

**Butch Nightingale?
Lesbians and AIDS Work in Nova Scotia**

by

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Abstract

The entry point for this thesis is the development of a lesbian feminist critique of AIDS work. The critique hinges on the notion that lesbians who chose to do AIDS work are acting like nurses, taking on caring roles, as women tend to do. Such a critique of lesbians' involvement in the AIDS epidemic is first explored, then used to spur an inquiry into the social relations surrounding lesbians and AIDS work, and finally shown to have theoretical shortcomings. The literature is surveyed providing a context within which the six informants from Nova Scotia are used to discover some of the ways that lesbians become involved in AIDS work. The analysis suggests that lesbians' participation in responding to AIDS arises through community affiliations not limited to the lesbian identity. As a theoretical approach arising from, and somewhat limited to, the sociology of gender and sexuality, the lesbian feminist critique of AIDS work is demonstrated to lack the ability to account for the complex identities of the six lesbians in this thesis.

Chapter One

Introduction

Before North Americans knew what Acquired Immune Deficiency Syndrome, or AIDS, was in any epidemiological sense, a social movement arose to meet the needs of those affected by it. In 1981, a few metropolitan areas of North America saw groups of people beginning to understand that there was an attack on their communities. Some understood it as a physical and medical problem. Others quickly understood that this apparently new ailment could have far-reaching social and political implications. It is from that early point that many of those who were or are engaged in responding to AIDS began to grapple with the effects and the meaning of AIDS, and how they could best address the AIDS epidemic.

From the moment that it was understood that there was a new disease affecting gay men in North America, and throughout the intervening seventeen years, lesbians have been affected by this epidemic. At the same time that lesbians were seeing friends, family and lovers devastated by the syndrome, many chose to fight AIDS on multiple levels. In responding to the disease as a health issue or as a social and political issue, lesbians have contributed much energy and knowledge (Schulman, 1994: 172), just as they have learned new skills and have found insight in the work done (Glassman, 1995: 69; Stone 1988: 148). In 1998, lesbians continue to be an important part of organizing against AIDS and meeting the needs of those most affected, working in literally every aspect of the response to AIDS.

Lesbians have also been among those most affected, living with HIV infection themselves.¹

Throughout the epidemic, sociologists and activists have analysed the various responses to AIDS. Cindy Patton in the US, Simon Watney in the UK and Gary Kinsman here in Canada have explicated various social relations throughout the epidemic. These theorists, AIDS activists themselves, have shown the political and social impact of AIDS, as well as illuminating the social organization involved in (re)creating this disease as a social phenomenon. Recently, books like *Policing Public Sex: Queer Politics and The Future of AIDS Activism* (Dangerous Bedfellows, 1996) and *Reviving the Tribe: Regenerating Gay Men's Sexuality and Culture in the Ongoing Epidemic* (Rofes, 1996) attempt to chart a course for the direction that AIDS organizing should take by looking at its history, including its successes and failures. The sociology of AIDS makes apparent the social construction of AIDS, allowing activists to critically analyze the complex social activity latent in the experiences of each person touched by AIDS.

This thesis is a continuation of the critical assessment of lesbians' involvement in the AIDS epidemic that lesbians themselves began in the late 1980s. Such reflection should be ongoing, with a view to improving the lives of people living with HIV/AIDS and the social positions of lesbians, and influencing the

¹Health Canada's AIDS In Canada: Quarterly Surveillance Update released in August 1997 indicated that the proportion of AIDS cases diagnosed among women in 1997 (up to June 30, 1997) was 13.2%, the highest proportion recorded. This figure is part of a trend of recorded proportional increases in women's AIDS diagnoses. Before 1993, the ratio of females to males diagnosed with AIDS was 1 to 15. In 1995, it was 1 to 11; in 1996 1 to 8, and in 1997 (to June 30) the ratio was 1 to 7 (3).

future of AIDS activism. In this research, I document social and historical aspects of lesbians' relationships to AIDS, from individual experiences and lesbians' interpretations of them, to broad social relations, and the linkages between the two. This thesis describes and analyses lesbians' involvement in AIDS work over the course of the epidemic. The idea is that through documentation and analysis of lesbians' work, lesbians and others involved in AIDS work will be able to envision the future of responding to AIDS that seems most appropriate and one in which they would like to participate.

Organisation of this thesis

Qualitative sociology must strive to be rigorous if we are to rely on it to help us comprehend the social organization of the realities we inhabit. Indeed, the work of such theorists as Dorothy Smith shows great promise for such a useful sociology. The reliance on a systematic approach in this research should be apparent in its organization as well. The chapter which you are now reading outlines the parameters of this thesis, just as the researcher's first step is to define research questions. The next step in the research process is to decide which tools - methodological and theoretical - will be used to probe into the social relations surrounding the questions with which the researcher is concerned. The tools and concepts of the particular sociological approaches used in this thesis are elaborated upon in the second chapter.

The information gathered through this sociological investigation, the sociological data, is laid out in the third and fourth chapters. As history cannot actually be separated from these women's experiences of it, it was necessary to utilize an analytical construct to separate the historical context within which lesbians became involved in AIDS from the experiences of Nova Scotia lesbians who have done AIDS work. The former is crucial to understand before contemplating the latter, therefore it is presented in chapter three. The information about lesbians involved in the response to AIDS as told to me in interviews with Nova Scotian lesbians is discussed in the fourth chapter.

Finally, in the sociology of this thesis, the researcher seeks to create knowledge which is useful to the research subjects. This theorizing is in the fifth and last chapter, where reflection on the research questions is accomplished in the light of the data. By the time this final chapter is reached, having systematically gathered the information, I will be able to draw conclusions about lesbians' involvement in the AIDS epidemic.

Research question

In this project, constructed to critically analyse the AIDS work that lesbians do, the guiding question is, "How is it that lesbians are involved in the response to AIDS?" One useful aspect of this question is its probing at just what it is that lesbians do to respond to AIDS. Rieder and Ruppelt maintain that women's work in the AIDS movement has been studied little and is hardly quantifiable, but it has clearly been

crucial to the successes of organizing (1988:177). What are the specifics and everyday accomplishments that lesbians have contributed to AIDS organizing? In answer to this question, I am not only expanding the understanding of lesbians in relation to the AIDS pandemic, but also enlightening our understanding of AIDS organizing.

One objective of the present study is to describe the actual work of lesbians in the epidemic, which has ranged from caregiving to developing educational programs for HIV prevention; from answering phones and fundraising to organizing demonstrations. In this account, the descriptive aspects may also be seen as the constituent historical parts of the realities that exist(ed) for lesbians. In this, lesbians are seen as subjects at once creating and being created within the contexts. The discussion moves from focusing on individuated parts of the work of lesbians to understanding how it is interconnected.

The guiding question of how it is that lesbians become involved in AIDS work also encompasses our inquiry about the relationships surrounding lesbians' involvement. It is not simply by accident that (some) lesbians became involved with the response to AIDS.² How is it, then, that relations were organized in such a way that lesbians were in a position to respond to AIDS? Understanding the focusing question in this way, I may begin to analyze the social relations which intersect around AIDS and lesbians.

²We see in chapter 2 that not every lesbians was as likely to become part of the response to AIDS, and that there were very different contextual relations for different lesbians. These differences are largely organized around class and race.

Understanding how it is that lesbians first became involved in AIDS work is central to this study. However, their ongoing work is also of utmost interest. It is important to analyse the situations and relationships that lesbians experience while doing AIDS work if we are to understand the social and political realities of AIDS and of lesbians more fully. Both in terms of the personal and the political levels of analysis, the research will show how it is that lesbians first became involved in the response to AIDS and how it is that they did (or did not) remain involved.

"The personal is political" as heuristic

When twentieth century feminists first conceptualized the notion that "the personal is political," it brought together the dichotomy between women's personal or private lives and the greater sphere of the public realm where political activity was said to take place. Feminists maintained that what women did in their personal lives also had larger political implications. One of the key concepts that such feminists as Helen Levine theorized was that what happened on an individual level was not only individual but had implications for all of society (1982:177). Some 1970s feminists, such as the Redstockings collective, became involved in consciousness-raising, which was an attempt to encourage women to discuss their own "personal" experiences.³ Later, bell hooks cautioned feminists to remember that we must also

³Carol Anne Douglas explains in *Love & Politics* that the Redstockings were pioneers of consciousness raising groups. Consciousness-raising had limitations as a method of learning about the world because the groups were limited in their membership. The experiences many women, for example, women of color, women from

seek to understand the concrete material reality which lays the groundwork for personal experience (1988: 107).

In this thesis, there is, on the one hand, through the discussion of lesbians' experiences in the response to AIDS, a look at "the personal" aspects of this phenomenon as it relates to lesbians.⁴ This initial aspect may be further subdivided into a) a description of the particular kinds of involvement lesbians have had, and b) a discussion of the issues (insights, contradictions, problems, benefits, and opportunities) that this work creates. I shall show how AIDS has affected lesbians on a personal level. Beyond the HIV epidemic, I will also investigate lesbians' priorities, commitments and relationships.

Using "the personal is political," it is important to look at the social relations which organize the context within which lesbians live and work. This is the political. This aspect is crucial and forms the historical core of the research. The explication of the social relations that formed the context within which lesbians first became involved in AIDS work, as well as those that create the everyday realities for those who continue to be involved, provides us with a broader understanding of the condition of lesbians. Patton argues that early AIDS organizing would have benefited from understanding its historical context (1986: 17). Closing in on two

other countries, or women involved in the sex trade, were not part of theorizing within consciousness-raising groups (Douglas, 1990: 19).

⁴As Mariana Valverde points out in the opening pages of *Sex, Power, and Politics*, "experience" cannot be directly related. Rather, what I'll refer to as lesbians' experiences in AIDS organising are actually related through their interpretations of their experiences (Valverde, 1985:25).

decades of struggling with responses to AIDS, lesbians and the movement as a whole can still learn from historical analyses, both pre- and post-AIDS.

I find this analogy particularly compelling given the research topic is centered on the theme of work. One of the main feminist enterprises has been to show the relations between the public and the private (Dunne, 1997: 1). In this enterprise, feminist scholars have demonstrated how household work and sexual relations were relegated to "the personal" while work outside the home, especially for pay, was placed in "the political" realm. As feminists have shown that work and sexuality, to take two relevant examples, are both political and personal, I am here examining them on both levels. The work lesbians have done in the AIDS crisis is personal, insofar as that is how it is experienced. It is also political, not merely because it was work outside the home, but since AIDS work is embedded in a complex web of contradictory social relations. The same may be said of lesbianism.

