PHA involvement have been challenged to stop speaking on behalf of people who have proven themselves more than capable of articulating their own issues and concerns.

Part of the awakening that has taken place is resulting in PHAs demanding a more representative voice throughout the AIDS movement generally, as well as within particular communities. At the same time, with the growing public awareness of AIDS – its history and the politics – PHAs are beginning to be perceived as having the moral authority to address issues that the agency otherwise cannot address.

Skills and knowledge

AIDS, which, in Canada, first affected the gay community, 'chose' a community of people who are highly educated, above-average income earners, and have fewer parenting responsibilities than heterosexuals in the same age categories. This means that gay people are highly resourced. This above-average resourcefulness within the gay community has also translated to the group of people infected with HIV. PHAs are doctors, lawyers, accountants, social workers, nurses – virtually every professional group imaginable. PHAs have greatly enhanced every aspect of the AIDS movement with our considerable and varied skill sets.

Skills and knowledge are often defined exclusively by level of education or other credentials. Not surprisingly, it is the well educated who have influenced such narrow and limiting definitions. Well-educated PHAs bring skills and knowledge, acquired through both more formal education and a lived experience, to the community-based AIDS movement. PHAs who do not have an extensive education can still bring a richness of skills and knowledge through their lived experience. AIDS organizations need to provide additional training to both of these groups of PHAs, so that their contributions can match the needs of the agency.

It is far easier to train most PHAs for a particular skill than it is to help someone not living with HIV to understand the experience of those infected. Yet, PHAs who do not possess certain skill-sets often experience agencies as unwelcoming. The opposite is rarely true. Well educated people, regardless of health status, are rarely discouraged from any type of participation.

A common example of knowledge gained by PHAs through life experience and not formal education is treatment information. Many PHAs, even those with minimal formal education, have acquired extensive knowledge in the complicated and ever-changing world of AIDS treatments. It is not uncommon for PHAs with no more than a high school education to be informing their physicians about available treatment options.

Perhaps the greatest asset that PHAs bring to the AIDS movement is the ability to provide peer support to other PHAs, especially the newly diagnosed. Unlike other institutions which provide professionals with academic credentials, the community-based movement has a rare opportunity to provide an alternative form of support – peer support.

Role models are valuable to PHAs. Many of us suffer not only from poor physical health, but have mental-health concerns such as poor self-esteem, depression, and suicidal ideation. Having well-functioning PHAs in highly visible, accessible positions offers the community a way of witnessing healthy forms of disclosure and ways of seeking support and affirmation. We can teach others by our actions, not just our words, that HIV does not mean we need to stop being productive members of society. PHAs of every educational background have a valuable role to play in this self-help movement.

Personal resources

PHAs bring a high degree of personal investment, motivation, dedication, compassion, and commitment to our work. These are advantages to the agency which organizations must be careful not to overlook.

One of the most important issues that lingers for PHAs, however, is how to set limits to our involvement in AIDS organizations. PHAs on staff often find themselves working long hours, and volunteers want to sign up for every vacant shift. Often, PHAs have left very stressful or unrewarding jobs to work or volunteer in an AIDS organization that will provide meaning in their lives, but they need help to set appropriate limits.

PHAs in this study tended to focus attention on personal resources. Only two PHAs referred to the political advantages they brought to their agencies. AIDS organizations, on the other hand, highlighted the political importance of involving PHAs. It appears as though AIDS organizations are more preoccupied with the political advantages surrounding PHA involvement, whereas PHAs tend to be more concerned with how they can influence programs and services through their skills and knowledge.

AIDS organizations, like any social service agency, can become rooted in a particular service system, addressing a particular set of problems in a particular way. The impact PHAs have on an agency can best be described under four headings: change, urgency, credibility, and motivation.

Change

By having PHAs work in all areas of an AIDS organization, the agency is in a better position to be alerted to and focused on the ever-changing needs of PHAs. From the comments received or recorded, it became clear that PHA involvement in the agencies helped put – and keep – the energies, priorities, and issues in their proper focus.

Because they are the 'living' reason for the existence of AIDS agencies, the PHAs' presence and work has challenged, changed, and sustained many such organizations.

> *I suspect we have avoided a split between PLWHIV/AIDS and our organization by increasing numbers [of PHAs] becoming involved and by encouraging involvement at all levels. They keep our organization and staff and volunteers focused on needs of PLWHIV/AIDS and motivated to face obstacles to our work. (GSO-S, Ontario).*

> *Their presence at work keeps us focused on our mandate. [PHAs] bring a very creative life force to [our agency]. (GSO-L, Ontario).*

As the medical and social realities of the illness change, the entire agency must be more responsive to these new realities. If, for example, the fund raiser, business manager and educators are as attuned to the changing needs of PHAs as those providing direct services, the agency becomes more motivated to adjust its strategic directions. Agencies that were established ten years ago, primarily to provide prevention education, must now re-examine their mission and mandate to make services to a growing number of PHAs more of a priority.

> *A lot goes to education and prevention because that has been seen as the role for this organization I think because there hasn't been a lot of us or we have just quietly crawled off in a closet somewhere and died. That has got to change as the numbers grow. It has to inevitably change. The mission of this organization is going to change. (PHA, Atlantic).*

Urgency

Because of PHAs' often fragile health, we bring a greater sense of urgency and importance to our work, which can permeate the workplace. If we determine something needs to be done immediately, we are more likely to ensure the task is completed immediately.

> *sens de l'urgence face aux problémes rencontres [a sense of urgency in dealing with the problems encountered]. (SS, Quebec).*

PHAs, especially those with an AIDS-defining illness, often do not see the relevance of long-term strategic planning. We force the agency to look at immediate and short-term goals. It is the fulfillment of these goals that seem relevant to PHAs.

Credibility

Because of the issues previously described – PHA empowerment, skills and knowledge, and personal resources – PHA involvement provides an agency with more credibility in the community. Other institutions, such as hospitals, clinics, medical doctors and traditional social service agencies, are often professionally driven – with little or no attention paid to involving clients or patients in any decision making. An AIDS organization that involves PHAs in decision making positions itself as having a unique perspective on issues.

> *Putting faces to the disease has helped to say things that the agency itself can't. (GSO-S, Ontario).*

PHA involvement in AIDS organizations legitimizes these organizations. Other organizations, such as government and corporate funders, are acquiring a new found respect for organizations that are consumer-driven, which they see as well positioned to maximize their investment in the agency.

> *There were horrendous fights, really significant fights, over the issue of financing . . . If you look at our budget [this AIDS agency] spends in direct services . . . something less than 2% [of the total budget]. It was felt that this was not really an organization for PHAs. (PHA, Atlantic).*

> *[PHAs] make sure agency responds to appropriate needs and responds to needs appropriately. (SS, Prairies).*

The 1990s have seen a growing trend towards consumer-oriented and -driven services.

> *We consider our agency to be consumer oriented and consumer driven. We couldn't claim this philosophy without the direct involvement of PLWHIV/AIDS. (GSO-L, Prairies).*

Community-based AIDS organizations are often viewed as less attractive employers than hospitals and traditional social service agencies, who offer better salaries, benefits, and working conditions. These professionally-driven institutions often view community-based agencies as lacking skills and knowledge, thereby having little influence on a larger AIDS agenda. By involving PHAs in leadership positions, AIDS organizations can speak as representatives of a PHA constituency, and therefore establish the credibility needed to influence the way in which services are delivered in a number of different settings.

PHAs are dedicated people who increase the agency's ability to be visibly active within the community.

> *Whenever I am needed I am there. I man tables and all that stuff, pass out information at Carabana. For me it's like putting a face on AIDS because I'm reaching the Black community. (PHA, Ontario).*

Some organizations are now establishing affirmative action programs to ensure that PHAs achieve a higher level of participation on boards of directors as well as staff and volunteer positions. By doing this, they are keeping their organizations accountable to its principal service users.

> *Accountability: keeping us on track, keeping us current, political, committed, passionate. (PWA Organization, Ontario).*

> *Allows for accountable, current, and sensitive representation. (GSO-L, Prairies).*

Motivation

Many of the AIDS organizations surveyed in Phase 1 noted the personal investment PHAs bring to their work and how this increases their commitment to the agency's work. Agencies reported that PHAs are highly motivated and therefore contribute to a productive workplace.

> *[PHAs offer] many advantages – experience, skill, personal investment, knowledge, background. (GSO-L, Ontario).*

> *I left work because I couldn't deal with 40 hours/week. I now average 20 hours per week [as a volunteer at the local AIDS organization]. This seems a lot more manageable. Some of the work I do from home on the telephone. I can keep flexible hours – this is easier to manage. (PHA, Quebec).*

> *I would be out three, four nights a week doing something or the other. I do a lot of volunteer work but I had to cut that down. Do a little more personal time. (PHA, Ontario).*

> *But you know we are the people who have work that is important to do and we will do that work from our hearts rather than just doing it because we are getting paid. (PHA, Prairies).*

Other personal characteristics mentioned include compassion, understanding, and insight, while other comments focused on the particular wisdom and guidance PHAs bring to their work.

> *We have found a particular wisdom and guidance that PLWHIV or AIDS have been able to provide. We encourage healing in a traditional sense as well as seek it, and many people can learn and benefit from healing as applied to PLWHIV/AIDS. (SC, Ontario).*

Both organizations and PHAs themselves recognize that, because of their medical condition, PHAs who are involved in the community-based AIDS movement bring a rich personal investment to their work. PHAs are highly motivated and have an increased commitment to the work of the agency.

The focus of this section was on how PHAs help an organization stay focused on issues of importance and relevance to the lives of its clients. The only type of organization that didn't highlight the impact PHAs had on the agency were PWA organizations. Understandably, this did not seem necessary to document, as PWA organizations are run by PHAs, and generally limit their services to providing direct support to only PHAs. Therefore, their services are already very focused and relevant. As for credibility, PWA organizations are well known for being built on the premise of self-help and leadership of the client.

IMPACT ON SERVICE DELIVERY

Community-based AIDS organizations provide a range of services in education, advocacy, and support. To provide the right set of services, agencies need the right vision, adequate financing and PHA involvement in all aspects of service delivery.

Vision

As the needs of PHAs change, and grow, some PHAs have provided AIDS organizations with the necessary leadership for expanding services and program direction.

> *PLWAs have expanded the services offered and are educating the Newfoundland community. (GSO-S, Atlantic).*

> *[He] was very instrumental in helping to organize a gathering that all of us participated in. A weekend workshop get-together for positive people from all over N.B. It was the first time this had ever been done in the province and [he] was instrumental as a [PHA] board member in making it happen. (PHA, Atlantic).*

PHAs have been especially helpful in identifying service gaps.

> *[She] mentioned the high cost of nutritional supplements for example. I was very interested in organizing a buyer's club that maybe could bring those costs down. (PHA, Atlantic).*

> *[We] have a broad spectrum mandate – prevention, education, support. I am one who feels that support needs to be strengthened, augmented. I think that the numbers are beginning to be there where they weren't initially a couple of years ago. This organization is going to have to change, like it or not, to an organization that lends more support to people with AIDS or HIV. I hope I can make that change happen. (PHA, Atlantic).*

Until two PHA board members decided to organize monthly Treatment Information Forums, other PHAs in Ottawa had no source of treatment information other than what their doctors provided.

> *Recognition and implementation of a program (Treatment Information Forum) to meet needs of PLWHIV. (GSO-L, Ontario).*

Education

Although many PHAs have focused their attention on services they may need, now or in the future, others have, by looking back on their lives, identified prevention education as a source of gratification.

> *[PHA provide a] balanced mission focus between education and support. (GSO-S, Atlantic).*

PHAs, largely through speakers bureaus in local agencies, have become effective educators in high schools as well as other community institutions.

> *A PLWHIV/AIDS can do a better job at education as happened when a PLWHIV did three high school classes with me. (GSO-L, Ontario).*

> *speaking to community groups and schools disclosing a personal experience on living with HIV/AIDS. (PWA Organization, Prairies).*

> *Qualité des services de soutien, meilleure compréhension, approche préventive accrue. [quality of support services, better understanding, greater emphasis on a preventive approach]. (GSO-L, Quebec).*

> *insight into treatment, assistance in prevention education. (GSO-S, Prairie).*

Peer education by someone who has become infected helps bring HIV and AIDS 'close to home'.

> *very strong people [PHAs] have helped educate the community so people better understand and learn compassion. (SC, Ontario).*

Advocacy

Agencies who involve PHAs increase their ability to advocate with other agencies, thereby being better able to provide quality services to their clients.

> *[PHAs provide] connection to the community and [help us identify] gaps in service. (SS, Ontario).*

Advocacy is a service that agencies can provide within a community. Agencies with greater PHA involvement are usually more attuned to the changing needs of PHAs and therefore are more effective advocates.

> *[PHAs do] more powerful advocacy and lobbying with political representatives. (GSO-S, Prairies).*

> *[PHAs are a] stronger voice in advocacy. (SC, Ontario).*

> *We mentioned the drug program. When he [a PHA] had problems, it was his job to go in there and fight that battle on behalf of all of us. He did that not only for himself. He fought and won the battle for all of us in the province. I'm not sure how much backing he got from the organization. I think that our president and executive director should be in there kicking down doors. (PHA, Atlantic).*

Support

PHAs bring a unique appreciation for and insight into issues that affect other PHAs. Many clients appreciate the comfort and wisdom that comes from a person with similar experiences and background. PHAs have a unique ability to relate to clients and offer peer support. Often, they identify personally with the issue of the client, thereby making them feel that they are not alone with their struggle.

> *Well I have had clients come in and say, "Oh, my T-cell count has dropped to 700." I say, "Oh, I've gone to 2." (PHA, Ontario).*

> *My doctor has AIDS. I believe this is the first time that this has happened to me. I find it terribly important to me that he is able to be a doctor to me in a way that, I am sure my other doctors, who have been wonderful, well, my doctor now just understands. When I was starting DDI, it's fine, it tastes awful but it is fine, and he said, "You're lucky, I couldn't tolerate DDI." (PHA, Ontario).*

A peer counsellor is often the only person a PHA will talk to about being infected. Some PHAs have issues related to guilt, shame, even disgust with themselves. By having people who themselves are infected working as peer counsellors, clients know that they will not be judged and will be able to talk more freely.

> *The fact that when you go see the counsellor, well, for instance, he is just not counselling you on the benefits. He cares about how you are. Like how are you, what's going on, is there anything else. He is with you and he is feeling with you. You don't feel the barrier. You also know that he is dealing with some of the same things you are dealing with. You can ask him anything. It is a totally open atmosphere. I'm not afraid to discuss anything. (PHA, Ontario).*

> *Families might not know, friends might not know. A very select group of people. [Peer counsellors] try to give them something to identify with. (PHA, Atlantic).*

> *For the need of being around people who are the same, it is like a bond and it's a common ground. So a lot of stuff is lifted. You won't automatically understand certain things people go through because some people would never understand who are HIV negative. They will empathize but they will never totally understand what we live. (PHA, Ontario).*

When asked what advantage a PHA brings to an organization, many answered simply, "peer support." By employing PHAs as program coordinators and counsellors, AIDS organizations offer clients valuable and accessible role models.

> *use of peer supports, HIV+ staff and volunteers means they can act as role models [e.g. models of hope] to others who are HIV+, particularly newly diagnosed. (PHA, Ontario).*

PHAs have been leaders in various aspects of the AIDS movement. Greater knowledge of treatment-related issues, holistic and traditional healing, and a variety of health promotion strategies have come about in the AIDS movement because of the leadership role PHAs have assumed.