While I will use the experiences of lesbians who have been working to respond to AIDS as an entry point into a fuller understanding of AIDS, I will avoid becoming stranded and limited by personal experiences by making connections to the political. It is not merely a matter of reporting lesbians' experiences and generalizing from them. It is also necessary to analyse the insights of Nova Scotian lesbians involved in AIDS work within the realities of the social relations in process over the past decades. "Politicization necessarily combines this process (the naming of one's experiences) with critical understanding of the concrete material reality that lays the groundwork for that experience" (hooks, 1989: 105). The

experiences of lesbians in Nova Scotia will be used to support or refute what has been presented in the literature.

Personal and political, individual and contextual, and the unseen relationships between these concepts are all studied in order to explicate lesbians' AIDS work. Six lesbians involved in AIDS work (at the time of the interview or previously) were interviewed about their insights and experiences. These interviewed individuals, along with my own experiences, are analysed along several key themes to build a representation of the social realities within which lesbians and AIDS continue to be re-invented. True to the theory that the personal is political, lesbians are at once challenging and changing the world within which they act, even as they are constrained and shaped by the social relations which create that world.

Scope of the research

Along with marginalising the different realities linked to race, age, or class, our understandings of the AIDS epidemic have tended to eclipse the importance of gender. Very often, the authors of various accounts of AIDS organizing will refer to the responses of the 'gay and lesbian community' as if there exists one monolithic community. Where there continues to exist an uncritical acceptance of a 'gay and lesbian community,' the situation is created where the experiences and realities of lesbians are made invisible. While there is some utility in presenting the 'gay and lesbian community' as a unified whole, too often in our discussions the experiences

of gay men in the AIDS epidemic come to stand in for the experiences of lesbians. This has had quite a distorting affect on the way the various lesbians' positions, involvement, and relationships to the AIDS pandemic are shown. For this reason and others, the present research focuses almost entirely on lesbians and AIDS rather than on gay men's involvement. The intent is not to take away from the importance of the efforts of gay men, nor the seriousness of the affect of AIDS on gay men as a community. Rather, the idea is to focus our attention on lesbians.

While heterosexual men seem to be very much in the minority within AIDS work, heterosexual women have participated in the response to AIDS. A critical discussion of the work of heterosexual women within the response to AIDS would contribute to our understanding of the relations within AIDS work. The discussion of heterosexual women's participation in the AIDS epidemic would also have comparative value for the present research in that one could contrast and compare the condition of lesbians and that of straight women doing AIDS work. However, in order to keep this research focused on the social relations which arise from lesbians' work, the study of heterosexual women and AIDS work will not be discussed in detail.

In her work which seeks to illuminate sexuality in the material world, Dunne explores the social relations between lesbianism and work. Dunne empirically shows how lesbians are involved in social relations at work that arise from sexuality (1997: 127). She points out that gender discrimination and inequality based on sexual orientation, for example, may appear similar but may have these different bases. Specifically lesbian research is able to illuminate these intricacies.

Furthermore, Dunne argues research from a heterosexual perspective "limits our ability to recognize the impact of heterosexuality itself on the conditions of women's lives" (1997: 2).

An additional factor that contributes to the focus of this work on lesbians and AIDS work is my own attempts to understand the relations that surround AIDS. The impetus for beginning this research came from my own commitment to AIDS work when, as a lesbian, I was challenged by the growing concern among other lesbians about our involvement in the response to AIDS. This concern ignited a research project designed to better understand that involvement. As the thesis took shape, it became apparent that the form that lesbians' concern was taking was itself problematic. The critical assessment of these lesbian issues should contribute to our knowledge for progressive and useful action.

Lesbians' critical reflection

Many lesbians have been given the opportunity to use and develop skills in organizing against AIDS as a social and political issue⁵. Those who are HIV positive have likely benefited in the long term from such activist work. On the other

⁵Although I am generally talking about the organizing lesbians have done on political and social levels to fight AIDS, Susan Sontag makes the point in *AIDS and its Metaphors* that, metaphorically, we may also think of a struggle against disease as a health issue. "The grosser metaphor survives in public health discourse where disease is regularly described as invading the society, and efforts to reduce mortality from a given disease are called a fight, a struggle, a war" (1990: 98). Indeed, among the many discourses and social relations surrounding AIDS, there have been lesbians throughout the course of the epidemic acting as caregivers, struggling against AIDS as a health issue, or participating in the public health education campaigns.

hand, lesbian feminists, some of whom have never been a part of the response to AIDS, have wondered if these skills and energy could have been better used somewhere else. This latter point ignited a low-scale debate by the end of the 1980s among lesbians, feminists, and those involved in AIDS organizing.

Among lesbian feminists, concern arose about the amount of energy and commitment that many lesbians were displaying toward AIDS (Brownworth, 1990; Schwartz, 1993; Stone, 1988). The struggle to understand exactly whose problem AIDS was had surfaced in the lesbian community, as some lesbians began to critically reflect on their participation in the response to the AIDS crisis. There were those who pointed out that AIDS primarily affected gay men in Canada.⁶ Lesbians perceived that AIDS was not a "lesbian issue," largely because AIDS in its short history had affected relatively few women who identified as lesbian (Califia, 1995). AIDS was a disease of other people, namely gay men and, perhaps, drug users.⁷

These were not new ideas. The notion that AIDS was gay men's problem coalesced, albeit fomenting somewhat later, with early mainstream (state and media) reactions to AIDS which understood AIDS as a gay men's disease and a

⁶Statistics from Health Canada continue to indicate that the exposure category "men who have sex with men" accounts for more than 7 out of 10 cases of AIDS reported to Health Canada (1997: 14). We must remember that AIDS cases are assigned to a single exposure category according to a hierarchy of modes of exposure, with 'men who have sex with men' at the top of the structure. With this in mind, the fact remains that men who have sex with men account for 72.5% of AIDS cases reported, by whatever mode of transmission infection occurred, and another 4.3% of reported cases are accounted for under the dual category 'men who have sex with men/IV drug use'.

⁷ Despite the fact that AIDS was perceived as a disease of IV drug users, Health Canada reports that only 4.4% of AIDS diagnoses that were reported from 1979 until 1997 were within the exposure category Injection Drug Use (Health Canada, 1997:14). Another 4.3% of reported cases were categorized as men who have sex with men/IV drug use.

gay men's problem (Patton, 1986:4). This train of thought was, however, new to lesbians as a group, many of whom had become part of the organized response to AIDS during the 1980s. The realization that so much energy had gone into something that was beginning to seem like someone else's problem precipitated critical reflection on the participation of lesbians in the AIDS crisis. Some lesbians began to wonder what had caused lesbians to become involved in the epidemic in the first place, rather than participating in responses to issues which appeared more directly related to lesbians' and women's lives.⁸

The questions posed by lesbian feminists (what I call the lesbian feminist critique of AIDS work) serve as a useful entry point for critically analysing lesbians' work in the AIDS epidemic. That critique, however, was a reaction based in a particular social context and was rather narrowly framed. As Smith says of a critique, it must be more than just a negative statement: it must be an attempt to define an alternative (1987: 78). While the lesbian feminist critique of AIDS work does shed light on some problems with lesbians involvement, it provides very little direction for those working in the response to AIDS. The idea that the critique rests on seems to be that AIDS is not a lesbian problem, and fighting this disease on medical and social levels should not be women's work.

⁸Lesbians were not the only ones to wonder what motivated women from their ranks to be so involved in the AIDS pandemic. Some gay men accused lesbians of having "AIDS envy", or jumping on the AIDS bandwagon by becoming involved with a disease that "really isn't a problem for (lesbians)" (Califia, 207:1995).

The notion that AIDS is not a lesbian problem arose as lesbian feminists took notice that gay men continued to be diagnosed with AIDS⁹ at a much higher rate than women, and especially higher than lesbians.¹⁰ Why, then, were so many lesbians committed to an issue that seemed not their own, but belonged to gay men? Lesbian feminists said that while there were a number of lesbians who were committed to responding to AIDS, there were too few dealing with "lesbian health" issues (Stone 1988:147).

Jackie Winnow, in a speech delivered at a caregivers conference, outlines some of the lesbian feminist concerns about lesbian (over)involvement in the AIDS epidemic:

I'm in a roomful of lesbian AIDS care-givers wondering why we're not also lesbian health care-givers. . . . In 1988, approximately forty thousand women are living with cancer in the San Francisco/Oakland area, at least four thousand of them are lesbians. The forty thousand don't have the services that one hundred women with AIDS have No one takes care of women or lesbians except women or lesbians, and we have a hard time taking care of ourselves, of finding ourselves worthy and important enough to pay attention to How is it that we are here today as lesbians working on AIDS? (Schwartz, 1993:230-231).

Here, then, is evidence of the importance of understanding lesbians' involvement in AIDS work. However, instead of addressing the problems recreated for women in AIDS work, the lesbian feminist critique seems to simply advocate for

⁹ For Health Canada, diagnosis with AIDS is based on the Canadian Surveillance Definition of AIDS. This is used as the standard inclusion/exclusion criterion to decide whether a case report is qualified to be entered in the AIDS surveillance database. It requires a positive HIV test result and the onset of one or more specifically defined clinical diseases that characterize a weakened immune system (Health Canada: 1997).

¹⁰ According to Health Canada, to June of 1997 the ratio of men to women with cases of AIDS reported was 7 to 1 (1997).

lesbians' departure from addressing the epidemic in favour of working on health and social issues that are ostensibly lesbian-centred. While such separatism may have certain theoretical and practical applications, if lesbians have truly been affected by AIDS, it is not useful to undermine their responses to it. Rather, we should look for ways to address the inequalities or oppression that lesbians face within AIDS work.

This research does not rest on the *a priori* notion that lesbians should limit their involvement in AIDS work. However, there may still be use for the feminist critique of AIDS work as a catalyst which allows us to problematize the social relations in order that we may emerge with a fuller comprehension of lesbian lives *vis à vis* this one complex phenomenon. Through expanding the lesbian feminist critique of AIDS work to encompass the broader social relations surrounding lesbians and AIDS, particularly as they converge where lesbians are involved in responding to the syndrome and its social implications, I show how it is that lesbians become involved on many levels in responding to AIDS. In bearing witness to the ways in which that involvement has been problematic, those concerned shall hopefully come to see directions for the future.