> *[PHAs have] greater awareness of HIV issues and concerns. (GSO-S, Atlantic).*

> *[He] has been the person I always call when I need information about any kind of therapy, more than [the local AIDS organization]. When I call [the local AIDS organization] they don't know and I don't feel the people [who work] there are as up to date as they should be. Things like where to get vitamins. I switched my doctor to one that he is going to just because I know he has been telling the doctor things and has information that people here are not giving us. (PHA, Atlantic).*

> *I am not a full-fledged counsellor but I do a fair amount of counselling in terms of the whole person and in terms of physically, mentally, emotionally and spiritually. The medicine wheel. Because we aren't just a physical entity. (PHA, Prairies).*

Peer counselling sometimes extends beyond one's HIV status. Some PHAs find comfort in talking to PHAs of similar cultural background whether the issue is isolation, political sensitivities, or culturally specific rituals.

> *Our cultural difference is important to the client. (PHA, Pacific).*

> *I said, "there has to be another Black person living with this disease". For me, that's where Black-CAP came in. (PHA, Ontario).*

> *[PHAs bring] a particular understanding about the needs of South Asian PLWHIV/AIDS and the lack of understanding/support within our own community. (PHA, Ontario).*

> *[Native sweat ritual] is a purification. A lot of it is symbolic. Technically it is a sauna. It is a sauna bath. The ceremony and the symbols that are used to purify that individual, they are all very important. (PHA, Prairies).*

Women are also comforted by sharing their stories with other women.

> *Often women want to talk to other women to know that they share a common experience as women. (PHA, Pacific).*

> *Really what was the turning point for me was when I went to the International AIDS Conference in Amsterdam and met with 60 other positive women around the world and finally had a chance to talk to women as a group about our issues and realize that some of the things that I was feeling were also shared by other women. (PHA, Pacific).*

One woman living with HIV, who was employed by an AIDS organization, was angry at the lack of information so-called professionals were providing women with HIV. Despite not having the same formal educational opportunities as others employed in the movement, her ability to communicate the knowledge she gained through her own experience was invaluable to other PHAs in her community.

> Nobody had advised any of them about PAP smears and the correlation of cervical cancer. I was really angry. I phoned five women – some of them had CD4 counts below 500 and I was under the impression if it's below 500, you should possibly be considering having one every three months. (PHA, Atlantic).

Fundraising

As government funding becomes more difficult to access, an agency's ability to attract private funding becomes vital to the success of its programs and services. Private individuals, small businesses, and corporations are often moved by first-hand accounts or testimonies of PHAs.

> *Mike spoke publicly about his status (first person in the Yukon to do so) – and I believe he was partly able to do this because of the support we provided to him. (GSO-S, Pacific).*

> *We did pretty good in the car wash. It was over $600. This is from a community that is very angry because they can stigmatize us in the Bay Roberts area – that is the AIDS capital of Newfoundland. To me it was kind of impressive. (PHA, Atlantic).*

Private donors are becoming increasingly vigilant in making sure their dollars go towards actual programs and services that improve the lives of individuals and not simply to 'general funds'. PHAs are therefore not only effective fund raisers, but are 'internal auditors', ensuring that funds are being spent appropriately.

PHAs have had a significant positive impact on the delivery of services within community-based AIDS organizations. Not only have we been leaders in the areas of treatment information and support, PHAs have been instrumental in providing leadership in the areas of education, advocacy, and fund raising.

IMPACT ON OTHER WORKERS

Those involved in a community-based AIDS organization are often affected by AIDS, either through their personal lives or the workplace. By having PHAs involved in the workplace, AIDS goes from theory to reality, thereby increasing the commitment and focus of everyone.

> *Elles font prendre conscience de la réalité du VIH/SIDA. Leur présence nous confronte a nous propres tabous et préjugés. Leur présence rend notre engagement concret. [They create an awareness of the HIV/AIDS reality. Their presence forces us to confront our own taboos and prejudices. Their presence gives concrete meaning to our commitment.] (GSO-S, Quebec).*

Staff, board members, and volunteers all have the opportunity to work side by side with PHAs through the various stages of the illness – from the newly diagnosed to the bereavement process. The experience of working with friends and colleagues who have AIDS motivates others to take actions that they might not otherwise take if they have only had the experience of working with clients from whom they feel somewhat removed.

PHAs become 'watch-dogs,' ensuring that everybody is dedicated to his or her work and to the cause of fighting AIDS in the community. One PHA critically observed that in his organization, where there was no PHA on staff, everyone appeared to be unaffected by the health crisis he was living. This, he felt, suggested an uncaring environment.

> *It seems to be relaxed, everyone is cozy and has a good job. (PHA, Atlantic).*

Most AIDS organizations do more than provide counselling and support groups. They employ educators, fund raisers, managers, and other administrators whose duties might never include working with clients who are PHAs. One board member, who otherwise does not have the opportunity to interact with clients, commented,

> *as a policy-making board, the presence of PLWHIV has allowed board members to feel more involved (i.e. we may be involved with supporting or assisting a board member in more direct ways than we support clients). (SS, Ontario).*

Having PHAs involved in every aspect of an AIDS organization prevents all workers, paid or volunteer, from losing touch with the reality facing PHAs.

> *Nous permet d'être continuellement en contacte avec la réalité que vit ces gens. [Prevents us from ever losing contact with the reality facing these people]. (GSO-S, Atlantic).*

It also provides an opportunity to remove barriers between those infected with – and affected by – the virus. A PHA working as a co-worker can no longer be considered someone 'other'. This enables workers, especially those involved in providing direct care, to be more compassionate and committed in the problems encountered by clients.

By having more than one or two PHAs around an agency, it allows those infected to be supportive of one another at the workplace, whether they be volunteers or paid staff. One woman with HIV talked about her isolation and her experience of finding other women living with HIV.

> *For the last year on a daily basis I have been the only positive woman. Last week there were five of us in the office changing it around, creating a space for us. I left and I went home and I cried. I don't do that. I don't cry. I was just totally overwhelmed. I've done a lot of stuff in Canada but [you rarely] see the energy and feel the healing that was going on. (PHA, Pacific).*

In large cities, workers are often more connected to the communities most affected by AIDS, and they may already have many meaningful relationships with PHAs. PHAs who work and volunteer in smaller centers often provide others with their only opportunity for a close personal relationship to someone with AIDS.

This highlights the importance of creating a welcoming environment for PHA involvement, especially in smaller communities.

IMPACT ON THE INDIVIDUAL

People with terminal illness often strive to live normal lives for as long as possible. Similarly, some PHAs continue to live their lives as they had lived before the diagnosis. This might include continuing to work in an occupation that gives joy and satisfaction.

Once diagnosed, however, some PHAs choose to immerse themselves in AIDS work. By working in the AIDS movement, PHAs often feel a greater sense of control over, and meaning for, their lives.

> *Les PAS/VIH se sentent plus en controle de leurs services. [PLWHIV/AIDS feel more in control of their services]. (GSO-L, Quebec).*

> *I want to get involved. I want to be successful at something, otherwise my life is totally worthless. I feel alone, even though I am married. I need that support and I need to do something for myself. (PHA, Quebec).*

> *I too would like to get very involved. Right now I'm beginning to get involved with [the newsletter] by writing a few articles. At least that way I have some control. It gives me something to do. At least it's work. (PHA, Quebec).*

Some PHAs see this work as an empowering process whereby they can gain more knowledge and promote better physical, mental, and spiritual health for themselves.

Retirement is often a very difficult time, especially for men, who are culturally conditioned to derive much of their self-esteem from their occupation. Similarly, when PHAs need to leave their paid work, this is often a tough adjustment.

> *It felt good to be doing something after I went on disability. It gave me a place to be creative, to be recognized, to contribute. It helped re-establish my self-esteem. (PHA, Quebec).*

> *The reason I stay busy is – I was thinking about that the other day, "What would I do if I stopped?" That's frightening. That's why I've been doing this for eight years now. (PHA, Ontario).*

While HIV can be isolating for anyone, PHAs from previously disenfranchised groups have additional reasons for seeking out a supportive environment.

> *Isolation. A sense of not feeling being alone and isolated. Feeling supported. Feeling like you understand my issues, being HIV and being a person of colour, not just HIV. (PHA, Ontario).*

> *Feeling understood. Where I was coming from people could understand. I could just go off into my patois and people could still understand me which – if I need to blow off some steam I tend to revert to patois. That was good. (PHA, Ontario).*

> *I got involved because I was looking for – that was shortly after I was first diagnosed – and I was looking for a connection with other positive women. That was sort of my quest in life. The goal in my life. I had already made connections with a couple of other women including one person who is here. But I felt so isolated. It was so sporadic. There was no means for us to be together regularly. (PHA, Pacific).*

Some PHAs have indicated that being involved in the delivery of AIDS services gives them a more privileged position – the organization will be around for them if they need it.

> *My natural support system is dead. I need them to care for me. I'm the last survivor of my contemporaries. I was very gay. Very active in the '70s. All my friends got sick and died. (PHA, Quebec).*

> *I had sort of a very closeted HIV existence up until I became a volunteer. That was good to become a volunteer to be a member of the community and become aware of a lot of things that were available as a service user as well as being aware of other programs or volunteer work that you could get involved in. (PHA, Ontario).*

> *One of the motivating factors for being involved is so that when you need a service you know how to get it. (PHA, Pacific).*

One of the themes that emerges in this section is that involvement helps to break down the isolation that PHAs experience. Surprisingly, perhaps, this isolation is identified primarily by PHAs in large cities – Toronto, Montreal and Vancouver – throughout the country, and is combatted through involvement in all types of AIDS organizations.

CONCLUSION

It was the overwhelming experience of the organizations surveyed (Phase 1), as well as the PHAs consulted through focus groups (Phase 2), that the active participation of PHAs greatly enriches the work done by community-based AIDS organizations. PHAs bring a diversity of skills as well as advanced knowledge in many key areas, including treatment information, health-promotion strategies, and a variety of complementary therapies. In addition to the contribution

PHAs make related to their own health status, prevention education was cited as an important area of work for PHAs.

In addition to the knowledge and skills that PHAs bring, they serve as valuable role models, particularly for the newly diagnosed. Peer support is believed by many to be the most important form of participation PHAs can make to the AIDS movement and is what sets the contribution of PHAs apart from that of others affected by the illness.

Because of the direct and severe impact AIDS has on the lives of PHAs, personal resources such as motivation, compassion, insight, and commitment were sighted as important considerations in praising the contributions of PHAs.

PHAs have contributed greatly to AIDS organizations. They have expanded services, as well as identified gaps in services, and provided leadership in program direction. The involvement of PHAs has been critical to assuring that agencies provide relevant and timely services.

Agencies have found that PHAs' involvement has become an essential part of their organization's acceptance and success in meeting the needs of the community. PHAs' involvement legitimizes AIDS organizations, ensuring that their activities are both timely and relevant. With the increased politicization of PHAs, and the demands of being a consumer-driven movement, community groups are recognizing the political liability of being in conflict with groups of potential service users.

Finally, PHAs bring a real humanity that can sometimes be missing in a workplace. PHAs make everyone remember why they are here. People are moved by the experience of being in a close working relationship with PHAs. They are able to see, first hand, the struggles, successes, sorrows, and joys that are essential parts of the lives of people living with HIV. They all recognize that people with or without AIDS are whole and are more than a collection of medical or psycho-social conditions. They also are in touch with the grief of losing friends and family members to AIDS – not just someone they saw for a few weeks of counselling or a familiar face in the waiting room or library.

By employing PHAs as staff and volunteers, you see us at our best and our worst. You see passion in our work, struggle for control over the lives that AIDS will eventually take from us. You enjoy and suffer the consequences of not only witnessing a life with AIDS, but being part of it. If the Canadian AIDS movement is truly going to be a self-help movement and embrace the concept of client-centered care, there will be no room for those who want to experience the reality of AIDS from a distance.

This chapter provided a rich overview of the benefits of PHA involvement in the community-based AIDS movement. Chapter 7 provides a similar overview of the barriers that prevent PHAs from greater or more meaningful involvement throughout the movement.

CHAPTER 7

Barriers to PHA Participation

This chapter, which is informed by both Phase 1 and Phase 2 of the research, outlines some of the perceived barriers that prevent greater or more meaningful involvement of PHAs in community-based AIDS organizations.

In Phase 1, those in leadership positions completed comprehensive written surveys. Many of the questions were open-ended, so that the authors could describe the experience of their organization. Although information has been extracted from various parts of the survey, questions 18 and 19 (see Appendix 1), which focused on problems or obstacles the organization encountered in involving PHAs, were of primary interest.

In Phase 2, the PHAs' focus-group discussions (audio-recorded) tended to be freewheeling. Five questions, which had been given to participants in advance, guided much of the discussion. Questions were designed to explore the barriers PHAs encounter in AIDS organizations. Information and citations for this chapter have been extracted from both Phase 1 and 2 of the research project.

For the same reasons outlined in Chapter 6, names of organizations as well as individuals are withheld. Each quotation is only identified either by organizational type and region (from Phase 1) or by the term PHA (from the fifteen focus groups who met for Phase 2) and region.

To help facilitate the discussion, barriers have been organized under five broad categories: Perception, Organizational Politics and Development, Health, Remuneration, and Practical Considerations.

Perception

Almost all the organizations and most PHAs listed disclosure as the primary barrier to PHAs becoming involved in community-based AIDS agencies. Organizations believe that PHAs fear disclosure of their HIV status, and avoid involvements that would jeopardize their anonymity or confidentiality. Individual PHAs articulated the same concern: fear of disclosure. Organizations and PHAs both referred to the stigma and discrimination that confront PHAs in our society. This is especially true in smaller communities.

> *Moncton est un petite communauté, les PAS/VIH sont tres hesitantes a s'identifier a notre organisme craite de perdue leur annonymat. Dans un cas en particulier, par exemple, des membre de sa famille ont fait pression afin qu'il cesse de sieger sur notre bureau de direction. Il a choisis de se retire du bureau de direction de peur de perdre le support de sa famille. [Moncton is a small community. PLWHIV/AIDS are very reluctant to associate themselves with our organization for fear of losing their anonymity. In one case, for example, family members pressured a certain person into withdrawing from our Board of Directors. The person complied to avoid losing his family's support.] (GSO-S, Atlantic).*

> *Similar to the lesbian and gay groups, some Windsor PLWHIV/AIDS are comfortable being 'out' and active in Detroit but not in Windsor. (GSO-S, Ontario).*

Not only is fear of disclosure exacerbated in smaller towns and cities, but within culturally specific communities that exist in larger, metropolitan areas.

> *I have had clients who are people of colour who chose to come here. So I told them about Black-CAP and they say, "I don't want people who I know knowing." (PHA, Ontario).*

> *For the longest time I was the only Native person involved in PWA. I remember walking up those stairs and just how horrible it was for me. Just the fact that I felt that I was up for a real good fight. Not only am I Indian, an aboriginal person, and being two-spirited I am up against a whole other system that is just inappropriate for one of the members of the First Nation to come in here. I have been talked down to . . . . (PHA, Pacific).*

> *I have brothers and sisters who use to come to the old office. It is intimidating for native people to have to walk through a lot of other organizations. So that is sort of the reason why people aren't getting involved. (PHA, Prairies).*

Women also find it very difficult to disclose their HIV status. Sometimes they need to respond to not only their own needs but to those of their husbands or boyfriends, or fear of the child welfare system.

> *This is a small area and when you do something everybody knows. They talk. If she [boyfriend's grandmother] knew about me, she would probably fall sick – put her in the grave really quickly. (PHA, Atlantic).*

> *I have a family. I've got a husband and a child. I was very quiet. My husband has started telling people at his work which is a big step. But that has only happened this year and I have been diagnosed for four years. You go through a long period of time when you need to protect yourself. (PHA, Pacific).*

Disclosure that you are HIV positive brings with it other forms of disclosure. This is what sets AIDS apart from other illnesses, which don't bring with them the same level of fear and hostility. For many, being gay is something they have not yet disclosed publicly, and it is this fear, as much as AIDS, that prevents them from becoming associated with an AIDS organization. For others, it is being associated with a 'gay' disease, or other assumptions such as being a drug user or a slut.