This study may be best described as a critical historical project on AIDS work, where work is understood to be that involvement that lesbians have had - from caregiving to organizing demonstrations - in organized responses to the AIDS crisis. In asking how lesbians became involved in the response to AIDS, in giving accounts of that involvement, and in discussion of the problems, contradictions, and opportunities afforded from that involvement, an analysis is developed here

with a view to explicating at least some key aspects of the relations arising from the juncture of lesbians and AIDS.

Of course lesbians do AIDS work

At first, it may not even seem apparent why there should be any questions surrounding lesbians' involvement in the AIDS epidemic. There is a logic that may lead to the conclusion that lesbians are naturally involved in the response. Some of this logic may be heterosexist. For example, the idea that lesbians have been at risk for HIV infection simply because they are lesbians is even farther from truth than the idea that gay men are at risk because of their sexual identity. In other ways, it seems natural for lesbians to be involved in the response to AIDS because lesbians and gay men supposedly constitute a community. Lesbians are responding to a situation where their 'brothers' are in danger.

The feminist critique problematizes lesbians' involvement with AIDS, rather than taking that involvement for granted. The critique says lesbian AIDS work is a phenomenon that is rooted in the gender relations of our society (Stone, 1988:143). By this argument, lesbian feminists maintain that lesbians are caught up in historical social relations where women have been constituted as the care-givers for all. Because lesbians are women, the work that they do in the response to AIDS is a recreation of larger social relations where women are expected to be not only the caregivers, but volunteers as well.

The feminist critique also interrogates the idea that gay men and lesbians are 'a community.' If many lesbians were in the social position to act in the response to AIDS, the lesbian feminist critique does not see that this was necessarily because lesbians and gay men were in mutually beneficial relationships in their political work, or in their social lives. Even while there may have been political organizing as allies prior to the advent of AIDS, lesbian feminists find that much of this organizing was advantageous for the gay men but less so for the lesbians. As AIDS became a situation requiring organising, the previous efforts of gay men and lesbians together may have created a situation where some lesbians were in a place to act. However, the lesbian feminist argument is that it was once again women's energy that was being used to the advantage of men. Taken one step farther, the idea that this was another instance of patriarchal misuse of women's energy gives rise to the notion that women's energy should be women-centred. Behind this, there is the undercurrent that it is best for women to find their community with other women.

According to the logic of the lesbian feminist critique of AIDS work, such separatism seems to be the alternative for lesbians. However, other alternatives exist that are based on the actual experiences of women who became involved in AIDS work. When I examine the social relations underpinning that response, the importance of lesbian involvement as well as the affect that AIDS has had on lesbians is evident.

The sociology of lesbians' AIDS work

Examining the social relations surrounding AIDS work is intended to take us beyond the limits of the lesbian feminist critique. That criticism of AIDS work does allow us to begin to see some of the social relations involved in lesbians' response to AIDS. The critique, however, does not go so far as to examine the context which allowed some lesbians to be in a place where it seemed logical to join the fight against AIDS. There is an exploration of many of the relations around gender, but not an examination of the many other complexities surrounding AIDS. This thesis examines the particular historical relations - including relations surrounding work, volunteerism, gender, sexuality, the organization of feminist movements, and others - to understand how it is that the response from lesbians unfolded as it did.

While the feminist critique alludes to many of the difficulties, the benefits both for the AIDS movement as well as for lesbians may be more difficult to realise from within that critique. The contradictory nature of the work betrays its complexity. Thus, the analysis of lesbians and AIDS work must be fairly sophisticated in terms of accounting for the various social relations. As with any complex relationship, there are many intricacies to the phenomenon of lesbians doing AIDS work. When I ask, "How is it that lesbians come to do AIDS work?" I am opening up a web of interconnected social relations. In this study, I am disentangling some of these relations in the hopes that enhanced understanding of them will contribute to our ability to act for our common good.

In the analysis which unfolds on the pages that follow, I show the ways lesbians have contributed to the response to AIDS, as well as the ways that being a part of that work has shaped their lives and the course of lesbian politics. With the necessity of an organized response to AIDS, it has been of real importance that lesbians contribute skills, knowledge, and energy. What is more, the impact that AIDS has had on the lives of lesbians, an impact which they described in our discussions, seemed to warrant their involvement.

The feminist critique of lesbians' AIDS work helps us to see contradictions within the work that lesbians are doing. From these contradictions, we are able to learn.¹¹ By then further explicating the relations surrounding AIDS, lesbians will be better able to assess a course for progressive action that addresses the needs of all involved. In thinking our way through the contradictions, by theorizing, the aim is to build alliances where we are able, to work through tensions so that they do not divide us, and finally to work toward a liberatory agenda for lesbians, women, gay men, and people living with AIDS.

¹¹In the biographical video *A Litany for Survival: The Life and Work of Audre Lorde*, Lorde speaks of how there are times when we come to recognize contradictions. She proposes that we embrace these contradictions and learn from them how our world is constructed.

Chapter 2

Methodology And Theoretical Perspectives

The tools for sociological investigation are far from consistent throughout the discipline. In the absence of a multidimensional theory, sociologists construct theories and methodologies which attempt to make sense of some facet of our social being. The information gathering approaches used in contemporary sociology vary with the type of theorising. All of these approaches are based on assumptions about the world around us, and how we may best discover the ordering of that world.

In this chapter, I discuss the tools used in this thesis to understand how it is that lesbians become involved in the responses to AIDS. This thesis draws frequently on feminist thought, and its foundations rest on social constructionism. As an exploratory work, methodologically it utilizes a qualitative approach. Along with describing how these tools were applied in the research process, it is important to comprehend the epistemological issues inherent to the methodological and theoretical approaches of the sociology that is used. Within these fairly well articulated sociological approaches, there remain various interpretations, usages, criticisms, strengths, and weaknesses.

Methodological considerations

There are many areas of sociological inquiry that have similar methods for data collection. An example which is relevant in this thesis is the many parallels between action and feminist research methods. While this thesis cannot be properly identified as action research, I have borrowed from its approach. Yet, it seems that the promise for a rigorous sociology, an academic sociology that could usefully study women, comes strongest from some feminist work.

Over their years of development, action research and feminist methods have built upon and borrowed from each other. While not all action research is feminist in character, nor all feminist research action oriented, both approaches recognize the need to address social problems through investigation. One of the primary characteristics of action research is that it has as its objective the creation of knowledge for action (Barnsley and Ellis, 1987: 2). People involved in the research set out to study a problem or situation in order to do something about it. Generally, the problem or situation is directly relevant to those involved in the research.

There are parallels here between action research and qualitative feminist research. First, the idea that research may begin from concerns that are directly affecting the researcher is important to both approaches. According to feminist methodologists, research need not be "objective" as in the tradition of social scientific study where the researcher must not have a "vested interest" when studying issues that affect her in a personal way (Smith, 1991: 112). Feminist researchers have found that in order to produce sound sociological findings the

methodology must be systematic, but the researcher may investigate social issues and phenomena which are immediately relevant to her life. Although it remains true that not all research that may be labeled feminist investigates the most personal issues, feminist social research has succeeded in drawing attention to the dichotomy between the personal and political in research, and in rejecting the assertion that the personal does not have a place in research. Feminist action research tends to look into these areas of personal concern.

Both feminist and action research rely on methods of data collection which are sometimes seen as "subjective." For example, in the methodology proposed by Smith for a sociology for women, the researcher must rely on what people tell her. For Barnsley and Ellis (1987), the "subjectivity" of the data is a useful thing because it provides depth to the topic. For Smith, a sociological method must begin with the experiences of those researched, with subjectivity. Further, it must maintain that subjectivity beyond the particular ways the interviews are carried out:

The development of a feminist method in sociology has to go beyond our interviewing practices and our research relationships to explore methods of thinking that will organize our inquiry and write our sociological texts so as to preserve the presence of actual subjects while exploring and explicating the relations in which our everyday worlds are embedded (Smith, 1991: 111).

While action research, among other sub-fields of sociology, has been developing particular methods for inquiry which are relevant to this thesis, the proposals that Smith is making are for an entire systematic feminist sociology.

Smith advocates working from the social position, or "standpoint," of research subjects to explicate the social relations that organize their reality.

Working from a particular social position (or the various social positions of lesbians

doing AIDS work) to produce analyses will tend to lead to a view of the world that is unlike that which we would have if we had started the inquiry from a different social position.¹ One need not have participated in this work to research it; one needs only to undertake the process of understanding social relations from the *standpoint* of lesbians involved in the work, or from their social position, to create a study that contributes to our understanding of the social relations surrounding lesbians and AIDS work.

In deciding where to find information and knowledge about how it is that lesbians come to do AIDS work, it is, then, immediately clear that those with first-hand experience, i.e. lesbians who have participated in the response to AIDS, would be the most useful informants. Nevertheless, even with this group of the most logical informants, a number of considerations must be made.

Two such considerations for the research process hinge on the fact that I, too, was involved in the "AIDS community," or, perhaps more accurately, in some of the organizational responses to AIDS in Nova Scotia during and previous to the time of this research.² One consideration has to do with my knowledge of lesbians and AIDS work in this province, including knowledge of many of the women doing

¹Smith discusses the social position of women in particular, whom she says are outside the relations of ruling. Research from the standpoints of women, then, can illuminate those relations in a manner not otherwise possible (Smith, 1987: 78).

²If there is an AIDS community in Nova Scotia, it is divided in many ways. Involvement in organizations does not necessarily mean that one is up to date on all that is happening. For example, involvement with a service-providing organization may not allow opportunity to understand what is happening with HIV+ gay men at a grass roots level, and those involved at that level may not know much about what is going on to address AIDS impact on specific populations such as Native communities or Black Nova Scotians.

this work. The other, which is linked to the first, is that I had a familiarity with many of the issues surrounding lesbians and AIDS, including those linked to the work. Neither in the research nor in the analysis do I claim to be an outsider looking into the world of AIDS work. Instead, I use my own knowledge of AIDS work to contribute to the research just as the information from the other women interviewed is used. In their 1989 research guide, *Experience, Research, Social Change*, Kirby and McKenna set out a methodology for researchers who are as concerned about a phenomenon as are the other subjects of research. Kirby and McKenna maintain that "we must include our own experience and understanding as part of doing research" (1989: 7). In this way my own involvement with AIDS organizations contributes to the research project.

At the same time, however, my knowledge of lesbians and AIDS work may be seen as presenting something of a methodological dilemma to the research based on the fact that I knew many of the interview participants prior to the actual interviews. This situation may lead some to question the accuracy of the information later gathered from these same people. Would friends and acquaintances give their honest ideas about the work that they do? Would they want to keep their impressions and experiences from another person involved in the same field as themselves? The effects of such familiarity are discussed below in terms of the impact on the data gathered.