> *I think much of it comes from dysfunctional people get AIDS. Sluts get AIDS. IV drug users get AIDS. And faggots, yes. (PHA, Pacific).*

> *White males saying, I'm HIV positive, it is an immediate assumption that he is gay. Black male, HIV positive, oh, he must be a drug user. (PHA, Ontario).*

> *I invited [my boyfriend] to come here but he couldn't. He's scared that people will think that he's gay because he has HIV or that he was sleeping with men. That he was bisexual. (PHA, Prairies).*

Because HIV transmission is usually associated with gay sex or drugs, many PHAs, as well as organizations, focused on the shame that PHAs experience – and the judgment that they fear or receive from others.

> *They will not think, well, I got it accidentally or something like that. It's the stigma, the blame and the shame that comes with it. What people want to think of you. (PHA, Ontario).*

> *When the first meeting started, I did not want to come because I didn't want to come in and see someone that I know. (PHA, Ontario).*

> *Maybe part of it is a fear of being judged around that. So he might go and get a couple of bags of groceries and then someone will see him going into Woody's [local gay bar] and having a couple of beer and say, "How dare you do that." How dare you be good to yourself and provide some entertainment for yourself. And then come and get groceries. There is a real fear of being judged out there. (PHA, Ontario).*

HIV is a fairly invisible disease until symptoms begin to occur. Sometimes it is the symptoms and not free choice that force some PHAs 'out of the closet' and into more active roles within the AIDS movement.

> *il est important de noter que les personnes atteintes du sida sont généralement plus inclines que les PAVIH a adhérer aux travaux des comités (CA inclus); elles n'ont généralement pas (ou moins) de réserves a déclarer leur état sérologique. [we should mention that persons living with AIDS are usually more inclined than PLWHIV to participate in committee work (Boards included); they generally have no (or few) reservations about disclosing their seropositivity]. (GSO-L, Quebec).*

As mentioned earlier, community can be defined by more than geography. Culture, as well as occupation, can create barriers to disclosure.

> *Prostitutes won't disclose because of the attitudes they would get in the community, and legal persecution and the general attitude of the population. Prostitutes with HIV are very, very vulnerable and usually very isolated. (SC, Ontario).*

HIV is an isolating experience. If you are already isolated because of your sexual orientation, or race, you may not want your social circle further limited through disclosure of your HIV status.

> *He is afraid. He is single. He is courting people and he is really afraid that people are going to find out about his status or whatever. (PHA, Ontario).*

Other reasons for being fearful of disclosure include the fear of violence and discrimination in the work place.

> *I did Midday [national television news show] last week. I've had death threats. I had to call the police. So your anonymity is a wonderful, wonderful thing to keep. (PHA, Pacific).*

> *If I speak out, you guys can rest assured that next week I will not have a job. We're not talking so much about just being afraid to come out, were talking about sustaining your very life. (PHA, Pacific).*

Ironically, many organizations have difficulty involving PHAs because of their narrow and invidious perception of PHAs – lack of talent, skills, education, experience – and they think that many of them are illiterate.

> *finding PLWHIV/AIDS who have skills you believe are important and that you want is difficult. (GSO-L, Pacific).*

> *obstacles qui ne sont pas encore surmontér: anaephabétisme; problémes reliés a l'anonymot. (obstacles which have not yet been overcome: illiteracy, problems related to anonymity). (SC, Quebec).*

Some people believe that PHAs are only capable of low-level, task-oriented activities, such as stuffing envelopes. Other concerns go beyond skill and knowledge and are more personal in nature. One agency stated that they also feared that PHAs would breach confidentiality.

> *fear of confidentiality breach, lack of calibre of PLWHIV/AIDS, staff and volunteer abuse (i.e. verbal abuse, monopoly of time, etc.). (GSO-S, Atlantic).*

Others fear that PHAs are too "self-oriented" and, therefore, because they are "too needy" could not be helpful to others.

> *Many are self oriented (what can I get for nothing). Most are street oriented. 'Well' PHAs tend to decide on things without our organization's involvement. (PWA Organization, Prairies).*

Dysfunctional behavior, lack of interest, being "street-oriented" as well as stretching the limited resources of the agency were listed among the barriers that prevent PHAs from becoming involved in the AIDS movement.

> *Dysfunctional behavior or dementia has made it difficult at times. These people can be very needy and will lean on our organization for everything. (SS, Prairies).*

Some PHAs are very specific as to how they wish to become involved.

> *Various PLWHIV/AIDS members only want to work on issues related to health status. (GSO-L, Prairies).*

When an agency is unable to provide this opportunity, the PHA will move on and not be interested in performing other tasks.

Another common belief is that only very ill PHAs are involved in AIDS organizations, and to become involved will cause more psychological harm than good. PHAs will sometimes stay away because they are afraid of the emotional consequences of seeing PHAs who are more advanced in their illness.

> *I expected the worse when I walked up the stairs for the first time. I just thought I would see a bunch of sick people who were physically sick. It was my attitude that kept me from coming down here or my ignorance I guess. (GSO-L, Pacific).*

Some PHAs are concerned that even in the organizations where they are involved, they do not rise through the ranks or are not hired for more senior positions.

> *HIV positive people would like to be more involved in the decision-making. I have been battling for three years on this but we now have an HIV positive person on the management team. (GSO-L, Ontario).*

> *It is their interpretation of what the voice of HIV infected people are saying. This is why I think it is a huge step and finally happening so that we can have an HIV infected person on the management team that can hear and also take issues. (GSO-L, Ontario).*

Certain positions within the movement obviously require certain skill-sets. Some PHAs are not suited for certain tasks. While sometimes this is an accurate assessment of the situation, at other times it is due to the person's low self-esteem – or a manager's misperception.

> *Some PHAs feel that they will never be able to contribute at the same level as others. The work requires a certain degree of intelligence, ability to reason. (SS, Ontario).*

These barriers are undoubtedly true reflections of some experiences within the AIDS movement: some PHAs do have limited skills and behave inappropriately. The greater concern, however, is the narrow experience or perception that some leaders in the community-based AIDS movement have of PHAs. If the only PHAs that they are in contact with are illiterate or behave in an inappropriate manner, then two observations need to be made: first, the educated, skilled, and appropriately behaved PHAs are not coming into contact with some AIDS organizations. (One explanation could be that services are designed exclusively for a highly dysfunctional, poorly educated client group.) The second observation is that although skills and knowledge will influence the nature of participation with PHAs, as with the community in general, they do not necessarily prevent meaningful involvement that is compatible with their abilities and interests.

Virtually every organization and focus group raised the issue of stigma as a barrier to PHAs becoming involved in the AIDS movement. Clearly, this obstacle is one we are most familiar with. Of the five organizational types, those who provide services to a specific community (SC) have a higher degree of concern for this issue than others. Of the twenty-three references to stigma, from the fifteen focus groups, more than 60 percent were from the three organizations serving specific communities. Fear of disclosure was the central issue in the focus groups of the organizations serving women, people of color, and aboriginals.

Although stigma and discrimination is a reality for all PHAs, groups wanting to involve previously marginalized communities will have to pay special attention to the issue of anonymity.

Organizational Politics and Development

As Chapter 2 outlines, the AIDS movement grew out of a highly political and mobilized gay and lesbian community. As PHAs gain more influence in decision-making, tensions between competing political agendas have emerged.

> *I think it goes back to the document that states we are a gay and lesbian organization. . . . we turned away from HIV and became more political than disease oriented. I think we are getting broader and broader and broader. Not broad in the HIV sense, but broad in making the world a better place for gay men and lesbians. (PHA, Ontario).*

> *. . . gay and lesbian issues or racism issues came in through the door. All kinds of things came in through at the expense of HIV issues. (PHA, Ontario).*

Not surprisingly, PHAs see immediate and practical needs as priorities for service agencies. Others want to pay more attention to issues of infrastructure such as mission, vision, and value statements. Ongoing debate exists in almost every agency as to the distribution of resources. It is the tension that comes with the debate, as much as the issues, that drives those who most need the services away from AIDS organizations. The disease itself has brought more than enough turmoil into our lives, without the organizations that are here to support us adding more.

> *I just find the political upheaval all the time in here – men against women, lesbians against gay, positive and negative – as a client, I feel it puts us second. (PHA, Ontario).*

Perhaps it is not surprising, but the issue of politicization getting in the way of PHA involvement was a key issue for PHAs in the larger metropolitan communities.

> *When it was much smaller, the client was the focus. I just find the larger it has gotten, the more political it has gotten and the client is secondary. (PHA, Ontario).*

It would be far too simple to reduce the debate to PHAs wanting more resources devoted to support services, while the gay community in general wants prevention education and political advocacy better resourced. Balance in resource distribution is always a delicate subject -- especially when the needs far outweigh the means.

PHAs are involved in AIDS organizations for a variety of reasons. While some PHAs are interested in the internal politics of an organization, other see their involvement as a means of socializing, a comfortable place to gain support.

> *I have never been involved as a volunteer until this time, mostly because of political stuff. I didn't want to join an organization where there was battle upon battle ... Everybody just seemed to be in turmoil, conflict and I never wanted to get involved in that. (PHA, Atlantic).*

In some communities this debate has contributed to large groups of PHAs not being supportive of their local AIDS organization.

> *PLWHIV/AIDS believing we cannot meet their needs. PLWA wanting a separate organization. (GSO-L, Ontario).*

> *I have been invited sometime to participate in such and such a committee and do this or do that but because I know that [very few PHAs are involved throughout this AIDS organization] I don't want to participate in that. I would rather spend my time and my energy in the Foundation or Voices of Positive Women because I know it is predominantly for and involved with HIV positive people. (PHA, Ontario).*

Splinter groups have formed in many communities, making it difficult for PHAs to participate in the life of competing organizations.

> *Local PWA group tends to recruit many skilled PLWHIV/AIDS to their board and to volunteer in program areas [leaving few for our agency]. (GSO-L, Pacific).*

> *We [PHAs] just ignore them [general services AIDS organization]. We are going about our business. We are doing what we need to be doing. They are useless. It is a terrible and a sad situation because there are so many in the community involved there. A huge budget, ten employees. What could be done with that? Yet, look what's being done. Nothing. I can't tell you how sad and frustrating it is. (PHA, Pacific).*

> *There is also bitter feelings to me that the [local PWA organization] is a bunch of idiots from people on this side and there is the feeling on the [local PWA organization] side that the [local AIDS service organization] was a big AIDS corporation that they had forgotten about the people that have AIDS. So there is always that battle going on too. (PHA, Prairies).*

Some organizations have complained that other institutions and individuals, such as hospitals, clinics and primary care physicians, do not cooperate and do not make their services known to PHAs.

> *Limited cooperation with local hospital in accessing PLWHIV/AIDS. (GSO-L, Ontario).*

The emerging politics within AIDS organizations has influenced hiring practices. Some have expressed discontent when an HIV-negative applicant is hired over a HIV-positive applicant.

One organization noted that without a clear hiring policy that designates positions for PHAs, an employer could face legal suits. In Canada, employers can seek human rights exemptions that will allow them to discriminate in favour of hiring people with disabilities, such as HIV.

> *At the moment there is no opportunity. I don't know what the policy is with hiring people with HIV. (PHA, Prairies).*

Managers who are not HIV positive have found it difficult giving HIV-positive employees a negative performance appraisal.

> *A problem is being able to address performance issues of HIV positive employees. Unclear about*

> *how much intervention you can do when they are behaving inappropriately. (GSO-L, Ontario).*

Some organizations have argued that the purpose of involving PHAs is to give clients a voice in the decision-making of the agency.

> *If we are going to maintain ourselves as a community-based organization, then we need to be reflected in the primary concern that we are an organization involved with people with HIV. Therefore people living with HIV need to be involved in the decision-making process. (PHA, Ontario).*

They go on to argue that PHAs who are interested in participating don't reflect the socio-economic realities of the clients.

> *It has been our experience that PLWHIV who are interested in or empowered through Board participation do not reflect our client base. We have found it difficult to recruit PLWHIV directly, but have had considerable success recruiting those significantly affected (partners, family members, etc.). We feel that this is primarily the result that our clientele is largely socially and economically disenfranchised. (SS, Ontario).*

> *Yes it is good that they are HIV positive but if they are not using the services, a lot of time it means that their circumstances are different; so they are not representing the overall use of the organization. (PHA, Ontario).*

Because AIDS organizations have assumed a high-profile education and advocacy role in the community, some PHAs find them intimidating.

> *We are seen by some as intimidating – a perception that you have to be a seasoned activist to participate. (SS, Ontario).*

Other PHAs find it difficult to be both a client and staff person. Some community leaders have complained that by encouraging PHAs to get more involved, it looks like the agency is harassing clients. This type of behavior could lead to compromising the access clients have to the agency.

> *Support groups are not a recruiting ground for volunteers. Some [clients] will choose to volunteer, but we should not expect it. (PHA, Quebec).*

> *Les personnes choisissent de demeurer "occultes". Elles viennent nous voir comme "clients". Nous devons éviter que le recrutement devienne du harelement. La relation est déja délicate. Nous ne voulons pas compromettre leur acces au Mouvement comme clients en faisant une démarche de recrutement. [People chose to remain obscure. They come to see us as clients. We cannot allow recruitment to turn into harassment. The relationship is already delicate. We don't want to compromise their access to the movement as clients by trying to recruit them.]. (GSO-S, Quebec).*

> *Accessing services because I am now staff also presents a problem. The fact is as a client and then as a volunteer, I perceived clients and volunteers different from staff. In that way that I should get the services and the staff shouldn't because we got paid. Now that I am in the other position of the staff, now I can see their point of views, "Well, we're HIV as well and we should access some of these services as well." And I thought that if I had thought about that as a client I would be angry at the staff for taking my time away from me as a client. (PHA, Ontario).*

PHAs sometimes feel that serving the needs of people living with HIV and AIDS are secondary considerations for AIDS organizations. Political, or macro, issues have eclipsed the provision of services that help PHAs meet their basic needs. As a result, many PHAs believe that AIDS organizations are not relevant to their lives. Although broader political issues such as racism, sexism, and homophobia are undeniably linked to the fight against AIDS, PHAs tend to focus more of their concerns on micro issues as the illness progresses.

Although the issue of organizational politics was raised by a number of different types of organizations, through Phase 1, over 85 percent of all the quotes from focus groups (Phase 2) came from PHAs in Toronto, Montreal, or Vancouver.

Despite the tremendous contribution the gay and lesbian community has made to the AIDS movement, this community's agenda is sometimes in conflict with the much more practical, service-oriented agenda of PHAs.

> *On another front, organizational development can present, perhaps, the most common, yet under-reported, barrier to PHA involvement.*

> *Most community-based agencies, even if they have a positive philosophy and good will, still do not possess the skills necessary to make their workplace attractive to PHAs. Lack of response to initiatives inviting their [PHA] participation in decision-making. (GSO-S, Ontario).*

Often, when agencies identify a PHA with a needed skill-set, they immediately try to recruit that person to a volunteer activity. PHAs need to be given time, first, to get the help they are asking for. Unless the first experience of the agency is a helpful and welcoming one, it is unlikely that a PHA will be interested in prolonging and developing the relationship.

> *That is the whole problem. [PHAs] are coming in and seeing how fucked up things may be or how disorganized things are and saying, "No, I'm not going to touch that." (PHA, Pacific).*

Some agencies indicated that it was difficult getting qualified PHAs to apply for positions. Yet, in cities like Toronto, Montreal, and Vancouver, there is no shortage of highly qualified PHAs. Other agencies confess that they bypass qualified PHAs applicants in favor of others who have more impressive credentials or experience.

> *Overlooking of those who are willing to work. (PHA, Ontario).*

Naturally, the pool of PHA applicants for any position will always be smaller than those not infected. Consideration must be given to how the agency weighs the experience of, and knowledge gained by, those people who are living with HIV or AIDS with other experiences or knowledge.