Let us first be quite sure that my familiarity with the issues surrounding AIDS in Nova Scotia will not present a problem to the research process. As "methodology from the margins," in Kirby and McKenna's terms, it would be

expected that my experiences would be part of the data. But, with my knowledge of AIDS issues in Nova Scotia before beginning the research, the question becomes: was there any adverse effect on data-collection or on the conclusions that were drawn from the data?

My closeness to the issues gave me insight into what was of concern to lesbians and others involved in the responses to AIDS such that, for example, my own questions about the involvement of lesbians were echoed by others. In this way, my comprehension of AIDS issues does not present a problem to the data collection, but helps to frame the type of data that will be gathered. Rather than searching for questions, relevant ones were already on my mind. My own understanding of the issues should not, however, provide the basis for the explication of the questions of interest in the present research. Instead, it should assist in shaping the direction of the inquiry. In this way, my experience and insights do not form the answers but the questions. In the logic of feminist thought, what was known to me before beginning the research is a point of entry rather than an end point.

In feminist and action research where there has been a movement toward doing research that contributes knowledge or information to a given situation or struggle (Kirby and McKenna, 1989: 54), often the researcher is someone who is a part of that phenomenon, someone with a desire for useful information that will help to resolve some problem or add understanding to a given situation. In such "research from the margins," the researcher includes meta-analysis in order to

account for the impact that prior understanding, or what Kirby and McKenna refer to as "conceptual baggage," has on the research process and its outcomes.

As a way of examining the impact of the researcher's conceptual baggage on the research, Kirby and McKenna advocate that the researcher keep notes about thoughts and ideas *vis à vis* the data. "Writing your conceptual baggage allows you to identify, at a later point in the research, whether any pre-established goals, assumptions, or responsibilities may be overly influencing how your research is developing" (1989: 51). The researcher should identify conceptual baggage from the beginning of the research process and revisit it from time to time.

Through the course of the research for this thesis, my own ideas were challenged and changed as I re-visited my own conceptual baggage. The course of the research was also altered. When I began, it was largely because I was starting to question whether lesbians should be involved in AIDS organizing, considering the many health and other issues facing lesbians and women as a group. Through the course of the research, my thoughts on the subject became more sophisticated, as I realized that lesbians' involvement in responding to AIDS was and is much more complex than I had originally understood. The parameters of inquiry broadened to allow for an understanding of the complexity of lesbians responses to AIDS to develop.

Definitions

There are some common references which I will make time and again in the text which require some elaboration, explanation or definition. Perhaps the most

elusive of these is "lesbian". Dunne points out that defining "lesbian" has been highly problematic for lesbian scholars (1997: 25). For the purpose of this research, a lesbian is any woman who says that she is. Because of the sensitivity of sexual identity, it was not possible for the researcher to apply this category without the approval of the women to whom it was being applied. The definition stays at this simplified level since the enterprise of developing working definitions of lesbian is more crucial when the research seeks to identify lesbians throughout past history.

The idea of "AIDS work" encompasses many activities that people have performed in responding to AIDS. The types of work may be anything from caregiving to administration, paid or unpaid, the details of which might include assisting a person living with AIDS eat lunch or typing a letter to a government agency. For the purpose of this research, participation in AIDS activism was also considered AIDS work. The interviews included in the analysis were from six subjects who completed their "AIDS work" through some sort of tie with an AIDS organization or group. There are other women who work in the response to AIDS by caring for a friend or offering support to a family member. While I would argue that this is valuable work and part of a larger response to AIDS, the relations of interest in this study were limited to those involved in organising with other people to respond to AIDS, and these relations were taken to be found in groups and organisations.

Groups of people who share a common history and a common identity are labeled a "community." This is often pluralized to reflect the multiple allegiances of

a community's constitutive members. Thus, "gay communities" could mean those men who identify themselves as gay and may also identify themselves as Native, middle class, transgendered, or as a member of a variety of smaller groupings. The concepts of community and identity are important in this thesis, especially in terms of the limits of these notions. In particular, the lesbian community is revealed as constructed by individuals with multiple and often conflicting identities. The analytical construct of community was used to further the political struggles of marginalised groups during the 1980's by focusing on the unity of the group. By the 1990s theorists realized the limits of this construct, as the rhetoric of "community" participated in re-articulating ideologies of difference (Patton, 1990: 8). For a woman who is not only lesbian but also Native, even the idea of "lesbian communities" could not encompass her lived experience as a woman with the multiple and sometimes conflicting identities of Native/lesbian/woman. The idea of community is, however, used in this thesis as it continues to have valid political and social meaning. At the same time, this research illuminates the problematic construction of notions of community as they relate to the lives of women who do AIDS work and have and multiple identities and allegiances.

One type of organization referred to is the "ASO," which is an acronym for "AIDS service organisation". These organisations are focused on the provision of services to people living with HIV. In Nova Scotia, ASOs are also engaged in public education around HIV and AIDS, seeing this as part of their mandate. The services available from ASOs follow a range of possibilities, depending on the need, the location of the agency, and the level of funding the organisation receives,

but tend to include at least some form of counseling and emergency funds for persons with HIV or AIDS. AIDS service organisations, state agencies which fund and regulate AIDS organizations and initiatives, and the medical professions have created what Cindy Patton calls the "AIDS service industry" (1990).

There are many difficult issues to be addressed when naming a group of people. As Aptheker observes, naming is important because it is connected to identity (1989: 20). In this research, one of the groups I have to name are people who have HIV infection or AIDS. Although the research is not exactly about people with AIDS, the research may have an impact on the lives of people with AIDS. I want that impact to be positive, always remembering that when discussing HIV/AIDS, those most affected must be understood to be integral to that discussion. In deciding on the name to use from the lexicon of AIDS discourse, then, it is important to choose a name that people with AIDS themselves find to be accurate and useful.

Since the early 1980s, people with AIDS have been saying that the terminology used to label those most affected by AIDS is important. In an article in the journal *October*, Max Navarre articulates the growing dissatisfaction with popular characterisations of a person with AIDS as "an AIDS victim, an AIDS sufferer, an AIDS case" (1987: 143). Navarre contests these terms on the grounds that they present a hopeless image. "I am a person with a condition," Navarre tells the reader, "I am not the condition itself." In *Vamps, Tramps, and Victims*, Gorna points out in her discussion of AIDS discourse that disability activists have also resisted the tendency to be identified by their disability (1996: 136).

In the same issue of *October* Navarre writes in, Jan Zita Grover writes that by 1987 people with AIDS "took the naming of their condition one step further, announcing that they are 'people *living* with AIDS'" (1987: 26). The emphasis on "living" was an attempt by people living with AIDS to undermine constructions, especially in the media, of people with AIDS as victims of the syndrome helplessly waiting on death's door. Grover explains that there is importance in people living with AIDS naming themselves, not only because this contests media, public, and government constructions of people with AIDS, but also because there is strength gained through self-acclamation.

Robin Gorna points out that in the attempt to empower people with AIDS, there may have been a shift too far which had the effect of negating the difficulties suffered by those who are HIV positive. In fact, when I attended the 1995 Atlantic AIDS Network Conference held in Newfoundland, some of the people with AIDS rejected the idea that they were living with AIDS. Instead, the group of mostly gay men said that naming them in this way allowed government funders and ASOs to neglect the urgency of the situation and discontinue programs aimed at gay men who were already HIV positive.

State funders of AIDS programs, ASOs, and other players in the AIDS service industry, have played a part in naming during this epidemic. About 1993 in Canada, a new acronym, "PHA," began to be used within groups such as the Canadian AIDS Society to refer to people living with HIV/AIDS. Kinsman suggests of this new acronym that "many AIDS activists (for instance, people in AIDS ACTION NOW!) and many people involved in the self-organization of PLWA/HIVs

did not use it" (Kinsman, personal communication, 1996). Rather than people living with AIDS naming themselves, "PHA" arises from institutional sources.

Within the AIDS industry and community, acronyms abound, although using an acronym to name individuals is not a particularly humanizing proposition (Gorna, 1996: 136). Of the acronyms available, "PLWHIV/AIDS" is quite cumbersome, and neither "PWA" (person with AIDS) or "PLWA" (person living with AIDS) seem to refer to people living with an HIV infection but without an actual AIDS diagnosis. "PHA" is rooted more in the AIDS industry than within PLWA organizing. Given the choices, I prefer to refer to people living with AIDS just as I have done here, written in long form.

Finding respondents

Although right from the first conceptualization of this thesis I certainly wanted to interview lesbians involved in AIDS work, I recognized that there were some difficulties with finding these respondents. Random sampling with a population such as lesbians, where marginality and secrecy complicate matters, was not a workable technique (Dunne, 1997: 27). Instead, snowball sampling where leads were gained from other lesbians was used. Individuals who knew of the research project or discussed it with me often came up with names of other people with whom I should talk. Most of the leads on interviews were gained through the research process itself, through other people who were interested in the research, or through my own knowledge of people to approach.

The question of sexuality made it difficult to compile any list of interview participants before beginning the research. When the project began, there were some women involved in AIDS work whose sexuality was unknown to me. Since interviewing them was contingent on their identification as lesbian, I chose to wait until such time as I ascertained whether they were lesbian before approaching some women for this research. One interview participant was added to the list after the interview process had already begun because she approached me with interest about the research and said that she would like to be interviewed. Although I had known her previously, her sexual identification was a mystery to me and she may have been skipped over for interviewing if I had chosen to work from a pre-defined list.

The individual women who were interviewed are not intended to be "representative" of all lesbians who participate in AIDS work. Rather they provide us with knowledge about the subject. Kirby and McKenna (1989:97) caution social researchers that in looking for sources of information (in this case interview participants) the researcher must remember that the search is, in fact, for *information* rather than representatives of a specific sample population. In sampling information, whatever information gathered will be of use to understanding the social world more clearly. Further, since there were several respondents, the body of information derived from all participants will yield more information than if only one or two people had taken part. Dunne emphasizes that with one person there may be individual anomalies, a second person may contradict the first, but as the

sample grows, the stories taken together make up a strong body of evidence (Dunne, 1997: 36).