Newer agencies indicated that they were not yet known in the community.

> *Il a fallu se faire connuitie comme organisme. [We had to make ourselves known as an organization]. (GSO-L, Quebec).*

> *We are very new and not that well known. We have held support groups and no one has shown up. (SC, Pacific).*

Without clear communications, which include job postings and job descriptions for both staff and volunteer positions, and a published list of programs and services, PHAs often find it difficult to know how to get involved.

> *Myself, I just don't know what I can do for this organization. I don't know what they require. I hear they have people that go and talk to students and other different groups. I don't know if I'm that great of a speaker to be able to do that. I don't think I know enough about HIV or AIDS to be able to do that. I don't know if doing that those people can relate to me or if I can relate to them. (PHA, Prairies).*

> *You have [PHAs] walking into a PWA group who are quite capable of doing stuff – working on computers. I know people who came in 9 or 10 months ago, filled out an application. They know computers inside out. They never even bothered calling these people. They walk in. They can't find anything to do. They walk out. (PHA, Pacific).*

> *It's just that I would like to see management open the doors more and more. Maybe have more meetings. Give a seminar. Like I did last year, I went to a seminar orientation for volunteers, which I felt very helpful. (PHA, Ontario).*

Sometimes PHAs shy away from involvement because they are not able, or willing, to contribute in the same way, or same degree, as others.

> *We didn't want to take ownership because that kind of alienates other people. So we kind of pulled back, other people have kind of gotten better involved. (PHA, Pacific).*

Other times, the agency is simply not providing opportunities appropriate for the skills PHAs bring.

> *I don't want to work in reception. I want to do something that will challenge me. So you want to talk about empowering. Don't give me this bull shit of empowering by sitting at a desk and stuffing envelopes. That's not empowering anybody. (PHA, Pacific).*

> *The structure of the Board dictates that you need to be on the Board for a long period of time before you can become chair. The structure therefore discriminates against those of us who don't have the luxury of time. (PHA, Ontario).*

Many agencies, as well as participants in focus groups, commented that a limited number of

PHAs were interested in active participation, beyond that of a client. This places too many demands on a few PHAs, which causes burn-out.

> *You volunteer to do one thing, and then the organization expects you to do more. There is a lack of clear boundaries. A job description for volunteers would be useful. Especially those PHAs who have poor interpersonal skills and can't say no. (PHA, Quebec).*

> *One of the things that I find very difficult in being involved is the fact that there is too much to do. From the moment that I started getting involved, and I didn't know anything about the foundation when I first became involved with the foundation. Being a woman there was all of a sudden this demand for HIV positive women to be involved in everything. I just happened to be around at that time. It just seems that there is so many things to do now that I hardly have time to have any time for myself. (PHA, Ontario).*

> *I am constantly facing decisions of "Can I commit to another six hours a week for another six weeks so that I can get this done?" or am I then sacrificing some 'me' time that is necessary. So there is a constant evaluation and then guilt plays a role and fatigue. (PHA, Pacific).*

The active participation of PHAs needs to be cultivated within AIDS organizations. There is a balance between support that clients are seeking and opportunity to contribute meaningfully and take ownership of an organization. PHAs need an opportunity to grow in their knowledge of themselves as people now living with what might be a fairly new diagnosis, and knowledge of the agency in which they are seeking involvement. The role a PHA will want to play will change over time and will be different for each person.

The initial experience of an organization is important. If a PHA walks into an environment where PHAs are unhappy, complaining, frantically overworked, and generally feeling disempowered, this atmosphere is not likely to entice a newcomer. If, on the other hand, a newcomer is greeted warmly, and is efficiently served (e.g. provided with the service that they were seeking), the agency will seem more attractive. It is vital, also, that volunteer as well as staff positions are well advertised with clear job descriptions for both. The agency must not only advertise that PHAs are welcome to apply, but must have a clear policy affirming the importance of their role within the agency.

Health

Most agencies cited illness as the main barrier to employing PHAs.

> *Agencies need to hire 'healthy' people, otherwise the demands of the job will further contribute to their illness. Health limitations. [PHAs] choose not to identify HIV status until quite ill. Involvement often tends to be crisis oriented. (GSO-L, Pacific).*

AIDS organizations are often perceived as unusually demanding – and underfunded – workplaces. PHAs whose health and energy might fluctuate could find it difficult to maintain the pace and volume of work necessary. PHAs could find these agencies difficult environments in which to maintain or promote good health.

> *I think it may be, quite frankly, doing more harm than good in my life to be working in an AIDS organization as someone who is HIV positive. (PHA, Prairies).*

> *Does the honour system work both ways? To make sure that you work as much as 40 hours a week. Does the honour system work the other way, that you are not expected to work more than 40 hours? (PHA, Pacific).*

> *Then stop coming to me and asking me to sit on ten committees over here, being 'schlepped' out as an HIV infected person to make your organization look really good and you haven't even asked me what it takes to run my job. I can't even do the support service job I have at 37.5 hours. (PHA, Ontario).*

Other agencies as well as PHAs indicated that they did not have wheelchair-accessible buildings, and were therefore not able to employ PHAs.

> *Illness prevents them from committing their time. Our office location is not accessible. (GSO-L, Ontario).*

> *There is no ramp out front, so if I was in a wheelchair I couldn't get in. That's a problem. (PHA, Ontario).*

This response overlooks the fact that very few PHAs actually use wheelchairs or that it is the building that is inappropriately serviced, not only as a potential employer but as a service provider. Wheelchair accessibility is only one of the environmental limitations PHAs can experience in the workplace.

> *We have to become a little more aware if we are going to involve PWAs in the organization. You cannot have four people working in 40 sq. feet. There has to be a recognition of that and that starts with the Board in my opinion. (PHA, Pacific).*

Several agencies made reference to the emotional and mental health of the PHA as barriers to greater involvement in AIDS organizations.

> *I don't want to go into that building because of all the politics. We are generally talking about anger ... I don't want to go into this building because I will be forced to deal with other people's anger and I'd just as soon stay away because it is unhealthy for me. (PHA, Pacific).*

When you are a PHA on staff, or volunteering at an AIDS organization, there is a lot of pressure to be the perfect role model. PHAs can experience difficulty giving themselves permission to move through various stages of living with AIDS – i.e. anger, denial, passivity, etc.

The pressure to be the 'perfect' PHA comes from all segments of the organization and applies to all aspects of the person's life. In the most extreme examples, PHAs who are peer counsellors can never show signs of depression, and educators can take no degree of risk in their sexual practices.

> *I go through really rough stages and I have a hard time sometimes. But just because you do all these things people automatically assume that you are a person that people can turn to. That you are not a person that needs support as well. That I find very difficult. (PHA, Ontario).*

These expectations are, of course, unrealistic for anyone, PHAs included. Failure to be 'perfect' may bring the judgment of your peers and the entire community. Because few PHAs actually work in AIDS organizations (see Chapter 5), the pressure is particularly intense on a few individuals. When one PHA, who may be well known in the community because of his or her work and health status, fails to meet these high standards, other PHAs are often cast in the same light.

> *Young people are more surprised that I smoke cigarettes now that I am HIV positive. They think, "Oh my God, I don't believe you do that." (PHA, Atlantic).*

Some PHAs might find that working or volunteering in an AIDS organization will mean that AIDS has taken over their lives. For others, the workplace is the only respite they have from AIDS. But working for an AIDS organization can further isolate PHAs from a world without AIDS.

> *The more you are here, the more you do, the more they want from you. At some point you really have to put on the brakes. You have to really say, "No, I'm involved enough and I don't want to do that." At some point you forget yourself and I think too for people with HIV, I really wonder if becoming involved [in an AIDS organization] isn't a health hazard, isn't dangerous for the health of people with HIV, because at some point you start to do one thing and then somebody wants something else, and something else again, and something else again, then all of a sudden you're living here and you have no life of your own. (PHA, Quebec).*

People living with HIV and AIDS have a life-threatening condition that has severe physical as well as emotional consequences. Maintaining one's physical, mental, emotional and spiritual health is a full-time job for most PHAs. One PHA best summed up the dilemma facing PHAs who want to get involved in the movement.

> *If we weren't all dying, we might not need HIV-negative people. We could do it on our own. (PHA, Ontario).*

The AIDS movement must, unlike some other social movements, address the serious nature of the health considerations that face its consumers.

Not only do health considerations affect the PHA, they also affect the organization. Work continuity, high turnover, disruption of projects, and lack of consistent service due to illness were four ways in which this concern was expressed.

> *Probleme de continuite dans les taches. Remplacements au C.A. (3 fois). [Problems related to the continuity of work. Replacement of Board of Directors members (three times)]. (SS, Quebec).*

> *Limited ability to provide consistent service because of unreliable or declining health status. (GSO-L, Prairies).*

> *They may become ill, illness may become frequent; some die – if these members have been very active, there is often some disruption and loss of continuity in projects, etc. (PWA Organization, Pacific).*

Other groups acknowledged the difficulty in organizing work in ways which realistically accommodate sick-time or the loss of key members. When some employees or volunteers are ill, this will, of course, have an impact on others in the organization. Accommodation by others within the organization needs to take place, not only for physical illness, but also for changing mental and emotional states.

> *par rapport aux PAS et aux PAVIH, il faut considérer les états d'ame des participants dans l'evolution des discussions et dans la prisede décision (cela exige plus de finesse pour le président dans la résolution des conflits, par exemple). [In terms of PLWHIV/AIDS, we must consider the emotional state of the participants during the course of discussions and in decision-making. This requires more tact from the President in resolving conflict, for example]. (GSO-L, Quebec).*

> *The cost of insurance premiums was also cited as a barrier by some of the GSOs in large cities who had been successful in employing PHAs.*
> *Expensive benefits. (GSO-L, Ontario).*

Another group raised concerns about the morale of staff when a colleague died of AIDS.

> *The repeated absence due to illness and finally the death of that member was very demoralizing to the group. (SS, Quebec).*

Bereavement, therefore, is an issue that needs to be addressed in AIDS organizations. This is particularly acute when the agency experiences the death of not only clients but volunteers and staff.

> *People in here do not acknowledge death. It is not dealt with. They have their blinders on. We need to acknowledge people who are dying. I have screamed and yelled at education meetings and staff meetings and nothing has happened. We cannot have them facing that every time they walk in the door. What a fucking crock of shit. I am sorry. (PHA, Pacific).*

> *Death within this organization affects people. It affects every person in a different way. First of all, everyone has to go through the cycle that they go through when they've lost somebody who is close and dear to them. However, for some people it enables them to be more powerful and to have more energy to go on. For other people it becomes the straw that breaks the camel's back. They need to stay away for awhile and they need some space because it is just too emotional for them. (PHA, Pacific).*

In some organizations, bereavement services are available for some and not others. Clearly, loss is something that affects everyone involved in an AIDS organization. If an agency is going to successfully involve PHAs, grief will necessarily be part of the experience.

> *I am experiencing just the same amount of multiple loss and yet we are not entitled to the service that staff is entitled to. It's that line that staff are here, volunteers are here, and clients are here. I would like to see it a bit more equal. (PHA, Ontario).*

Two very distinct themes emerge from this section. Organizations are preoccupied with the volume of work that needs to be done and are worried that PHAs who are ill might not be able to contribute to the same level as uninfected employees. On the other hand, PHAs are primarily concerned with stress issues, including grief, and how working in an environment where death is so prevalent will affect them and their colleagues.

Remuneration

Salaries in community-based organizations are not competitive with hospitals, schools, and other larger, more-established institutions. Teachers and social workers can earn in excess of $20,000 a year more than educators and counsellors in AIDS service organizations who often have the same credentials. (The starting salary for a first-year hospital social worker with an MSW, in Toronto, is $52,000. The starting salary for a counsellor at the AIDS Committee of Toronto is $30,500).

This large discrepancy in potential earnings makes it difficult for PHAs to work in the community-based AIDS movement. PHAs already face the loss of future years as an income earner as a result of their illness. Future security, however brief the future, becomes more problematic when you earn far less than your potential.

> *I could never go to work for [an AIDS organization], because I would lose my salary and benefits. [They] can't compete with this. (PHA, Quebec).*

> *We have a lot of volunteers here that have considered coming to work for this organization [becoming employees] because they want to make a difference. I say, "Well dear, you better think about that because you are getting $36,000 a year on long term disability. You ain't going to get that here as a salary, never mind being sick again." Dream on. How about $12,000, without the drug coverage. So how can we entice [PHAs]? (PHA, Ontario).*

> *It's really important for an organization such as ours to try and offer paid opportunities to positive women so they can get involved and get reimbursed for it. It's so frightening to not know where your finances are going to come from. (PHA, Pacific).*

> *Money isn't the issue. I would be doing this even if I wasn't on salary. I think none of us are here for the money. For God's sake, we don't even work minimum wage if you divide it by the number of hours we put in. You have to look beyond that. (PHA, Pacific).*

More problematic than low salaries is the community-based AIDS movement's inability to secure adequate health and disability benefits. CAS has served as an umbrella agency for many of its members who otherwise were unable to secure, or afford, insurance coverage for their employees. Other, larger organizations, have secured their own policies. Recently, CAS and several of its members have lost group coverage for life and disability insurance. The cost of extended health benefits continue to climb at rates that prohibit some groups from offering this coverage to their employees.

The insurance industry makes purchasing life insurance for PHAs, as well as others with pre-existing conditions, virtually impossible. The only opportunity that exists is through group plans offered through the workplace. Most PHAs at some point in their lives require disability insurance. Without this coverage, a PHA who becomes disabled will need to exhaust all savings before becoming eligible for government assistance. Welfare never provides enough for many of the necessities a PHA will need such as drugs, food, warm clothing and shelter.

> *When we had to argue and push to get benefits for our staff, I said, "Don't we have a disability plan?" "Well no we don't." "Don't you think that that would be a priority? If we are going to have people here who are HIV positive or if one of our staff becomes HIV positive, we should be involved. We should be a model in benefits." (PHA, Pacific).*

> *I was sick for two weeks and wanted to know what the sick leave policy was. I had never been told. Do I have to use my holidays? Being positive I do not want to use every sick day I have accrued because who knows what is down the road. There were no answers and I was sick and fed up. (PHA, Pacific).*

Although Canada boasts about having superior universal health benefits, most PHAs must rely on private, extended health benefits to supplement government-sponsored programs. In Canada, health is a provincial responsibility and each province provides its residents with different coverage. Prescription drugs are generally not covered by provincial programs, unless you are on government assistance (welfare) or a senior citizen. In addition to drugs, private plans in Canada usually cover dental costs, as well as the difference in the hospital cost between a ward and semi-private room.

> *The health plan here is good until you become ill and then it is no good at all. When you go on long-term disability you have no drug coverage. It certainly doesn't encourage you to take the time to look after yourself. What it says to me is, when you really become ill and need the support of the organization, it is not there. (PHA, Ontario).*

It is understandable that PHAs who undoubtedly will need to access these benefits are reluctant to forfeit extended drug coverage, disability insurance and life insurance for an inferior plan or no coverage at all.

> *Salaries do not make us competitive with other service agencies. No drug benefit or LTD [long-term disability]. [PHAs] are often on contract and not entitled to benefits. (GSO-L, Ontario).*

The issue of contracts, as opposed to permanent positions, is an important one in the AIDS movement. Often, staff positions at AIDS organizations are posted as temporary or contract positions before they become permanent. Usually, only permanent positions carry insurance benefits or job security. Temporary positions, then, are usually of interest to those who are unemployed or who dislike their current jobs. PHAs who have secure, enjoyable jobs, with good benefit packages, have little incentive to work in a contract position.

> *I am on long-term disability through my past job, which makes it a bit difficult because since I own that benefit package that if I decide to take, say a contract position or anything else, then I would lose that benefit package. Then, when the contract was finished, what would I have? Nothing at all. (PHA, Ontario).*

> *I would love to become permanent but I know that is not the case. And I know that my contract even though it is a one year contract it is up on March 31 because that is when government funding or their year end finishes. It is conceivable that I will not be working past that day. I did apply for a position that became available but they did find somebody else. (PHA, Ontario).*

Some PHAs have complained that the organization was happy with their work as volunteers, but reluctant to hire them into paid positions.