With the interviews for this research, it was not possible to estimate how large the population of lesbians who had been involved in AIDS work in Nova Scotia was. Yet, by seeking out information, it was not necessary to calculate a mathematical sample size for this population. Instead, the interviews proceeded until as many as possible were completed. In the analysis, factors of class and race must be considered as the information may or may not exist for making statements about lesbians of a certain class or race who do AIDS work. From the information that has been collected, the analysis will seek to draw out the connections that are possible. Yet, there may be some information missing, information which would indicate areas for future study.

The interview

Feminist methodology teaches that, in an interview situation, there need not be the traditional structure with a one-way flow of information. In data-collection which is structured in a traditional manner, the researcher may be seen to be usurping the knowledge of the interviewed for the purposes of research. Instead, feminist research methodology proposes that the researcher make attempts to level the field on which the information exchange takes place. Kirby and McKenna (1989: 66-74) suggest principles of interactive interviews, many of which point to the notion that there is a power relationship involved in the interview process that the feminist researcher must work to balance. Kirby and McKenna suggest, for example, that

for a quality interview to take place, "there must exist a sense of equality between the person gathering the information and the person whose knowledge is sought" (p.67).

This type of non-hierarchical interview technique is not without its own set of methodological issues. In terms of social power, there are many instances where there remains an imbalance that is only hidden when the researcher claims to be breaking down relations of power. In fact, the researcher often maintains the position of greater power, given that she has the status of one who knows how to do the research. Also, she maintains power because after the research is completed with the interview subjects, the information is in her hands to use to create meaning.

In the case of the present research, the first concern of maintaining the position of power as the researcher poses less difficulty than the second. As a student doing research, there is less status attributed to the researcher than there would be for a *bona fide* "researcher." Further, in this instance the researcher and the researched have a prior relationship of working together in the response to AIDS as colleagues. While it remains true that the researcher in this case maintains the power to create meaning from the knowledge of interview participants, the meaning is grounded in women's experiences. The test for the conclusions drawn in this research is whether or not they actually help us to understand the situations of lesbians involved with AIDS work.

Another fact contributed to the equity of the interview situations. That is, before any interviews took place, I knew all of the people who would eventually

become informants. While this addresses power imbalances, it also creates some other issues in the research process. The first issue is the effect that such familiarity has on the interview situation. For example, some informants may feel more comfortable having open discussions with a known interviewer while others may be uncomfortable talking about sensitive issues with someone who is perceived as being involved with those issues.

The other issue is about the personal interactions which preceded the interviews. I had already exchanged information about lesbians and AIDS work with the women that later became interview participants. What impact would this knowledge of the researcher's interests have on the respondents' information?

Kirby and McKenna question how concerned methodologists should be that the researcher and participants are known to one another. "Interviewing is not about meeting strangers, sharing information and then parting forever" (1989: 69). Where researchers are trying to understand a phenomenon which is of interest not only to the subjects but to the researcher as well, exchanges of information help the participants to reflect on the issue at hand. When the research is meant to have an impact on the actions of all those concerned, Kirby and McKenna would rather see as much interchange and communication as possible. Any information which can be exchanged may be useful to the research and to positive social change.

Barnsley and Ellis, however, caution against discussing ongoing research in any substantive way until the research process is completed and the researcher has had an opportunity to review all of the data gathered (1987: 24). This

procedure is meant to ensure that the researcher avoids making premature judgments about outcomes.

In this case there remained the fact that conversations took place before I began my research (or had any notion of interviewing specific individuals) thus building the expectation with acquaintances involved in working with AIDS that such conversations would continue. There was also the fact that in having acquaintance with many of the women who would later become interview participants there was a relationship established that fostered discussion of such important topics as our own and others' involvement in the AIDS movement. The idea that there should be no public discussion of the research themes teamed with the expectation that I would (and perhaps should) discuss the phenomenon of lesbians involved in the response to AIDS contributed to what Barnsley and Ellis might see as a methodological dilemma: is there to be no conversation of my research with lesbians involved in responding to AIDS or does conversation continue and somehow alter the information obtainable in the interviews?

This supposed dilemma is not such a problem within a methodological framework such as the one which Kerby and McKenna propose . This methodology has similar premises to the one which Smith outlines in *The Everyday World as Problematic: A Feminist Sociology* (1987). Smith advocates a type of research whereby, while possessing specialized skills for examining social relations, "sociologists and those who want to understand the social matrices of their experiences" engage in a work of cooperation (p.154). According to Smith,

there is value in exploring the knowledge and experiences of each. This exploration may be accomplished together:

For each of us is an expert practitioner in our everyday world, knowledgeable in the most intimate ways of how it is put together and of its routine daily accomplishment. It is the individual's working knowledge of her everyday world that provides the beginning of inquiry. The end product is not, of course, intended to be private. The sociologist is not an astrologer giving private consultations. Rather the approach attempted here offers something comparable to consciousness-raising (1987:154).

This conceptualisation works particularly well when both the sociologist and the subjects of the study share a common attachment to the issue at hand, as was the case in the present research. The indication is that since we are all concerned with the social relations which provide the context for our daily experiences *vis à vis* AIDS, we should be working together towards a better understanding of those relations. Discussions of the phenomenon, whether before, during, or after the research process, further the overarching projects of explicating the social relations and working for progressive social change.

Together, we are constantly refining our understandings of the world around us. Rather than remaining concerned only with our immediate and personal lives, a problem which has limited consciousness-raising, the sociologist's task is to construct a representation of those social relations creating the material reality. So, while I wanted to avoid drawing and disclosing conclusions prematurely in discussions between the researcher and the informants, I was consistently checking the theoretical formulations against people's experiences.

Aptheker (1989), in her discussion of women and work, encourages researchers to keep in mind what the purpose of the research is when designing a

methodology. Aptheker points out that with many research projects, where the goal is to create some type of grand theory, in the end the theoretical framework often has no significance to women's lives. What she advocates when researching women's lives is an approach not dissimilar to that of Smith, whereby the researcher begins from the experiences of women and forms patterns from that experience. The agenda of this type of research is clear:

The purpose [is] to interpret, to form patterns, to make intelligible the multiple, highly complex, and ever-changing ensemble of social relations in which women are lodged (Aptheker, 1989: 12).

The idea behind this type of research is not so much to generalize or to manufacture grand theoretical frameworks as it is to make visible the dialectics of social relations where women participate in the response to AIDS while that work alters their lives. This may then be used to inform our knowledge building, but not to the end of totalizing theory. Since I began this thesis with impetus from the lesbian feminist critique of AIDS work, that theory will be tested against the knowledge gained from the lives of the women in this research.

Given this as the research project, wherever the experiences of women involved in the response to AIDS may be found they are valuable and relevant in understanding the "ensemble of social relations in which women are lodged" (Aptheker, 1989: 12). Informal discussions are a part of the process of discovering the complex relations within which lesbians are embedded, although these exchanges may not appear in this research thesis in as formal a manner as the interviews do.

In the end, my choice was to follow Smith's methodological suggestions for partnership with the subjects of investigation, and to engage in limited conversations - beyond the interview scenario - with women (and men) who wanted to talk about the research. After some time, I came to appreciate this decision even more, as I realised that the main project of this thesis was to describe the social relations surrounding lesbians and AIDS and that each lesbian who told me about her experiences working in the response to AIDS would be assisting in constructing an ethnology of AIDS work in Nova Scotia. Most of the time, these people were never interviewed. However, in four instances, individuals with whom I had had prior conversation went on to be interviewed for this research project.

In my conversations, every measure was taken to maintain the confidentiality of other informants so that they would not be identifiable to those with whom I discussed my research. In addition, no conclusions were drawn or put forward by myself during conversations.

A part of the impetus behind this study was, in fact, to encourage discussion among lesbians and others about working to respond to AIDS. For this reason, I wanted to encourage rather than stifle discussion of the topic. Instead of withdrawing from discussion, care was taken to encourage others to present their ideas on the phenomenon of lesbians and AIDS work. For those with whom I had carried on prior conversations about lesbians and AIDS work, I suspect that this may mean that their responses to interview questions will be more reflective than if I had never engaged in conversation with them.

In another attempt to encourage reflective responses to the probing during the interviews, I gave each person who agreed to be interviewed a copy of a list of sixteen questions. I told the interviewee that the questions were meant to help her focus on the areas that the interview would cover. Within two weeks of giving the list of questions to an interview participant, I interviewed her. These interviews were recorded and later I transcribed them.

In the case of this research, I anticipated that a potential area of sensitivity was going to be dealing with any feelings that could be construed as negative about lesbians doing AIDS work. There could be fear for those still working in the response to AIDS that to have doubts and questions about the work lesbians have done was tantamount to debasing that work or questioning its utility.

A second area of sensitivity had to do with the issue of relations between colleagues. For the purposes of the research it was important to talk about where there had been conflict or difficulties with others involved in the response to AIDS. However, I anticipated that the women I talked to would have some reluctance to discuss situations where there must be an ongoing working relationship, especially if the relationship is one of supervisor to staff.

To address these concerns, in the interview I stressed the condition of confidentiality. By assuring the research participants that they would not be identifiable, it was hoped that they would feel more at ease to discuss in depth the particulars of their own experience.

Kirby and McKenna point out that potential research participants each have the choice to decline participation in the research process (1989: 70). If there are

any concerns over sensitive topics, or any other hesitations, the participants may choose not to participate at all. Since this option is available, those who did participate were likely comfortable doing so.

When I first contacted those whom I wanted to participate, I informed them that the interview itself would take about one hour. Using an *aide memoir* (Table 2.1), the interviews covered themes relevant to the research. Dunne also used this research technique in her study of lesbians and work, finding it to be useful for covering the necessary topics while not being too leading (1997: 29).

Analysis

Just as there are problems with objectifying the informants in "data collection," the analysis may also be constructed in such a way as to objectify those with whom the study is concerned. Where there is no responsibility to create knowledge which will contribute directly to the lives of those who are being studied, or even to represent the world as they know it, there is a great danger of objectifying the "subjects" of research.

In the analysis and discussions of research findings, feminist research principles guide me to work toward a representation or explication which approximates what the informants know to be their reality (Kirby and McKenna, 1989: 96). Further, in the present thesis the feminist notion that research is not simply *about* lesbians and AIDS work, but is also *for* lesbians who do AIDS work, directs the analysis of information toward building knowledge that is useful for lesbians.

The methodological approaches of Barnsley and Ellis (1987), Kirby and McKenna (1989), and Smith (1991) all suggest that creating knowledge, or researching for the researched, should be the aim of feminist research. The knowledge created is rooted in the reality of those with whom the research is concerned. It also casts the researched as subjects: lesbians who do AIDS work are not merely the objects which I am studying; they are recognized as knowledgeable about their own lives and experiences.