> *If we got paid for the work we were doing it would be much better. We don't need a thousand dollars, just something that would get us along awhile to where we are comfortable enough to say yes, I could get involved and get paid for it. (PHA, Prairies).*

> *Peer counselling. That is how I want to get involved. I am not going to waste my time on people who are not going to listen or to not want to take my experiences and say well, do that on a volunteer basis. (PHA, Prairies).*

Some PHAs don't know what benefits are available, and therefore may never consider leaving their employment for work at an AIDS organization. PHAs often can't figure out what benefits are available once they are employed. Clarity concerning benefits is essential, given the regulations of the insurance industry in regard to those of us with pre-existing conditions.

> *One of the basic things that I would find helpful is that upon employment you be given a copy of a policy manual and a copy of your group benefit package with some type of personnel manager, executive director or general manager. Kind of reviewing for the person with HIV, how to access the benefit package so it is really clear. (PHA, Pacific).*

In order to hire PHAs with the most skills and experience, AIDS organizations need to offer more competitive salary and insurance benefits. PHAs with successful careers are reluctant to compromise their income and benefits. Because many PHAs believe we may only have a few years left to earn a salary, we are hesitant to give up our jobs for ones that pay less. Of even greater concern to the PHA are the employee benefits: sick leave, extended health, short- and long-term disability and group life. Because of the 'pre-existing' conditions, and the lack of portable insurance coverage, PHAs often experience what is known as 'job-lock'.

Failing to articulate the benefits an organization provides, and posting jobs on a temporary basis before they become permanent, only serves to discourage those PHAs who might otherwise be willing to give up much to join a movement about which they feel passionate.

Practical Considerations

In addition to the barriers already outlined, a number of PHAs (Phase 2) identified barriers that no organization (Phase 1) had mentioned. These can best be described as practical considerations that discourage the involvement of PHAs.

Not surprisingly, the involvement of women requires greater accommodation of practical needs. Child care is difficult for families to arrange, even when they have the advantages of two parents, good health, and adequate income. Many women living with HIV do not have these advantages.

> *It's much more difficult for women to get in, particularly with children because husbands do control so much of that. If they are poor or are single moms there is just no way. The increasing need to get out to doctors to clinics, whatever. There are so many other things to do that this is just one more thing. You need child care. (PHA, Pacific).*

> *One obstacle would be people coming to baby-sit. If they know you are HIV positive and have kids,*

> *they are not going to come, they will say, "Your kid probably has it too." (PHA, Pacific).*
>
> *And the transportation involved in getting that kid to the baby-sitter and then getting to a meeting. So that means like four rides. (PHA, Pacific).*

Transportation is a problem for anyone with a disability, including PHAs. Those on a limited income, who do not own a car, or cannot afford a taxi are further restricted.

> *I have a lot of transportation problems. I don't always have the money to get around easily. I live pretty far from here. I get here by subway and bus sometimes. It's very, very exhausting, but I have no alternative. (PHA, Quebec).*
>
> *I have done voluntary talks at schools, but I have had to hitch hike up from Coal Lake to do them. (PHA, Prairies).*
>
> *If I was to move back up north [to the Native Reserve] which I might be doing this summer, again if they want my involvement, if they are going to ask me to be on a committee, they will have to pay for my travel. (PHA, Prairies).*

If an agency limits itself to standard business hours, PHAs with daytime jobs often cannot volunteer, let alone access services. These agencies essentially eliminate any opportunity for the majority of PHAs to become involved.

> *I have tried to get involved but I work full time during the day. Most of the activities take place during the day. They cater to the unemployed. So basically, I have to wait until my health deteriorates before I can get involved. (GSO-S, Prairies).*
>
> *I asked a client, "Could you come in between 10 and 6." He said, "If I take one more day off work, because I've already had so many medicals and stuff like that, the boss is just going to be crazed. (PHA, Ontario).*

In addition to practical considerations such as child care and transportation, women are further disadvantaged through their own enculturation within our society. It was remarkable how the women who attended focus groups continually spoke about the needs of others, and diminished their own needs. This was in striking contrast to the men, none of whom stopped to consider that maybe others were more deserving. The nurturing behavior of women, therefore, became an obstacle to accessing services, thereby limiting their access to an agency. The following three quotes, all from women, best illustrate the point.

> *I've kind of avoided using a lot of the services. Part of that in a sense is maybe I'm not the most needy person but also part of it is – for a long time – it was more awkward to try and reach out and get those services. (PHA, Pacific).*
>
> *I have not taken advantage of a lot of the services just because I'm in a financial situation or I wanted other members that maybe didn't have any financial ability on their own to access them. (PHA, Pacific).*
>
> *I am not on the housing subsidy. I am on the list, though, but there are other people who are living on the streets and things like that. They need them more than I. (PHA, Pacific).*

AIDS organizations, many of which were originally established to serve urban-dwelling gay men who were acutely ill, have not adapted well to the changing demographics of HIV illness. Practical considerations have been significant barriers, particularly for women, to participation in AIDS organizations. Many women have the additional burden of feeling responsible for nurturing others, thereby placing the concerns of other PHAs over their own.

Many AIDS organizations have not adjusted their hours of business to accommodate the growing number of PHAs who experience good health and continue to work. These PHAs need support around health promotion. They represent a growing number of PHAs who could become involved, as staff or as volunteers.

CONCLUSION

Both leaders in community-based AIDS organizations (Phase 1) and PHAs (Phase 2) throughout Canada agree that significant barriers exist which prevent greater and meaningful participation of PHAs in the AIDS movement.

HIV and AIDS, unlike other disease groups, carry an extraordinary stigma. Many PHAs, therefore, find it difficult to acknowledge their HIV status, and are reluctant to identify with any part of the AIDS movement. For those who are able to identify and seek out the services of an AIDS organization, the transition from service user to service provider is often difficult.

Some AIDS organizations have a very limited view of the potential contribution PHAs can make. If agencies only provide services to the poorly educated or very ill, or as one person graphically put it, "the never read, or the almost dead," then this will unfairly influence everyone's perception of PHAs.

Community-based AIDS organizations are known for providing low salaries and poor employee-benefit packages. Because the private insurance industry only provides coverage to those of us with a pre-existing condition through pre-existing group plans, many PHAs experience what is known as 'job-lock'. To leave a job for another will likely mean giving up any opportunity for disability, life insurance, or extended health-insurance coverage. These benefits are vital to PHAs. Many AIDS organizations post temporary or contract positions before making a permanent position available. This further discourages qualified PHAs from leaving a job for one that provides little security.

Health, naturally, influences the participation of PHAs. AIDS organizations can be very demanding workplaces. The physical, emotional, mental, and spiritual health – of PHAs and their colleagues – can be challenged by working in such demanding environments. Illness will sometimes mean that others will need to pick up the slack, and everyone experiences grief when someone in the workplace dies.

The community-based AIDS movement in Canada grew out of a highly political and mobilized lesbian and gay community. As AIDS affects a more heterogeneous community of people, mandates for agencies are becoming increasingly broad. Competing agendas combined with decreasing government support inevitably leads to conflict. Many PHAs choose to remove themselves from high-conflict and stressful situations.

Barriers for PHAs can sometimes be very basic. Child care, transportation, and limited hours of business can especially affect women, rural dwellers, and the employed.

Finally, many organizations simply do not know how to make their environments more welcoming for PHAs. It is my hope that this research paper will serve as a practical tool for individuals and organizations to work together to overcome the many barriers that exist for PHAs.

The final chapter will summarize the findings of this research, as well as provide a list of recommendations that organizations might use to make their agencies more accessible and welcoming to PHAs.

CHAPTER 8

Summary and Recommendations

This chapter will, first, summarize the findings of the study. It will outline the current involvement of PHAs within the community-based AIDS movement in Canada, the advantages of having PHAs participate in the movement, and the barriers PHA experience in the movement that prevent greater or more meaningful involvement.

Second, the chapter will provide a list of recommendations that AIDS organizations, as well as individuals involved in the movement, should find useful in creating a more welcoming environment for PHA participation.

The recommendations in this chapter flow from two sources. Phases 1 and 2 of this research set the stage for many suggestions. Phase 3 of the research was conducted at the Canadian AIDS Society's 1993 annual general meeting. At that time, members of the national coalition were given a brief outline of the findings in Phase 1 of this study, and participants at this plenary session were then asked to self-select into one of thirteen discussion groups. Each group was assigned the task of generating a list of strategies to help overcome the barriers PHAs experience in AIDS organizations. Each group documented its list on a form provided (Appendix 3). Phase 3 focused on strategies that both organizations and individuals could employ within these organizations. A compilation of the ideas generated in Phase 3 helped form the foundation for the recommendations section of this chapter.

Finally, this research not only generates some answers to important questions, but raises more questions. Implications for further research will be examined in the hope that, after studying this work, others will want to continue the exploration of these questions.

SUMMARY

The AIDS movement is a relatively young social movement that grew out of a medical crisis and an existing political ideology. Borrowing from the feminist movement, the lesbian and gay community introduced "health from below" as a guiding principle for the community-based AIDS movement. This principle promotes the participation in decision-making by those most affected by a disease or disability. In the early years of the pandemic, this meant that the gay and lesbian community wanted to play a greater role in the politics surrounding AIDS. These politics have long threatened the authority of the state and medical establishments.

Similarly, PHAs today want to play a greater role in the organizations that are designed to serve us. The empowerment of PHAs within the AIDS movement is a logical and inevitable extension of the ideology introduced to the AIDS movement over a decade ago. As AIDS continues to affect a wider community, PHAs identify increasingly with HIV as a primary identity and less with other identities such as gender, race and sexual orientation. The will of PHAs to become more involved in AIDS organizations has, at times, caused tension between those infected and others who are 'affected' – those who are very committed to the fight against AIDS, but not infected themselves. Consequently, barriers that prevent the full participation of PHAs in this movement have often been ignored.

This research, therefore, had the following four goals: first, to measure the current level of PHA participation within the Canadian AIDS movement. The second goal was to determine whether greater, or a different type of, PHA participation would enhance the community-based AIDS movement. The third aim of the research was to determine the barriers that PHAs experience that prevent greater or more meaningful involvement. Finally, the research hoped to generate a list of recommendations that could, practically, serve those AIDS organizations that wanted their agencies to be more welcoming and accessible to PHA participation.

Current participation of PHAs

Both local and national AIDS organizations have had more success involving PHAs in voluntary board positions than in paid staff positions. In terms of total participants, just over one-fifth of board members in community-based AIDS organizations are PHAs. But fewer than one in ten people employed by an AIDS organization in Canada is infected with HIV.

Even less impressive are the facts that only one in ten of CAS member groups is governed by a PHA majority, and that, of the CAS members who employed staff, over 60% had no PHA employees. Only five organizations had a majority of PHAs on staff.

Advantages of PHA participation

Although the level of participation by PHAs is relatively low on boards and in staff positions, AIDS organizations recognize the positive impact PHAs have on their success. In all phases of the research, those in leadership positions recognize that PHAs bring skill and knowledge as well as passion and commitment to their work in the field of AIDS.

The presence of PHAs in the workplace ensures that colleagues, in fact the entire agency, stay focused on the goal of providing quality education and support services. The presence of PHAs in the workplace ensures that AIDS does not become a forum for 'professional' caregivers to become experts, and for those receiving the care to be passive 'recipients' of this wisdom. PHAs guarantee that the principles of health from below, self-help, client-centered care, empowerment, and community-based are practiced, not just preached.

PHAs can best identify gaps in programs and services as well as changing needs, therefore making organizations more timely and responsive to client needs. Organizations, as well as PHAs themselves, emphasized the importance of positive role models through peer-support opportunities. Organizations also realize that, with the politicization of PHAs, it is politically wise to involve PHAs. Energy and resources can otherwise be foolishly spent on fighting the people the organization is funded to serve. This type of adversarial relationship serves nobody.

Barriers that PHAs experience

PHAs experience many barriers that either prevent them from being involved at all in the community-based AIDS movement or discourage greater or more meaningful involvement. These barriers are as diverse as the PHAs themselves and the organizations who serve them.

Many PHAs indicated that the need to disclose their health status was an immediate barrier. Other PHAs were victims of narrow-mindedness within some organizations that saw PHAs as people who were unable to help themselves or others. For other PHAs, it was more practical considerations, such as low wages and poor benefits.

Health was naturally a major barrier for PHAs. AIDS agencies, like most community-based organizations, have a lot of work to do with few resources. Like most of society, AIDS organizations are reluctant to hire someone with an illness when a perfectly healthy person is available.

Although the demands are great, most organizations are still in an infantile stage of development. The stress and the politics of AIDS keeps many PHAs away.

The twelve recommendations listed below, if followed, will guide organizations in providing a more supportive environment for PHAs.

RECOMMENDATIONS FOR CHANGE

Recommendation #1:
Respect a PHA's right to privacy and confidentiality.

Confidentiality was a barrier acknowledged in all three phases of the research. Although PHAs should be given the same right to privacy as others, this is sometimes difficult for AIDS organizations to execute practically.

Clients

Respecting a person's right to privacy should be entrenched into every relationship a PHA has with an AIDS organization. Clients are usually afforded this right. In most organizations, both PHAs and others can access services. When offering services, organizations can limit the flow of confidential information to only those in the organization who need to know. For instance, only the person doing the counselling needs to know a client's status. Others do not need this information. Statistics on clients can easily be reported through the use of codes or other name-free methods.

Sometimes, merely participating in certain types of activity (i.e. a support group for PHAs) or having membership in a particular type of organization (PWA organization) requires disclosure of HIV status. Again, access to membership lists, whether they be for an entire agency or for a particular agency activity such as a support group, should be limited to those who need to know. Clients joining organizations or accessing services should be informed of the degree and nature of the confidentiality afforded them in the agency.

Volunteers

Obtaining accurate Phase 1 statistics for PHA participation as volunteers proved to be difficult for most agencies. AIDS organizations who are interested in PHA participation in all levels of their agencies need to pay attention to PHA volunteerism. Similar to the policy for clients, everyone in the agency does not need to know which volunteers are negative and which are positive. The volunteer coordinator could make this issue part of the screening interview. At the same time, the prospective volunteer should be told why the information is important and how the information will be coded for statistical purposes. The disclosure of volunteers' HIV status is their business, not that of the agency. Strong interpersonal and assessment skills, as well as a code of conduct that respects the confidentiality of others, is necessary not only for counsellors in AIDS organizations, but for others, including the volunteer coordinator.

Boards of Directors

Some agencies have already established affirmative action policies for PHAs on boards of directors. If an agency has a set number of designated seats, then only the nomination committee and scrutineers need to know who is positive. Generally the membership is satisfied in knowing that the set number or percentage of PHAs has been met, and don't need to know who is and who isn't HIV positive. AIDS ACTION NOW!, for example, has a system in place where the majority of people on their steering committee need to be PHAs, yet the responsibility to ensure this happens is entrusted to one member of the steering committee who assumes the role of nominations coordinator. Only this person knows the HIV status of everyone on the steering committee and reports back to the membership when this requirement is fulfilled. Other organizations, such as the AIDS Committee of Toronto, have more complicated systems, yet provide an opportunity for anonymity.

Staff

If PHAs are given preference in hiring, that fact should be stated publicly so the applicants can decide if they want their status known to the organization. PHAs who apply for jobs at AIDS organizations might want to disclose their HIV status only if they are the successful applicants. If an applicant decides to disclose his or her HIV status during an interview, it should be made clear that only the person(s) doing the hiring needs to know. If the specific position has been publicly posted as being designated for a PHA, then the mere application is a form of disclosure.

Some agencies, however, have established quotas, as opposed to designating specific positions. In these agencies, recruitment should include clearly communicating that preference is given to PHAs, but that public disclosure is not necessary.

Working at an AIDS organization, as a volunteer or on staff, is often the first step PHAs take in disclosing their HIV status. If disclosure is not mandatory, more PHAs will feel safe in associating with AIDS organizations. Once working in this supportive environment, PHAs will often disclose their HIV status, as a way of seeking support from others. This step not only provides PHAs with an opportunity to grow in acceptance of their status, but helps them become more accessible role models for others.

Recommendation #2:
Change the community's perception of PHAs through public education.

AIDS organizations' education programs should include measures to change the public's perception of PHAs. Many individuals in AIDS organizations, as well as the larger community, often have a skewed perception of PHAs. Nowhere is this more visible than on the boards of directors of many AIDS organizations. In community-based organizations, the board members are elected from the wider community. Without the broader education of the community, this influential group will continue inappropriate policies. Boards should recognize the need for and advantage of increased PHA participation.

Public education campaigns not only enhance the knowledge of those who are HIV negative, but also PHAs themselves. Poor self-image is a major reason why PHAs fear disclosure, and therefore involvement with an AIDS organization. Public awareness that AIDS is a disease, and not something to be ashamed of, will help PHAs take steps towards feeling empowered, thereby creating more health-promotion opportunities for themselves.

Recommendation #3:
Create supportive environments for all PHAs.
AIDS organizations can be intimidating, places of doom and gloom, for PHAs. It is important that people coming into an AIDS organization are greeted by someone who is friendly and warm. The reception area, especially, should be a welcoming place.

When decorating a reception area, it is important to remember that every PHA coming into the agency is not gay. Posters depicting explicit gay sex can be unwelcoming signs for straight people. Many PHAs also find these posters offensive. For many of us, images of hot, hunky men having sex, albeit safe sex, are yet another reminder of what AIDS has taken away from us. However, the reception area should be decorated in a way that affirms gay sexuality. Finding the balance is important in creating a warm, welcoming first impression for all PHAs.

In AIDS organizations, expectations set by colleagues can also alienate PHAs. When staff and volunteers work themselves to exhaustion, the implicit message is that health promotion is not a priority in the agency. Managers need to establish reasonable expectations for all employees. Job descriptions need to be clear, with regular supervision and performance evaluations serving as methods of support, not threats. Self-care or health-promotion strategies for staff and volunteers, as well as clients, need to be part of the ongoing work of the agency.

One way in which PHAs have provided support for ourselves is through the development of caucuses. PHA caucuses of staff, volunteers, and board members are important opportunities to share ideas and develop health-promotion strategies. These ideas can then be brought to the appropriate forum by PHAs ourselves, knowing that we have the support of others. All too often one or two PHAs are expected to represent the needs of all PHAs. This, of course, is not only unrealistic, but is unfair and isolating, setting the PHA up for failure.

AIDS organizations have a duty to accommodate anyone with a disability, especially PHAs. Health promotion and self-care are often spoken about, but rarely implemented by AIDS organizations. Accommodation requires less formulae than flexibility. To provide PHAs with a healthy workplace, AIDS organizations must create options in work styles, such as job-sharing and part-time employment. Work schedules could be made flexible for PHAs. When mild symptoms such as diarrhea keep a PHA out of the workplace, provisions can sometimes be made for work to be taken home.

Recommendation #4:
Develop a strategy that makes PHA participation a priority in your agency.
Increasing the participation of PHAs within the community-based AIDS movement is almost like a motherhood statement. It is all too easy to say, "Of course we want this, and we will do it". Agencies should be explicit and should set a deadline for developing an action plan. It does not need to be elaborate or take up a lot of time. Reading through this document, agencies should note the changes they wish to make. They should set deadlines for accomplishing tasks and assign them to the appropriate person, or group of people, to develop. They should ensure that PHAs are involved in the process but that others are not excluded. PHA participation is everyone's responsibility.

AIDS organizations will only be successful in promoting self-help and becoming client-centered if PHAs participate in all facets of the agency. PHAs are the primary users of services in the vast majority of AIDS organizations. These organizations need to find more creative ways of involving PHAs if they intend on being client-centered.

PHAs who are frustrated with an organization often alienate the service providers. Agencies need to become adept at coping with the frustrations of PHAs. They need to find ways to listen to PHAs' concerns and why they feel unwelcomed. Inviting clients to express their thoughts and opinions through suggestion boxes, focus groups, evaluation of services, advisory committees and community consultations are just some ways of involving clients.

If the AIDS movement truly strives to become a self-help movement, then providing PHAs with an opportunity to be vocal clients is insufficient. Agencies should not limit their thinking to any one part of the organization. PHAs should be active as front-line staff, as well as in management. We should be clients, as well as volunteers and board members. Agencies should measure the participation in each of these areas and set a reasonable goal of involvement in each area for the following year. Volunteer, staff member, board member and manager are all important roles for the primary client group of a self-help, client-centered organization.

Boards need to develop comprehensive policy initiatives to ensure that PHA participation becomes a priority for their organizations. In 1991, the Canadian AIDS Society began AIDS in the Workplace projects in Toronto, Montreal, and Vancouver. The primary goal of these initiatives was to assist private and government-sector employers in creating supportive environments in their workplace for PHAs. They recommended workplace policies that would enable PHAs to continue working without facing discrimination. They also recommended how employers might accommodate PHAs to make the arrangement a favorable one for both the employer and employee.

Support service workers in AIDS organizations are often advocates for individual PHAs regarding workplace issues. Education departments will often give workshops for employers that have PHAs on staff. Despite this expertise, most AIDS organizations have not developed policies to protect their own employees who are HIV positive. Despite being leaders in the development of workplace resources , the Canadian AIDS Society member groups do not always practice what they preach.

Areas of policy development should range from general policies addressing the need for inclusion of PHAs in the life of the organization to hiring practices and procedures. Without clear policies from an elected board, community groups do not have a mandate to make the choices and sacrifices necessary to include PHAs in all areas of an organization. Policy development must include a position on affirmative action and accommodation of PHAs.

Good intentions are rarely a substitute for affirmative action. Boards must direct their organizations on what acceptable minimal levels of PHA participation will be in all aspects of the organization. The composition of boards, staff, management, volunteers, and client groups will be influenced by an affirmative action policy. These policies should not be dictated by an outside or umbrella organization, but should be determined within each community group.

It is interesting to note that after hearing of the barriers PHAs experience, almost all of the Phase 3 discussion groups recommended some form of affirmative action program. It is recognized that in order for an affirmative action policy to be successful, many of the other recommendations of this report need to be implemented.

Recommendation #5:
Communicate the agency's position on PHA participation to your community.

Encouraging PHAs to apply for work or volunteer at an AIDS organization can be as simple as asking them. Self-esteem is one of the many victims of AIDS. Personal invitations by staff and board members can be an affirming and effective means of recruiting PHAs to your organization. Agencies should let PHAs know they can make an important contribution to the organization.

All three phases of the research highlighted job postings as an area that needs to be improved in order to reach out to PHAs. AIDS organizations need to search beyond the normal pool of job hunters. Notices can be posted in the AIDS clinics of local hospitals, HIV primary-care physician offices, local PWA organizations, support groups, newsletters and journals. A special effort should be made to reach out to your volunteers in the organization who may be interested in employment opportunities.

Not only is posting job notices important, but the wording of notices can attract or discourage PHAs from applying. Job notices should state clearly if the agency has a policy on affirmative action or employment equity. As mentioned in an earlier recommendation, confidentiality is also important. If applicants believe their chances for success are enhanced by declaring their HIV status, then they should know who is privy to this highly personal information.

Recommendation #6:
Provide positive role models for PHAs.
An HIV diagnosis is usually a devastating experience. Often we think that our lives have come to an end. Having other PHAs to provide formal or informal counselling can be an affirming experience, especially for the newly diagnosed.

One common argument for hiring publicly, self-declared PHAs to designated positions, is that the AIDS community needs to provide accessible role models. Obviously, if the only PHAs involved in an AIDS organization are 'closeted' about their HIV status, then their experience is neither accessible nor affirming. This position, however, needs to be balanced with providing the opportunity for PHAs to get involved and allowing time to receive the support they need to become more comfortable with their status. If an organization has a tradition of making PHAs feel welcomed, then there will be PHAs at a variety of places on the disclosure continuum.

Recommendation #7:
Respond to the cultural diversity of PHAs in your community.
If programs and services are designed only to serve the uneducated, unemployable, and otherwise disenfranchised, then participation of PHAs will reflect this skill-set. Conversely, if programs and services are designed only for the well educated and wealthy, then the organization will likely have a distorted view of the real needs of the community. PHAs' involvement in an organization is often dictated by the services that are available to them. If the service is inaccessible or not of interest, then chances are that PHAs will not be interested in becoming more involved.

An agency that provides a broad range of programming will be more successful in attracting a broad range of PHAs to participate in the life of the organization. With the involvement of a diverse group of PHAs, the organization stands a better chance of remaining relevant to the changing needs of a diverse community.

As has often been stated, AIDS does not discriminate, people do. AIDS affects people from all walks of life: women, men, black, white, old, young, gay, straight, uneducated, educated, poor, wealthy. PHAs, therefore, are a diverse group of people. To engage in self-help and provide accessible role models successfully, AIDS organizations need to represent this diversity in the workplace.

The agency must, therefore, take seriously its responsibility to sensitize its workplace on issues of difference, such as homophobia, sexism and racism. It must also provide adequate training and skills-building opportunities.

Diversity brings with it a need to accommodate different people in different ways. Where a gay, white man might see an agency membership to the YMCA as an important health-promotion tool, a single mother might only be able to work for an AIDS organization if it provided daycare or paid leave when her child is home sick.

Recommendation #8:
Offer skills-development opportunities for PHAs.
If AIDS organizations want to involve the PHAs who accurately reflect the profile of its service users, it must provide training and skills-building opportunities. Many PHAs possess the potential but do not have the same advantages as others to develop skills. Many government job-training programs exist – at the local, provincial and federal levels – to assist organizations in hiring the unemployed, disabled, as well as visible minorities. AIDS organizations must not, however, rely solely on government programs, but should commit existing resources to affirmative action.

AIDS organizations have a limited view of what is an asset or necessary qualification. Traditional educational training found in colleges and universities is often prized over more practical, hands-on methods of learning. PHAs often have valuable knowledge and experience, but need to enhance their skills in order to deliver services better.

Agencies need to invest in training not only volunteers but PHAs on staff.

Recommendation #9:
Learn from other self-help, client-centered organizations in the community.
AIDS, largely because of the stigma that surrounds it, certainly presents many unique challenges. As a result, the community-based AIDS movement in Canada has become somewhat insular. Other health and social movements have

decades of resource development from which the AIDS movement could benefit. Affirmative-action policies and volunteer training programs are only two examples of policies and programs that the AIDS movement could adapt, instead of starting from scratch.

AIDS organizations could also benefit from joining various regional coalitions related to, but outside of, the AIDS movement. Groups dealing with palliative care, bereavement counselling, and self-help all have supportive coalitions where valuable information can be shared with the AIDS community.

Recommendation #10:
Promote and develop volunteerism among PHAs.
Many PHAs prefer volunteerism over paid work. This can be motivated by not wanting to give up current employment or disability benefits. It also can be motivated by the PHA wanting to have more control over his or her time commitment. Whatever the reason, volunteerism is a primary way in which PHAs get involved in the life of an AIDS organization. Comprehensive volunteer training programs, accurate job descriptions, specified time commitment, and access to support and supervision are all important elements to any volunteer experience. All of these elements need to be in place to make the experience a positive one for the PHA.

Volunteers should be valued and respected. PHAs often use volunteerism as a 'back-door' approach to employment opportunities. Volunteer activity is a good way to assess whether work in an AIDS organization is comfortable and affirming. It is also a way of gaining more knowledge, experience and skills. When a job becomes available, volunteers should be informed about it, even if it is not widely advertised.

Recommendation #11:
Provide more competitive salaries in order to attract the most skilled and knowledgeable PHAs.
AIDS organizations can be attractive workplaces for a recent graduate or anyone wanting to gain valuable job experience. After a period of time, employees can use this experience as a springboard to a more lucrative job. PHAs, on the other hand, often feel our current or next job might be our last one. We are already disadvantaged: our potential years of lost income has been increased significantly due to our illness.

Salaries in community-based AIDS organizations do not compete with those in government agencies or the private sector. To attract PHAs who are already employed in professional jobs, and therefore bring skills that might enhance the workplace, AIDS organizations must offer more competitive salaries. Low salaries, combined with the potential lost years of income, have a significant impact on attracting PHAs to any position within an AIDS organization. This is especially true in management positions where organizations are least likely to compromise on traditional skill-sets.

Recommendation #12:
Provide more attractive employee benefit packages to attract PHAs to the workplace.
Because of the vulnerability PHAs experience, employment security is of primary concern. Sick leave, short- and long-term disability, extended health benefits, and drug and dental coverage are all important benefits for the PHA to consider. Psychotherapy, chiropractic care, physiotherapy, massage, Chinese medicine and naturopathic medicine are among other services that many government and private-sector employee benefits plans cover.

PHAs who enjoy the security of these benefits are naturally reluctant to give them up for a sub-par plan or no plan at all. AIDS organizations must make the provision of adequate insurance coverage a priority and commit the necessary funds. AIDS organizations must also invest some resources into lobbying government for changes in the legislation that governs the insurance industry, as well as the preservation and expansion of government health plans.

One example of a recent success is in Ontario, where after years of lobbying by AIDS ACTION NOW!, the provincial government announced the establishment of the Trillium Drug Program. This program is offered to all Ontarians, on a sliding scale, and not just those receiving social assistance.

Organizations need to work more closely with insurance carriers to allow PHAs to work part-time and not lose pre-existing employee benefits. Instead of going on long-term disability, allowing a PHA to work part-time and access part-time benefits could benefit the PHA, insurance carrier and AIDS organization.

IMPLICATIONS FOR FUTURE RESEARCH

This work raises many questions that would be worthy of further investigation. Two broad areas stand out as needing more research.

Diversity

We need to examine whether the participation in the community-based AIDS movement reflects the range of people affected by the epidemic. This research specifically looks at the participation of those infected with the virus. Race, gender, age, education, language and sexual orientation are some other ways in which the community can be further examined.

If we truly want to embrace the concepts of self-help and client-centeredness, then surely there are more ways of viewing communities than just by health status. It would be rewarding to see others who define their primary identity differently than I do investigate some of these questions. As the demographics of the AIDS movement change these other questions will have a significant impact on PHA participation.

Sharing of knowledge

The second area that I believe could benefit from more research is the way in which the AIDS movement has acquired its knowledge. Because of the stigma associated with AIDS, the movement has been very insular. Today, as AIDS begins to affect every segment of Canadian society, the movement has gained wider support.

Valuable resources such as volunteer training programs, as well as obstacles such as insurance industry policies, exist in other communities. The AIDS movement could use research to borrow knowledge from other segments of society to help advance its cause. The AIDS movement does not have to re-invent the wheel each time it faces a new challenge. Other organizations face similar challenges. It is much more resourceful to adapt existing resources and work in partnership with others than to work, unnecessarily, in isolation. As governments cut spending, communities will need to learn to share knowledge more efficiently. Research can play an important role in transferring knowledge from one community to another, thereby maximizing limited resources.

Role of CAS in research

In closing, national coalitions, such as the Canadian AIDS Society, have an important role to play in the advancement of research within the community-based AIDS movement. First, CAS needs to conduct annual surveys to monitor the progress its members are making in the participation of PHAs throughout its agencies. This needs to be expanded beyond staff and board members to include volunteers and clients. Annual surveys should also attempt to document leadership roles PHAs play, such as executive positions on boards and management positions on staff. Such surveys will help ensure that the issue of PHA participation is always seen as an important priority within the community-based AIDS movement.