Subjectivity, then, plays a tremendous role in feminist methodology. Subjectivity is understood as consequential to formulating the type of knowledge required to inform those most concerned by the research questions: the lesbians who are involved in AIDS work. At the same time, there is a rejection of objective knowledge, both the utilisation of such knowledge in the research process (objective data collection) and the creation of such knowledge as the project of research (objective analysis).

While my own insights and questions help to shape this work, I hope that they will be "the beginning and not the end of the discussion" (Valverde, 1984:25). While my own interest in lesbian AIDS work may have served to demarcate the boundaries of inquiry for this particular thesis, the knowledge and information shared by participants, as well as that which was gained through a thorough reading of relevant materials, must become the focus of the present paper. I have endeavored to allow the knowledge of the informants to speak to us of what is true for them, so that the research I am left with goes beyond anything that I would have been able to conceive of on my own. This is not only a cumulative process, adding

new information to that which I may have been able to understand without the benefits of informed interview participants, it is also a transformative process, as many of the original conceptualisations are challenged and give way to new understanding of the social context of lesbians doing AIDS work.

Experience, my own and others', is given a voice throughout, for how people recount their experience is important³. The process of making sense of experience, or theory building, must also be given the space to come to fruition. Neither experience nor theory should overwhelm the other, for both are necessary for understanding.

Carol Anne Douglas encourages the project of theory building as one that will radicalise the participants (1990). Douglas works within the field of feminist theory, which relies on the experiences of individuals, usually researched in a qualitative manner, to generalise about the world. As with other epistemological underpinnings in this thesis, this aspect is not simply descriptive but may also be transformative. The idea is not simply to relate the way things are, but also to come to an understanding of the way things could be.

Theorizing is a way of stretching the imagination, of trying to make generalizations about our individual experiences, trying to visualize how the world can be changed so that oppressive structures are eliminated. . . .The process of imagining that the world could be different and trying to imagine how to get there destroys apathy and passivity(Douglas, 1990: 20).

³The idea of experience is highlighted in this way so that we might remember that the concept is actually descriptive of one's recounting of what was perceived as experiences. "What we call 'experience' is the end result of a complex process of interpretation" (Valverde, 1994: 23).

The research process, understood in these feminist conceptualizations, can lead to both personal change through radicalisation, as well as to systemic change. The latter comes as theory informs activists' work, or through socially progressive praxis.

The analysis and explication of social relations surrounding AIDS in this thesis is constructed using these principles within the "personal is political" framework. The information concerning what I have called the political realm of social relations comes largely from the literature. The presentation of this material is intended to describe the social context within which the two phenomena with which I am concerned, lesbians and AIDS, are articulated.

For the personal realm of social relations, the interviews with lesbians involved in AIDS work will serve to highlight many of the issues. In the analysis of the interviews, there are a number of themes which will be covered that shed light on the everyday work and lives of lesbians. The topics have been developed largely through reviewing the literature. Once the interviews were completed, an initial assessment of the important issues covered helped to fill out the themes which would be covered in the analysis.

Other qualitative sociological researchers, such as Dunne, choose to analyse the data with the help of computer programs which find and organize themes (1997: 36). Dunne's sample however, was ten times the size of the sample in this thesis. Since there are only six interviews, I chose to organize themes without digital assistance from qualitative computer analysis. There remains similarity between this thesis and Dunne's in the analysis. We share the use of the

accounts of women, of relevant literature, and of personal experience to formulate new understandings of social phenomena. While the women will recognize their own accounts (although I have changed the names of the women), the analysis should yield new explications of that information (Dunne, 1997: 37).

Theoretical perspectives

The theoretical position upon which this thesis sets forth is known as social constructionism. In this sociological theory, individuals participate through complex social interaction in the formation of the social realities in which they live (Stein, 1992: 5). Social institutions are understood to be the accomplishments of social relations rather than preceding human agency. By this theory, social activists find hope for changing injustice and oppression wherever it is found.

Through complex interactions negotiated on an everyday level, social relations come to demarcate the bounds of human action. Humans are at once re-creating their own social realities, and being limited by those realities. These otherwise invisible social relations may be described through inquiry into the various terrains of struggle where they intersect and through tracing their organization. There is, then, an analytical nod to critical structural theory. It assists us in abstracting the patterns of social relations from the experiences and actions of people who must live in the micro-existence of the everyday.

With some acknowledgment of the part that critical structural sociological theory plays in this thesis, the larger explicative weight is placed on constructionist

theory. The agency of actors in constructing the world, whether willful or not, is postulated to be of greater import than the structure of social or material reality. Indeed, in putting forward that human agents are involved in complex social relationships which construct social reality, constructionists argue that these relations arise from human actions. They argue that there is a dialectic between human action and social relations.

With this theoretical grounding, it follows that this thesis would take a historical look at the social relations of concern. As Malcolm Waters states in his survey of sociological thought, *Modern Sociological Theory*, history shares a similar methodology and pattern of explanation to constructionist sociology (1994: 7). This, however, is a critical historical project in that I am not simply recounting the history of AIDS. Rather, I am concerned with a particular version of this history where the positions, relationships, and actions of lesbians are visible. I want to explicate the social relations of lesbian AIDS work.

Historical sociology, when used in this critical manner, may allow us to see the experiences of people who otherwise appear marginal to the production of history. Those experiences show social relations which would not be visible if it were not for our inquiry into lesbians and AIDS work. The ways in which lesbians were involved in responding to AIDS and the ways they were affected by AIDS are not readily apparent (or are distorted) in most recountings of the history of AIDS since those versions of history are not constructed from the standpoint of lesbians. This, in itself, should not be surprising since in many ways, lesbians were not the ones most directly affected in Canada or the world.

However, if I were to argue that gay men were the most severely affected by AIDS in Canada, an argument could be made that the history of AIDS should be articulated from gay men's perspective. Indeed, Douglas Crimp said in 1987 that "Anything said or done about AIDS that does not give precedence to the knowledge, the needs, and the demands of people living with AIDS must be condemned" (p.236). At the time, Crimp was arguing that the insights and experiences of people most affected by the syndrome, those living with it, should not continue to be ignored as they had been by all manner of policy-makers. While I could hardly disagree with such sentiment, nor would I want to work against such a progressive ideal, the effect of this argument should not be to marginalise other oppressed groups, such as lesbians. In fact, by explicating the social relations of AIDS from gay men's standpoint, other important things about the relations of ruling are revealed.⁴ However, if I want to develop a sophisticated historical view of AIDS as it intersected with the lives of lesbians, it is a lesbian's standpoint that I must begin with.

Jeffrey Weeks (1985) says that the present is also part of history, the "historical present," and as such historical social relations participate in forming the current context. The critical historical perspective brings lesbians' experiences to the fore and also helps us to account for the current AIDS phenomena.

⁴Smith asserts that when we begin from the standpoint of any group that is marginalised from the relations of ruling, different aspects of the ruling apparatus come into view. But she argues that "the standpoint of women is distinctive and has distinctive applications for the practice of sociology as a systematically developed consciousness of society" (1987: 107).

The idea that explications could be created that are useful and meaningful for both lesbians involved in responding to AIDS and those with HIV or AIDS is crucial to creating an understanding of AIDS that may contribute to progressive social action and policy, as well as personal decisions *vis à vis* AIDS. The discussion that has evolved around lesbians' participation in the response to AIDS often sets them apart from gay men, questioning the relationships of each to the other and to the AIDS epidemic. In this way, lesbians and HIV positive gay men may seem to be coming to AIDS from very different places. There is a delicate balance to achieve in writing the explication of the social relations surrounding AIDS where the weight of women's history of oppression intersects with a pressing crisis where gay men and others are dying.

This particular contradiction is only one among many that I discovered. Power relations abound in the analysis of the historical past and present of lesbian AIDS work. Conflicts, struggles, and contradictory relationships arise with lesbians and with AIDS as in the greater society. Illuminating these relationships may be a step toward progressive resolutions of contradictions. E.M. Ettore says, "Power is possible only for and through material being" (1980: 159). Such beings are also constantly struggling to redefine relations of power, and remake social reality.

Such struggle is what makes reviewing history such a hopeful pursuit. As Kinsman (1996: 25) argues, the fact that history is a constantly evolving process is the activist's best hope for enacting progressive social change. History does not stand still. Previous social power relations are undermined and transformed. Understanding the past, how social relations have been constructed and

challenged, and how new forms of social relations construct different types of regulation, along with understanding that history is in a constant state of becoming, lesbians and others involved may act in a more informed manner.

Barnsley and Ellis point to the idea that while the research can only truly claim to represent the experiences of those interviewed, the interviews allow the researchers a place to begin analysis of a phenomenon that is grounded in women's experiences and their understanding of those experiences:

Through interviewing, the research arrives at descriptions of women's situations and problems as they understand them – this is the basis on which the research analysis and understanding is grounded. (1987: 5)

With this approach that is grounded in women's actual lives, the researcher may go on to develop analysis and further understanding of a situation, or "theorise."

There is, then, no need to claim to be representing a specific population, but only to be developing a better understanding of a situation through analysis which arises from the people who were spoken to.

One of the theoretical concepts that proved its importance through the course of the research is identity politics. As I will show in the next chapter, the lesbian identity first arose through medical, specifically psychological, discourse. Shane Phelan, in developing a postmodern critique of lesbian feminism, writes that the second phase of the articulation of this identity occurred through the development of urban subcultures (1989: 136). Lesbian feminism was part of theoretically accounting for lesbianism and also participated in defining the lesbian. Phelan points to a fundamental problem with lesbian feminism from the time of the Radicalesbians onward. That is, that lesbian feminism did not deal with the

problem of difference. Phelan says that any "sense of the plurality of lesbian lives was lost in the construction of 'the' lesbian" (1989: 38).

According to Phelan, the first great challenge to the totalizing of lesbian feminism came from lesbian sadomasochists. Those lesbians who did not approve of sadomasochism could not incorporate those women who practiced it into lesbian feminism. This difference was one among many that would come to challenge lesbian feminism, all coming from a place in the margins of lesbian identity or feminism.

There has been a demand that lesbian feminism begin its analysis from the lives of women (Phelan, 1989: 157). This has arisen from the sense that lesbian feminism is another assimilationist strategy that attempts to undermine the experiences of women of color, the poor, sadomasochists and others who live on the margins. The challenge of race has been a particularly compelling argument highlighting the problems still pervasive within lesbian feminism. The (white) lesbian feminists have ignored race in favour of a perceived "common bond" among all lesbian women (Phelan, 1989: 161).