A second area of CAS research is in the sharing of information within the movement. Important innovations and solutions are occurring every day in the AIDS movement, and CAS needs to research and communicate the activities of its members constantly. A recent example of this is when the AIDS Committee of Toronto created a self-administered pension plan where both employees and employers contribute. This will be used instead of a long-term disability plan through a private insurance carrier. Other organizations have solved the same problem in other ways. Just down the street from ACT, CATIE convinced their government funder to increase their contribution agreement to offset the cost of skyrocketing premiums by private insurance carriers.

A third project for CAS would be to establish a Research and Ethics Review Committee. Such a committee would establish guidelines and ensure that research principles are maintained, regardless of the type of research (e.g. social, treatment, legal) or which disciplines are conducting it (e.g. social work, medicine, law).

This committee could also make PHAs and agencies more accessible to researchers wanting to advance the knowledge base within the community-based AIDS movement. (For example: I am very grateful to CAS for working in partnership with me and making its membership receptive to my research.) A Research and Ethics Review Committee could act as an advisor to the board and membership by not only screening, but encouraging research, and then facilitating national studies.

Appendices

APPENDIX 1

National Survey: Final Version

Canadian AIDS Society
PLWHIV/AIDS Participation Survey

When we ask for # of PLWHIV/AIDS we are not expecting you to disclose confidential information.

BASIC INFORMATION

1. **Name of your organization:** ____________________

2. **Date of your founding meeting:** ___ ___
(M) (Y)

3. **Status within CAS:**
Member ___
Associate ___

4. **Who is completing this questionnaire?**
(check as many as apply)
Board President/Chairperson ___
Executive Director ___
Other ___
If other, please explain ____________________
____

5. **Which of the following best describes your organization:**
AIDS Service Organization ___
PWA Organization ___
AIDS Housing Organization ___
Other ___
If other, please explain ____________________
____

6. **What is your total annual budget for the current fiscal year?**
(to assist us in categorizing organizations by size)

$ __________

STAFF

(PLEASE NOTE: this section refers to full-time, part-time, permanent and temporary salaried staff)

7. **How many people do you currently have on staff?**
total # of people ___
# of PLWHIV/AIDS* ___
(*Self-disclosed PLWHIV/AIDS)

8. Does your organization have any staff positions specifically designed for PLWHIV/AIDS?

yes ___ no ___

If yes, please describe / If no, please explain ______________________

____

____

____

9. Does your organization have any staff positions that would be especially problematic for a PLWHIV/AIDS to fill?

yes ___ no ___

If yes, please describe / If no, please explain ______________________

____

____

____

10. Does your organization have a hiring policy (or equal opportunity statement) that applies to, or make specific reference to, PLWHIV/AIDS?

yes ___ no ___

If yes, please attach a copy to this completed questionnaire / If no, please explain ______________________________________

____

____

____

11. When advertising available staff positions, do you indicate the suitability of PLWHIV/AIDS?

yes ___ no ___

If yes, please attach a sample of advertisements and job postings / If no, please explain ____________________________________

____

____

____

BOARD OF DIRECTORS

12. How many positions does your organization have on its Board of Directors (or equivalent governing body)?

total # of positions ___

# of PLWHIV/AIDS currently on your board* ___

(*Self-disclosed PLWHIV/AIDS)

13. Does your organization have designated board positions for PLWHIV/AIDS?

yes ___ no ___

If yes, please describe / If no, please explain ______________________

____

____

____

14. Does your organization have a board representation policy that applies to, or makes specific reference to, PLWHIV/AIDS?

yes ___ no ___

If yes, please attach a copy to this completed questionnaire / If no, please explain ______________________

____

____

____

PARTICIPATION

15. How many people are currently participating in your organization?

(i) volunteer service providers * ___
*(how many of these are PLWHIV/AIDS ___)
(ii) clients/service users * ___
*(how many of these are PLWHIV/AIDS ___)
(iii) other ___

If other, please explain (PLEASE NOTE: you do not need to account for salaried staff or board members. We will refer to questions 7 & 12 for this information).

____

____

____

16. How are PLWHIV/AIDS organized within your organization?
(check as many as apply)

support group(s) ___
board caucus ___
staff caucus ___
general HIV caucus ___
not organized ___
other ___

If other, please explain ____
____
____
____

17. Describe the various ways by which PLWHIV/AIDS access decision-making within your organization.

____
____
____
____
____
____
____
____

18. Describe any problems/obstacles your organization has encountered in the recruitment of PLWHIV/AIDS.

____
____
____
____
____
____
____
____

19. Describe any problems/obstacles your organization has encountered through involving PLWHIV/AIDS.

____
____
____
____
____
____
____
____

20. Describe any strategies your organization has used in recruiting and involving PLWHIV/AIDS.

21. Describe any advantages your organization has encountered by involving PLWHIV/AIDS.

22. Describe any strategies your organization is considering using in the recruitment and involvement of PLWHIV/AIDS in the future.

23. Describe the likelihood of your organization being able to implement these strategies.

24. Under the following headings, briefly describe the various programs your organization offers for the benefit of PLWHIV/AIDS. (attach extra sheets if necessary)

PROGRAM	**DESCRIPTION**
Advocacy/Rights	
(1) ____________________	(1)____
(2) ____________________	(2)____
(3) ____________________	(3)____
(4) ____________________	(4)____
(5) ____________________	(5)____
(6) ____________________	(6)____
Education	
(1) ____________________	(1)____
(2) ____________________	(2)____
(3) ____________________	(3)____
(4) ____________________	(4)____
(5) ____________________	(5)____
(6) ____________________	(6)____
Support	
(1) ____________________	(1)____
(2) ____________________	(2)____
(3) ____________________	(3)____
(4) ____________________	(4)____
(5) ____________________	(5)____
(6) ____________________	(6)____
Other	
(1) ____________________	(1)____
(2) ____________________	(2)____
(3) ____________________	(3)____
(4) ____________________	(4)____
(5) ____________________	(5)____
(6) ____________________	(6)____

25. Additional Comments or Questions

(attach extra sheets if needed).

Please remember to attach copies of the following:

*hiring policy/equal opportunity statement
*sample of job postings/advertisements
*board representation policy
*other policies/initiatives that make your organization more accessible to PLWHIV/AIDS

Thank you for taking the time to complete this questionnaire. If you have any questions or concerns, please direct them to Grant McNeil at the CAS offfice.

Please return to:

Canadian AIDS Society
PLWHIV/AIDS Participation Survey
100 Sparks St., Suite 701
Ottawa, ON. K1P 5B7
Phone(613) 230-3580 or Fax(613)563-4998

Please return by:

May 01, 1992.

cmr/16.02.92

APPENDIX 2

Fact Sheet: Focus Group Participants

FACT SHEET
FOCUS GROUP PARTICIPANTS

Date__________ **Name of Organization** ____________________

1. How are you involved with this organization?
(check as many as apply)
[ ]Staff [ ]Board [ ]Volunteer [ ]Client

2. How often are you involved with activities related to this organization?
[ ]Daily [ ]Weekly [ ]Monthly [ ]Less than once per month

3. How long have you been involved with this organization?
[ ]more than 3 years [ ]more than 1 year
[ ]1-12 months [ ]less than 1 month

4. How would you describe your current health?
(check one only)
[ ]AIDS and very ill [ ]HIV and currently ill
[ ]AIDS and somewhat ill [ ]HIV and currently without symptom
[ ]AIDS and currently no illness [ ]HIV and never had symptoms

5.Age_____ **6.Gender** [ ]Female [ ]Male **7.Sex. Orientation** [ ]gay [ ]bisexual [ ]straight

8. Last Level of Education Completed:
[ ]Elementary School [ ]University
[ ]High School [ ]Graduate School
[ ]Community College

9. Are you currently employed? [ ]Yes [ ]No

10. Describe your last or current job.__________________________

11. Are you? [ ]Aboriginal [ ]Person of Colour
[ ]Other distinct cultural group (explain________________________)

12. How far do you live from this organization? _________Kms.

13. How do you usually travel here? ______________________

14. How would you rate this organization.
[ ]Excellent [ ]Good [ ]Fair [ ]Poor [ ]Terrible

APPENDIX 3

Comments Sheet: Strategies to Overcome Organizational Barriers

The Role of PLWHIV/AIDS Within the Canadian AIDS Society

Questions for small group discussions:

1. Organization strategies:

   What can an organization do to bring down the barriers to greater PLWHIV/AIDS participation on its staff?

2. Individual strategies:

   What can you do as an individual to support your organization to bring down the barriers to greater PLWHIV/AIDS participation on your staff?

We would appreciate hearing your strategies.

Please have one person list your strategies above and give to the person at the exit.

APPENDIX 4

Canadian AIDS Society Groups: Category/City/Population

CAS Groups by Category and City/Population

CATEGORY 1: GSO-L GENERAL SERVICES ORGANIZATIONS (IN CITIES OVER 200,000 POPULATION)	CITY (POPULATION)
1. AIDS Committee of Toronto (ACT)	Toronto* (2,275,771)
2. Comité sida aide Montréal (C-SAM)	Montreal** (1,775,871)
3. AIDS Vancouver (AV)	Vancouver*** (1,542,744)
4. AIDS Calgary Awareness Association	Calgary (717,133)
5. AIDS Committee of Ottawa (ACO)	Ottawa-Carleton* [Ottawa] (678,147)
6. Village Clinic	Winnipeg (618,300)
7. AIDS Network of Edmonton Society	Edmonton (618,195)
8. Mouvement d'information et d'entaide dans la lutte contre le sida à Québec (MIELS)	Quebec** (490,271)
9. Hamilton AIDS Network (HANDS)	Hamilton-Wentworth*[Hamilton] (451,665)
10. AIDS Committee of Durham	Durham* [Oshawa] (409,070)
11. AIDS Committee of Niagara	Niagara* [St. Catherine's] (393,936)
12. AIDS Committee of Cambridge, Kitchener/Waterloo and Area (ACCKWA)	Waterloo* [Kitchener] (377,762)
13. Action sida Laval	Laval (313,500)
14. AIDS Committee of London (ACOL)	London (302,679)
15. AIDS Vancouver Island (AVI)	Capital Region*** [Victoria] (299,550)
16. Bureau régional d'action sida (BRAS)	Outaouais** [Gatineau] (201,536)

CATEGORY 2: GSO-S GENERAL SERVICES ORGANIZATIONS (IN CITIES UNDER 200,000 POPULATION)	CITY (POPULATION)
1. AIDS Committee of Windsor	Windsor (190,954)
2. AIDS Saskatoon	Saskatoon (186,058)
3. AIDS Regina	Regina (179,178)
4. AIDS Committee of Sudbury (ACCESS)	Sudbury* (161,210)
5. AIDS Nova Scotia (ANS)	Halifax (114,455)
6. AIDS Committee of Thunder Bay (ACT-B)	Thunder Bay (110,289)
7. Newfoundland & Labrador AIDS Committee	St. John's (96,215)
8. AIDS Committee of Guelph	Guelph (85,625)
9. Intervention régionale et information sur le sida (IRIS/Estrie)	Sherbrooke (77,629)
10. AIDS Saint John	Saint John (76,381)
11. Peterborough AIDS Resource Network (PARN)	Peterborough (67,823)
12. Mouvement d'information, d'education et d'entraide dans la lutte contre le sida (MIENS)	Chicoutimi (64,100)
13. Lethbridge AIDS Connection	Lethbridge (63,390)
14. Kingston AIDS Project (KAP)	Kingston (60,930)
15. Central Alberta AIDS Network Society	Red Deer (58,656)
16. Sida AIDS Moncton	Moncton (55,468)
17. AIDS Committee of North Bay	North Bay (54,611)
18. AIDS New Brunswick (AIDS NB)	Fredericton (44,722)
19. Brandon AIDS Support	Brandon (38,708)
20. South Peace AIDS Council	Grande Prairie (28,271)
21. Bureau local d'intervention traitant du sida (BLITS)	Victoriaville (22,400)
22. Yukon AIDS Project	Whitehorse (21,543)
23. AIDS Prince Edward Island (AIDS PEI)	Charlottetown (15,396)
24. Foothills AIDS Awareness Association	Okotoks (7,148)
25. SIDA/AIDS Information & Ressources Québec Sud-ouest	Huntington (2,900)
26. AIDS: A Positive Co-ordinated Response Society of Jasper	Jasper****

CATEGORY 3: PWA ORGANIZATIONS	CITY (POPULATION)
1. Toronto PWA Foundation (TPWAF)	Toronto* (2,275,771)
2. Comité des personnes atteintes du VIH (CPAVIH)	Montréal** (1,775,871)
3. Vancouver PWA Society (VPWAS)	Vancouver*** (1,542,744)
4. Body Positive Coalition of Manitoba	Winnipeg (618,300)
5. Edmonton Persons Living With AIDS Society (EPLWAS)	Edmonton (618,195)
6. PLWA Network of Saskatchewan	Saskatoon (186,058)
7. Nova Scotia PWA Coalition (NSPWAC)	Halifax (114,455)

CATEGORY 4: SC GROUPS SERVING SPECIFIC COMMUNITIES	CITY (POPULATION)
1. Two-Spirited People of the First Nation	Toronto* (2,275,771)
2. Alliance for South Asian AIDS Prevention (ASAP)	Toronto* (2,275,771)
3. Gay Asian AIDS Project (GAAP)	Toronto* (2,275,771)
4. Black Coalition for AIDS Prevention (Black-CAP)	Toronto* (2,275,771)
5. Prostitutes' Safer Sex Project (PSSP)	Toronto* (2,275,771)
6. Centre d'action sida Montréal (Femmes)	Montreal** (1,775,871)
7. GAP-SIDA (Haitien)	Montreal** (1,775,871)
8. Positive Women's Network (PWN)	Vancouver*** (1,542,744)
9. B.C. Coalition of People With Disabilities (BCCPWD)	Vancouver*** (1,542,744)
10. Feather of Hope Aboriginal AIDS Prevention Society	Edmonton (618,195)

CATEGORY 5: SS GROUPS PROVIDING SPECIFIC SERVICES	CITY (POPULATION)
a) Housing & Hospice Services	
1. Fife House Foundation	Toronto* (2,275,771)
2. Casey House Hospice	Toronto* (2,275,771)
3. Chez Ma Cousine Evelyn	Montreal** (1,775,871)
4. AIDS Housing Group of Ottawa (AHGO)	Ottawa-Carleton* [Ottawa] (678,147)
5. AIDS Shelter Coalition of Manitoba	Winnipeg (618,300)
b) Support Services	
6. Centre Pierre Hénault	Montreal** (1,775,871)
7. AIDS Community Care of Montréal (ACCM)	Montreal** (1,775,871)
c) Treatment Services	
8. AIDS ACTION NOW! (AAN!)	Toronto* (2,275,771)
9. Community AIDS Treatment Information Exchange (CATIE)	Toronto* (2,275,771)
10. Community Research Initiatives of Toronto (CRIT)	Toronto* (2,275,771)
d) Coalition	
11. Coalition des organismes communautaires québécois de lutte contre le sida (COCQ-SIDA)	Montreal** (1,775,871)

*Ontario Regional Municipality
**Quebec Urban Community
***British Columbia Regional District
****Alberta does not report the population of towns under 2,000
[ ] Where Regional Governments exist, this indicates the city in which the organization is located

References

Adam, B. 1987. *The Rise of a gay and lesbian movement.* Boston: G.K. Hall Press.

________. 1992. Sociology and people living with AIDS. In *The social context of AIDS,* ed. J. Huber & B. Schneider. Newbury Park: Sage Publications.

Aggleton, P., J. Weeks and A. Taylor-Laybourn. 1993. Voluntary sector responses to HIV and AIDS: A framework for analysis. In *AIDS: Facing the second decade,* ed. P. Aggleton, P. Davies, and G. Hart. London: Falmer Press.