Phelan identifies the route of this inability to incorporate difference as the lesbian feminist process of totalization, whereby every aspect of life must be measured by what she calls one authentic yardstick (1989: 138). Phelan cautions that those on the margins are no more likely to have access to the complete truth, although she agrees with Smith (1987) that analysis from the standpoint of those on the margins will allow the theorist to recognize relations that she otherwise could not (Phelan, 1989: 158).

Some, such as Lisa Kahaleoie Chang Hall, reserve hope for identity politics. Hall asserts that the strength of identity politics, such as lesbian feminism, is in their potential to connect people of different gender, races, or classes (1993: 220). She acknowledges that, so far, it has not worked out like this. The result has been that people are asked to choose for the sake of unambiguous identity "between the intersections of inseparable realities" (p.221). Hall illustrates with the example of race versus gender where women are asked, "Which side are you on - race or gender?"

This theoretical problem in identity politics is amply confirmed in this thesis. Lesbian feminism as it is articulated in the critique of AIDS work is unable to recognize the many different social relations intersecting to bring complexity to lesbians' lives. By exploring lesbians lives and work in the AIDS epidemic I show the ways in which lesbian feminism was able to neglect the diverse and contradictory realities of lesbians' lives.

While those involved in responses to AIDS struggle to understand the social implications of the syndrome, Patton reminds us that it is a useful struggle to participate in. She says that those in this struggle must "render as data the individual social experiences out of which broader scientific and pedagogical strategies may be created" (1990: 2). As individuals tell their stories, researchers must take responsibility for using the information in such a way as to create knowledge and representations which are useful for people involved in the epidemic. In this process, representations of AIDS will be recreated, making them more meaningful to the lives of those on the front lines of the AIDS battle.

Feminist work and theoretical perspectives function on a number of levels in this thesis. One of these levels is the very impetus for inquiry into the idea of lesbians' involvement in AIDS work. The central critique of lesbian involvement in AIDS work is, in fact, a lesbian feminist one. It is this critique which acts as a springboard to this research project.

On another level, it is feminist contributions to our understanding of women and work which help to underpin many of the arguments made in this research. The feminist study of the work that women do, from defining the public and private realms where work takes place to investigating the actual kinds of work that women tend to do, lends some theoretical grounding to exploring AIDS work and women. Such work has been the project of feminist sociologists such as Sylvia Gold (1994).

More recent contributions to and critiques of feminist thought from women of colour are important to consider in that they expand the applicability of this research. Theorists such as Bettina Aptheker have encouraged feminist theorists to be sure to consider the experiences of women of colour when studying a phenomenon, rather than maintaining the standard "whitened center in conception and design" of a research project (1989: 15). This turned out to be crucial in analysing the experiences of Native lesbians involved in responding to AIDS. It will be obvious to some, but it must be stated that issues of class must also be investigated.

Finally, there is the contribution that this thesis makes to knowledge building, or theory. By using the types of sociological tools that I have described, this research also builds upon those theories and methodologies. This research

process leads to useful information for lesbians and everyone involved in the response to AIDS, and also to testing the applications of feminist theory and methodology.

Smith offers, "A sociology is a systematically developed knowledge of society and social relations" (1989: 105). I am using the standpoint of lesbians involved in AIDS work to understand the social, to "make it visible in sociological texts, in ways that explicate the problematic, the actuality of which is immanent in the everyday world" (106). The project of this thesis is, through the theoretical basis and methodologies that I have described, to generate a sociological text which makes visible the social relations surrounding lesbians and their AIDS work and to use that to inform our thought.

Chapter 3

Lesbians and AIDS: a social history

The Canadian experience of AIDS is inextricable from the social and political contexts in which the syndrome arose. The year 1981, the year AIDS was "discovered,"¹ provided a particular historical moment from which AIDS was articulated. However, the history of gay men and lesbians, and the social relations of power on the whole, set the context for that articulation. Also, the interactions that created that historical moment have continued to be made and re-made. History is ongoing and ever-changing. This view of history allows for social action to alter history's course. This view also requires that those involved in research are constantly doing the work of assessing the political context and explicating the social relations surrounding AIDS.

This chapter examines the broad context before, during, and after 1981, which gave rise to the phenomena with which I am concerned: AIDS, gay men, lesbians, feminists, and the various responses to the syndrome. This context may also be thought of in terms of being "the political" realm of social relations, which remains intertwined with the personal and everyday actions and experiences of people. As Dorothy Smith has noted, social relations are what organise the worlds

¹There is evidence that AIDS was present in the 1970s. After the medical profession conceptualized AIDS, they were able to retrospectively deduce that AIDS was around at least from 1979 (Campbell, 1997: A6). I refer to 1981 as a key year since that is the year that AIDS was recognized, and a direct social response began.

of each individual's everyday experience (1987: 153). As a construct, the political is the grand perpetually morphing organising forces which are embodied in the institutional relations (and discourses) of our society, as well as in social movements and any place where complex social relations converge.

The intersection of the social relations at work in the AIDS epidemic of 1981, as well as those which continued to re-construct AIDS throughout the last 17 years, will be deconstructed to better understand the relationships constructing AIDS. This will, in effect, construct an AIDS social history.

Similarly, lesbians' social history will be traced in order to better comprehend the social positions of lesbians at any historical moment. In this, what becomes apparent are the intersections with the social history of gay men, and that of lesbian and heterosexual feminists, as well as some of the institutional relations both constructing AIDS and shaping responses to it.

The social history of lesbians

"When a Vassar girl takes a shine to another, she straightway enters upon a regular course of bouquet sendings, interspersed with tinted notes, mysterious packages of 'Ridley's Mixed Candies,' locks of hair perhaps, and many other tender tokens, until the object of her attentions is captured, the two women become inseparable, and the aggressor is considered by her circle of acquaintances as — smashed."

- 1873 Yale student newspaper, quoted in Faderman, 1991

If I take a more or less chronological approach to recounting the social histories of lesbians (and of gay men), one starting point is with the appearance of the

categories of the lesbian woman (and the homosexual man). It merits noting here a point that is presumed in this research, but continues to be contested in some sociological and philosophical thought - that is, that human sexuality is not simply biologically determined, but is socially constructed (Foucault, 1978). The notions of a gay man or a lesbian woman developed at specific historical points, before which one cannot talk about those same social categories uncritically.² To refer to "a lesbian" in any other century but our own would be inaccurate since the particular social relations necessary for the articulation of lesbianism were not in operation.

Lillian Faderman argues in the introduction to her book tracing the social history of lesbians in the twentieth century that intimate relationships between women in past centuries could not be called "lesbian" since the concept "barely existed. . . . It was not until the second half of the twentieth century that the category of lesbian - or the female sexual invert - was formulated" (1992: 2). In centuries outside our own, "women's intimate relationships were universally encouraged" in America (p.2). These respected social institutions, referred to as "romantic friendships," were certainly loving and intimate, and may have even been erotic for some women, although that aspect of the relationships seems secondary (1991: 31). However, it was not until the notion of the lesbian was formulated, first by sexologists, in the twentieth century that we began to look back on women's

²Dunne points out that Foucault was silent on women's sexualities (1997: 7). Other theorists, like Faderman, have, however, applied the historical constructionist approach to lesbianism.

passionate attachments to other women as something which demanded further justifications.

For middle class girls, the women's colleges of the late nineteenth and early twentieth centuries provided an opportunity to form sometimes lifelong bonds with other women. The education the young women received at these institutions also afforded them the opportunity to support themselves, without the economic dependence on men that had previously been necessary. Colleges provided the venue, and economic self-sufficiency the independence from men, that were stepping stones towards the formation of long term relationships between women.

Middle class women in these relationships often found that they could pursue the works of their heart in ways that would not have been possible in relationships with men. Whether artist or suffragist, middle class career women could be self-supporting, leaving behind the expectations and responsibilities of marriage. This self-sufficiency also allowed the freedom to pursue long term living arrangements with other women (Dunne, 1997: 10).

Before the turn of the century, freedom from the responsibilities of marriage did not come in quite the same way for working class women who wanted to form relationships with other women, since the social space was not available for such women to come together. However, prostitutes and women in penal institutions had a great deal of contact with other women. Faderman argues that these women sometimes formed relationships (Faderman, 1991: 38). After the turn of the century, working class women gained more employment outside the domestic sphere, allowing more opportunities for same-sex relations to flourish.

It was not until nearly the turn of the century (somewhat earlier in Europe) that sexologists began to pathologize the loving bonds between women. The female "sexual invert" was first described based on working class women (Faderman, 1991: 41). Faderman argues that it was easier for the middle class sexologist to acknowledge that relationships between women could be anything other than platonic in the classes 'beneath' him. Before the early nineteenth hundreds, many women who lived in loving relationships together or who had intimate relationships with other women did not see themselves as lesbians. However, by the end of World War One, romantic friendships and other relationships between women were widely suspect. Tolerance for women's same-sex relationships declined, as these relationships became defined as lesbian. Women who partnered with other women were now forced to see themselves as lesbians, or to forego such relationships often in favour of companionate marriages.

This move toward pathologizing same-sex relationships also had the effect of creating "human sexuality" as a field of social and psychological investigation. Mariana Valverde points out that it was not feminists but men such as Havelock Ellis, Sigmund Freud, and Richard von Kraft-Ebing who created and invented human sexuality in the process of investigating it (1985: 13). What feminists, and then gay and lesbian activists, were then able to do in the later half of the twentieth century was politicize the area of inquiry that had been studied by "experts" primarily in the fields of sociology, medicine, and psychology. Non-expert discourse on sexuality among those who had been the objects of previous inquiry, mainly women, homosexuals, and other "deviants," became possible. The debate

on sexuality that began in the 1960s opened up the space for women, lesbians, and gay men to begin, in Valverde's words, "taking some control over the social forces that have determined our sexuality" (1985: 14).

Women's organizing

Throughout the mid 1900s, the identity of lesbian became more defined, although same-sex love went into hiding and lesbians remained largely invisible in the public sphere. By the second half of the twentieth century, women began to organize against their oppressors. Two movements, both with the aim of liberation, developed. The lesbian feminist movement is of particular interest in the present research, since it intersected with AIDS years later. Another lesbian movement, which could be called the gay women's movement, is useful to understand as well because it explicates a part of the social relations among lesbians and gay men previous to the advent of AIDS.