Altman, D. 1982. *The homosexualization of America.* Boston: Beacon Press.

________. 1986. *AIDS and the new puritanism.* Sydney: Pluto Press.

________. 1986. *AIDS in the mind of America.* New York: Double Day Press.

________. 1993. Expertise, legitimacy, and the centrality of community. In *AIDS: Facing the second decade,* ed. P. Aggleton, P. Davies, and G. Hart. London: Falmer Press.

Alperlin, D. and N. Richie. 1989. Community-based AIDS service organizations: Challenges and educational preparation. *Health and Social Work,* Aug: 165-173.

Arno, P. 1986. The nonprofit sector's responses to the AIDS epidemic: Community-based services in San Francisco. *American Journal of Public Health,* 76: 1325-1330.

Arno, P. and R. Hughes. 1989. Local policy responses to the AIDS epidemic: New York and San Francisco. In *AIDS: Public policy dimensions,* ed. P. Imperato. New York: Plenum Medical Books.

Banzhaf, M, T. Morgen, and K. Ramspacher. 1990. Reproductive rights and AIDS: The connections. *In Women, AIDS, and activism,* ed. ACT UP/New York Women and AIDS Book Group,199-209. Boston: South End Press.

Bayor, R. 1989. *Private acts and social consequences: AIDS and the politics of public health.* New York: Free Press.

Bayer, R. and D. Kirp. 1992. The United States: At the center of the storm. In *AIDS in the Industrialized Democracies: Passions, politics, and policies,* ed. D. Kirp and R. Bayer, 7-48. Montreal: McGill-Queen's University Press.

Berridge, V. 1993. AIDS: History and contemporary history. In *The time of AIDS: Social analysis, theory, and method,* ed. G. Herdt and S. Lindenbaum, 41-65. Newbury Park: Sage.

Berridge, V. and P. Strong, eds. 1993. *AIDS and contemporary history.* Cambridge: Cambridge University Press.

Burzynski, R. 1992. *The community-based AIDS movement: A portrait of CAS.* Ottawa: Canadian AIDS Society.

Cain, R. 1993a. *AIDS service organizations in context.* Unpublished report for Health Canada.

________. 1993b. Community based AIDS services: Formalization and depoliticalization. *International Journal of Health Services* 23(4): 665-684.

________. 1994. Managing impressions of an AIDS service organization: Into the mainstream or out of the closet? *Qualitative Sociology* 33(2): 43-71.

Callen, M. 1987. Founding statement of People with AIDS/ARC "The Denver Principles". In *Striving and thriving with AIDS: Collected wisdom,* ed. M. Callen, 1. New York: People with AIDS Coalition, Inc.

________. 1990. *Surviving AIDS.* New York: Harper Collins.

Callen, M and D. Turner. 1988. A History of the PWA self-empowerment movement. In *Striving and thriving with AIDS: Collected wisdom,* ed. M. Callen, 2. New York: People with AIDS Coalition, Inc.

Canadian AIDS Society. 1986. *Minutes of the 1986 annual general meeting.* Toronto.

________. 1987. *Minutes of the 1987 annual general meeting.* Ottawa.

________. 1988. *Minutes of the 1988 annual general meeting.* Toronto.

________. 1989. *Minutes of the 1989 annual general meeting.* Quebec City.

________. 1990. *Minutes of the 1990 annual general meeting.* Winnipeg.

________. 1991a. *Towards the Canadian AIDS Society of 1995: Final report on strategic planning,* May. Ottawa.

________. 1991b. *Minutes of the 1991 annual general meeting.* Ottawa.

________. 1991c. *Minutes of the meeting between representatives of the Canadian AIDS Society and the National Network of Organizations for People Living With HIV/AIDS.* Toronto.

________. 1991d. *Annual report.* Ottawa.

________. 1992a. *PLWHIV/AIDS forum participant's guide.* Halifax.

________. 1992b. *Minutes of the 1992 annual general meeting.* Halifax.

________. 1992c. Voices of Positive Women, *CASN,* winter: 5.

________. 1993a. *No time for complacency: A brief submitted to the Hon. Benôit Bouchard Minister of National Health and Welfare.* Ottawa.

________. 1993b. *Minutes of the 1993 annual general meeting.* Montreal.

________. 1994. *Minutes of the 1994 annual general meeting.* Toronto.

Canadian Network of Organizations for PLWHIV/AIDS. 1990. *People with HIV update.* (available from B.C. PWA Society, c/o Pacific AIDS Resource Centre, 1107 Seymour Street, Vancouver, Canada, V6B 5S8). Oct.

Carpenter, N. 1988. AIDS initiatives in Massachusetts: Building a continuum of care. *New England Journal of Public Policy,* 4(1): 429-440.

Carter, E. and S. Watney, eds. 1989. *Taking liberties: AIDS and cultural politics.* London: Serpent's Tail.

Carter, G. 1992. *ACT UP, the AIDS war and activism.* New Jersey: Open Magazine.

Chambre, S. 1991. Volunteers as witnesses: The mobilization of AIDS volunteers in New York city, 1981-1988. *Social Service Review* 65(4): 531-547.

Clarke, J. 1993. *Burlington Breast Cancer Support Services.* Unpublished manuscript, Wilfrid Laurier University, Waterloo, Ontario, Canada.

Clausson, N. 1989. AIDS: The community-based response. *Canadian Journal of Public Health,* 80(1): S18-S20.

Crimp, D. 1988. *AIDS: Cultural analysis, cultural activism.* Boston: MIT Press.

Crimp, D. and A. Rolston. 1990. *AIDS DEMO GRAPHICS.* Seattle: Bay Press.

DeJong, G. 1979. *The Movement for independent living: Origins, ideology, and implications of disability research.* Boston: Medical Rehabilitation Institute.

Delgado, M. and D. Delgado. 1982. Natural support systems: Source of strength in hispanic communities. *Social Work,* 27: 83-89.

D'Emilio, J. 1989. Gay politics and community in San Francisco since world war II. In *Hidden from History: Reclaiming the Gay and Lesbian Past,* eds. M. B. Dunerman, M. Vicinus, and G. Chauncy, Jr., 456-476. New York: NAL Books.

Dreifus, C. 1970. *Seizing Our Bodies: The Politics of the Women's Health.* New York: Vintage.

Epstein, S. 1991. Democratic science? AIDS activism and the contested construction of knowledge. *Socialist Review,* 21(2): 35-64.

Federal Centre for AIDS. 1989, July 4. *Surveillance update: AIDS in Canada.* Ottawa.

Fee, E. and D. Fox ,eds. 1988. *AIDS: The Burdens of History.* Berkeley: University of California Press.

________. 1992. *AIDS: The Making of a Chronic Disease.* Los Angeles: University of California Press.

Furstenberg, A. L. and M. M. Olson. 1984. Social work and AIDS. *Social Work in Health Care.* 9(4), 45-62.

Garmaise, D. 1993. *The numbers game.* Ottawa: Canadian AIDS Society.

Gillett Fruchter, R., N. Fatt, P. Booth and D. Leidel. 1977. The Women's Health Movement: Where are We Now? In *Seizing Our Bodies: The Politics of the Women's Health,* ed. C. Dreifus, 271-278, New York: Vintage.

Haney, P. 1988. Providing for empowerment to the person with AIDS. *Social Work*, 33(3), 251-253.

Health and Welfare Canada. 1993, April. *Quarterly surveillance update: AIDS in Canada.* Ottawa.

________. 1993. *National AIDS strategy. Phase II: Building on progress.* Ottawa.

Herdt, G. and S. Lindenbaum, eds. 1992. *The time of AIDS: Social analysis, theory, and method.* Newbury Park: Sage.

Jonsen, A. and J. Stryker, eds. 1993. *The social impact of AIDS in the United States.* Washington: National Academy Press.

Kawata, P. 1989. Community-Based Response to AIDS. In *AIDS and the historian: Proceedings of a conference at the National Institutes of Health,* ed.V. Harden and G. Risse, 116-123. Washington: National Institutes of Health.

Kayal, P. 1993. *Bearing witness: Gay Men's Health Crisis and the politics of AIDS.* Oxford: Westview Press.

Kessler, L., A. Silvia, D. Aronstein and C. Patton. 1988. Call to action: A community responds. *New England Journal of Public Policy,* 4(1): 441-453.

Kinsman, G. 1987. *The Regulation of Desire: Sexuality in Canada.* Montreal: Black Rose Press.

________. 1992. Managing AIDS organizing: "Consultation," "partnership," and the national AIDS strategy. In *Organizing dissent: Contemporary social movements in theory and practice,* ed. W.K. Carroll, 215-233. Toronto: Garamond Press.

Kirp, D. and R. Bayer, eds. 1992. *AIDS in the industrialized democracies: Passions, politics, and policies.* Montreal: McGill-Queen's University Press.

Kolbasa, S. 1991. AIDS volunteering: Links to the past and future. In *A Disease of Society: Cultural and Institutional Responses to AIDS,* eds. D. Nelkin, D. Willis, and S. Parris, 172-190. Cambridge: Cambridge University Press.

Kushner, R. 1984. *Alternatives: New Developments in the War On Breast Cancer.* New York: Warner Books.

Leonardis, O. and D. Mauri. 1992. From deinstitutionalization to the social enterprise. *Social Policy,* fall/winter: 50-54.

Lopez, D. J. and G.S. Getzel. 1984. Helping gay AIDS patients in crisis. *Social Casework,* 65(7), 387-394.

Macks, J. 1988. Women and AIDS: Countertransference issues. *Social Casework,* 69(6), 340-347.

MacLachlan, J. 1992. Managing AIDS: A phenomenology of experiment, empowerment and expediency. *Critique of Anthropology,* 12(4): 433-456.

Manhoff, M. 1989. Living With AIDS. In *The AIDS Reader,* ed. P. Cass and R. Gallagher. Dubuque: Kendall/Hunt.

Marger, M. 1984. Social movement organizations and response to environmental change: The NAACP, 1960-1973. *Social Problems,* 32, 16-30.

McGuire, J. 1989. AIDS: The community-based response. *AIDS*, 3(1): S279-S282.

O'Brien, M. 1992. *Living with HIV: Experiment in courage.* New York: Auburn House.

O'Sullivan, S. and K. Thomson. 1992. *Positively Women: Living with AIDS.* London: Sheba Feminist Press.

Padgug, R. & G. Oppenheimer. 1992. Riding the Tiger: AIDS and the Gay Community. In *AIDS: The making of a chronic disease,* eds. E. Fee and D. Fox, 245-278. Los Angeles: University of California Press.

Patton, C. 1986. *Sex & germs: The politics of AIDS.* Montreal: Black Rose Books.

________. 1990. *Inventing AIDS.* New York: Routledge, Chapman and Hall.

Pawluch, D., R. Cain, & J. Gillett. 1994. *Ideology and alternative therapy use among people living with HIV/AIDS.* A paper presented at the Qualitative Research Conference, Waterloo, Ontario.

Pearl, A. & F. Riessman. 1965. *New Careers for the Poor.* New York: Free Press.

Piven, F. & R. Cloward. 1977. *Poor People's Movements.* New York: Vintage Books.

Porter, V. 1988. Minorities and HIV infection. *New England Journal of Public Policy,* 4(1): 371-380.

Rayside, D. and E. Lindquist. 1992. Canada: Community Activism, Federalism, and the New Politics of Disease. In *AIDS in the industrialized democracies: Passions, politics, and policies,* eds. D. Kirp and R. Bayer,49-98. Montreal: McGill-Queen's University Press.

Rhoades, C., P. Brown, and E. Thorin. 1986. Self-help advocacy movement: A promising peer-support system for people with mental disabilities. *Rehabilitation-Literature,* 47(1-2): 2-7.

Reamer, F.G. 1988. AIDS and ethics: the agenda for social workers. *Social Work* 33(5): 460-464.

Rector, R. 1991. Maximizing the existing health potential of people with HIV/AIDS: Have we succeeded?. *AIDS Health Promotion Exchange,* 1, 1-4.

Rodriguez, N. 1988. A successful shelter: A case study of the family crisis shelter in Hawaii. *Journal of Applied Behavior Science,* 24, 235-250.

Roy, C.M. 1990. *AIDS literature in social work journals: Assessing, evaluating and orienting our response to the pandemic.* Unpublished manuscript, Hunter College School of Social Work, New York.

Rudd, A. & D. Taylor. 1992. *Positive women: Voices of women living with AIDS.* Toronto: Second Story Press.

Schecter, S. 1990. *The AIDS Notebooks.* New York: State University of New York Press.

Schechter, S. 1982. *Women and Male Violence: The Visions and Struggles of the Battered Women's Movement.* Boston: South End Press.

Sears, A. 1991. AIDS and the health of nations: The contradictions of public health. *Critical-Sociology,* 18(2): 31-50.

________1992. "To teach them how to live": The politics of public health from tuberculosis to AIDS. *Journal of Historical Sociology,* 5(1): 61-83.

Segal, L. 1989. Lessons from the Past: Feminism, Sexual Politics and the Challenge of AIDS. In *Taking Liberties: AIDS and Cultural Politics,* eds. E. Carter and S. Watney,133-146. London: Serpent's Tail.

Shilts, R., 1987. *And the Band Played On.* New York: St. Martin's Press.

Smith, D. 1977. Does government funding co-opt? *Kinesis,* 6, 5-6.

Smith, G. 1988. Talking politics. *Rites,* 5, 8-12.

Staggenborg, S. 1988. The consequence of professionalization and formalization in the pro-choice movement. *American Sociological Review,* 53, 585-606.

Stoddard, T. 1989. Paradox and Paralysis: An Overview of the American Response to AIDS. In *Taking Liberties: AIDS and Cultural Politics*, eds. E. Carter and S. Watney, 95-106. London: Serpent's Tail Press.

Schwartz, M., N. Rosenthal and L. Schwartz. 1981. Leader-member conflict in Protest Organizations: The case of the Southern Farmers Alliance. *Social Problems*, 29, 22-36.

Teal, D., (1971). The Gay Militants. New York: Stien and Day.

Toby, M. 1981. *The Politics of Homosexuality: How Lesbians and Gay Men Have Made Themselves a Political and Social Force in Modern America.* Boston: Houghton Mifflin.

TPA News 1989. Viewpoint: The Montréal Manifesto. October: 6.

Trussler, T. & R. Marchand. 1993. *Taking Care of Each Other: Health Promotion in Community Based AIDS Work.* Vancouver: AIDS Vancouver.

Wachter, R.M. 1991. *The fragile coalition: Scientist, activists and AIDS.* New York: St. Martin's Press.

Weeks, J. 1989. AIDS: The Intellectual Agenda. In *AIDS: Social Representations-Social Practices*, eds. P. Aggleton, G. Hart, & P. Davies, 1-20. London: Falmer Press.

Weeks, J. 1991. *Against nature: Essays on history, sexuality and identity.* London: River Oram Press.

Weitz, R. 1991. *Life with AIDS.* New Brunswick, N.J.: Rutger University Press.

Whitehead, M. & Patterson, B. 1993. *Managing your health: A guide for people living with HIV or AIDS.* Toronto: Community AIDS Treatment Information Exchange (CATIE).

Whyte, W.F., D.J. Greenwood & P. Lazes. 1991. Participatory action research: Through practice to science in social research. In *Participatory action research*, ed. W.F. Whyte. Newbury Park: Sage.

Wilkinson, S. & C. Kitzinger. 1993. Whose breast is it anyway? A feminist consideration of advice and "treatment" for breast cancer. *Women's Studies Forum*, 16(3): 229-238.

Winnow, J. 1992. Lesbians' evolving health care: Cancer and AIDS. *Feminist-Review*, 41: 68-76.

Withorn, A. 1980. Helping ourselves: The limits and potential of self-help. *Social-Policy*, 11(3): 20-27.

Zola, I. 1987. The politicization of the self-help movement. *Social-Policy*, 18(2): 32-33.