Faderman (1991: 189) identifies these two movements among North American lesbians in the 1960s and 70s.³ The gay women's movement was a part of what later became known as the gay rights movement.⁴ Homosexual women,

³In Germany, where nineteenth century sexologists had long-since formulated the concept of homosexuality, women who loved women had been involved in working on homosexual rights issues since the turn of the century (Faderman, 1992: 188).

⁴There were many women - "lesbian," "gay," "homosexual" - who were not involved in either movement in an ostensibly political or activist way. Early on, even those few working class women who participated in the Stonewall Rebellion had no articulated political vision (Faderman, 1992: 195). While many came to develop political conscience, throughout the 70s there remained lesbians for whom gay or women's organizing was

who called themselves "gay," banded together with homosexual men in coalitions organized to fight social oppression understood in terms of society's attitudes about homosexuality. The women who were active in these coalitions were most often essentialists, believing that same-sex attraction was innate or was learned early on. These activist women were sometimes classified as 'militants' by those working and middle class lesbians who were not part of organised activism.

In Canada during that era, progressive and leftist gay men and lesbians began organising. In 1964, a decade after Mattachine and Daughters of Bilitis (separate organisations for men and women) formed in America, the Association for Social Knowledge (ASK) began in Vancouver with a fairly balanced membership of lesbians and gay men (Kinsman, 1996: 231).

Shane Phelan, in her 1989 book, *Identity Politics*, asserts that lesbians working in these activist groups were not always utilized to the full extent of their capabilities, a situation that women who had been organising alongside men had seen before. "Lesbians in the gay rights and gay liberation movements found themselves in the position of women in the civil rights, anti-war, and New Left movements: conceptual appendages and organizational housekeepers/ secretaries/ sexual partners" (Phelan, 1989: 37). Lesbians began to see their sex as an issue perhaps more fundamental than that of sexual preference (1989: 38).

During the 1970s, women began organizing on their own. This second form of social activism was based more in gender politics than in sexual politics. With

beyond their realm of reality. The gay women's movement and the lesbian feminist movement emerged as the two most well-defined and influential social movements arising from within the ranks of women-loving women,

the second wave of feminism, some women were coming to understand themselves as "women-identified women" or "lesbian feminists." The Radicalesbians 1970 document "The Woman-identified Woman" is regarded as the definitive manifesto of lesbian feminism (Blasius and Phelan, 1997: 396). In that text, the notion that women serve men is explored. For example, "Those sex roles dehumanize women by defining us as a supportive/serving caste in relation to the master caste of men. . . ." (Blasius and Phelan, 1997: 396).

Women such as those in the Radicalesbians believed that they existentially "chose" to be lesbians: they desired to be in the company of other women because of a belief in building a community of women and an idea that lesbianism challenged male power (Douglas, 1990: 161). Some of the lesbian feminists sought the condition of a "lesbian nation" where women would rely on each other, meeting each other's needs.⁵

Many lesbian feminists came to articulate their sexuality through a political consciousness of the condition of women. Some, like Adrienne Rich in her famous 1980 paper "Compulsory heterosexuality and lesbian existence," argued that lesbianism could and should be open to all women (1986). As a "choice" for some women becoming a lesbian was less about the sexual object than about being "women-centred" (Trebilcot, 1983: 12).

but were not the only realities for lesbians in the 1960s and 1970s (Faderman, 1992:192).

⁵See Jill Johnston, *Lesbian Nation: The Feminist Solution*, Simon and Schuster, New York: 1973, as an example.

Lesbian feminists theorized that lesbian oppression arose from the conditions of a patriarchal society, rather than from social attitudes about same-sex erotic desire. They argued that the oppression of lesbians works by the same logic as the oppression of all women. The lesbian, however, is ultimate pariah, not only a woman, but a woman without man (Phelan, 1989: 41). Theoretically, radical lesbian feminists found that only through creating a community from women's experience, knowledge, and wisdom, could women liberate themselves from patriarchal oppression. As the radical lesbian feminist Carol Ann Douglas indicates, lesbian feminism was seen by many women as "an act of resistance against male supremacy and a major element in overthrowing it" (1990: 10). In this, coalition with men, gay or heterosexual, was not understood as beneficial for the cause of women's liberation. This stance was often resisted by heterosexual feminists, who felt that they were seen as "collaborators with the enemy" if they organised or had relationships with men (Mainardi, 1978: 120).

Tensions were so great between heterosexual feminists and lesbian feminists that lesbian feminists were not always welcomed to the mainstream struggle. While some heterosexual feminists understood that sexual choice (the ability for women to live as lesbians) was crucial for the liberation of all women, others argued that lesbian feminism was creating a public relations problem for feminism (Eisenstein, 1984: 49). Lesbian feminists were seen to be giving a poor image to feminism and causing problems for the women's movement on the whole. Ti-Grace Atkinson cautioned those involved in the women's movement against "lesbian-baiting," the practice of accusing every woman involved in attempts at

liberation of being a lesbian in order to encourage a purge of lesbians from the movement (Eisenstein, 1984: 50). While many lesbian feminists were trumpeting the necessity to focus all energy on women, women within the movement itself were allowing homophobia and heterosexism to create barriers between allies. Others were asserting, as Rita Mae Brown did, that if it was not possible to love men and women, then the situation was hopeless. In an interview in the *Washington Post*, Brown said, "If I thought I could only respond to half the human race, I'd jump off the Golden gate Bridge" (1981: C8).

The divisiveness of class, race, and gender is now apparent in the early activist groups, although during the years of organising, activists seemed to be oblivious to these social relations. While there were tensions born from the gender differences between the men and women in ASK, in gay and lesbian organising more generally there were also tensions between the most often middle class lesbians involved in activism and working class lesbians. In 1967, Norma Mitchell, then president of ASK put down the working class "dyke" in the ASK newsletter (Kinsman, 1996: 235). Throughout the 1960s, many working class lesbians found the activist lesbians to be too militant, and largely ignored their organising (Faderman, 1991: 191). Even many middle class lesbians (and gay men) resented the publicity being brought on homosexuality because they felt that it would have a negative impact on their lives (Faderman, 1991: 192; Kinsman, 1996: 251).

For many middle and working class lesbians, the political ideas and activist style of lesbian feminists were beyond the scope of their own experience. Lesbian feminists usurped the term lesbian, so that to be "lesbian" meant one also had

feminist inclinations. Working class women were more often referred to as dykes or gay women.

Race complicates feminist theoretical perspectives because it was not integral to its development. In her 1984 book, bell hooks points to the fact that not only were the women involved with the feminist movement middle class, they also were predominantly white. Hooks argues that there are many reasons that women of colour did not participate in the feminist movement. Perhaps a central reason was that the movement began as a white women's movement.

When Betty Friedan wrote the *Feminine Mystique*, hooks argues that classist and racist assumptions were made. According to hooks, "the problem that has no name" was written about a select group of middle class college educated women. Friedan completely ignored non-white women and poor women. At the time that the *Feminine Mystique* was written, more than 1/3 of all women were in the workforce (hooks, 1984). Some of these women longed to be housewives, or to have the sort of leisure time that was described by Friedan, rather than work long hours outside of the home for low pay.

The concerns of white middle class women came to dominate the agenda of the feminist movement in a way that the issues of other women could not (Banzaf, Morgan, and Ramspacher, 1990: 201). Hester Eisenstein describes the replication of class inequalities in one aspect of the feminist movement. Class tensions arose in consciousness-raising groups, where the terms of debate had been set by middle class women. Middle class women came to dominate the conversations

and, more subtly, to control what was discussed (Eisenstein, 1983: 40). While there was some common oppression shared by all women, hooks says that

. . . there is much evidence substantiating the reality that race and class identity creates differences in quality of life, social status, and lifestyle that take precedence over the common experience that women share -- differences which are rarely transcended (1984: 10).

Although feminism of the early 1970s had shown signs of an anti-racist and anti-classist agenda, throughout the 1970s and into the '1980s the feminist movement operated under the guise of dismantling women's oppression while conceptualizing of that oppression in racist and classist terms.

Although these tensions made organizing more difficult, gay men and women as well as lesbians and straight women, saw some value in working together. With the understanding that they were oppressed because of the society's intolerance for their same-sex desires, gay men and women were able to band together to fight what seemed to be their common sexual oppression. In feminist groups, lesbians also found that there were useful aspects to working together against what was understood as gender oppression.

The feminist critique of health care must be noted, since it later made great contributions to AIDS organising. The recognition that health care had been removed from people's everyday lives and had become the purview of so-called "experts" was of great importance to the gay response to AIDS. Brownworth notes that the origins of this historical gift from feminism to AIDS organizing have been forgotten by some. She quotes an anonymous lesbian who is angered by what she sees as a lack of recognition for this contribution:

Have you seen anyone anywhere - especially in the gay male press - give credit to lesbians for the AIDS health care movement? I know that Larry Kramer et al. think they started it, but the reality is that feminists - primarily lesbians - started the self-help health-care movement 20 years ago because women were getting such terrible - no, criminal - health care in this country. The boys look at our model, decide it works, and move on (Brownworth, 1990: 44).

The intersection of lesbians and AIDS

The organizing that women undertook, both in the gay movement as well as in the women's movement, gave women many skills and a good deal of knowledge and understanding. Activist women learned how to organise other people to work towards a goal. The many small steps of organising, such as phone lists, media contacts, access to resources, or holding meetings, were learned in the hours and years of devotion that many women gave to social and political organising.

While there were a number of men involved with organising for homosexual liberation, in terms of their relationship to the total number of gays and lesbians, their numbers were fairly small. Most gay men, by 1981, did not have the skills to organise, nor did they have the benefit of the knowledge one gains in working in such an organised effort as the feminist movement. Sarah Shulman points out that gay men had little in the way of political savvy at the beginning of the AIDS epidemic, while lesbians had been involved in the feminist movement for ten years (1994). Shulman paints an image of gay men early in the epidemic who were resting their hopes on the state. It seemed to follow, in the reasoning of upwardly mobile gay men, that the state would care for the needs of the more mainstream,

white gay men who had worked so hard to gain access to the same power as their straight counterparts. Gay men came to learn the hard way, by living through the state's inaction and dying because of it, that they would have to struggle to have their needs met.⁶ To lesbians this was already obvious. Shulman wrote of the early years of the AIDS epidemic:

... lesbians had a more sophisticated analysis of the state and a clearer impetus towards direct action. Although gay men had access to significantly more resources and power than lesbians, they were just realizing that the state did not care whether they lived or died. This process of revelation was an obstacle that lesbians did not have to overcome, having been clear on their exclusion from the beginning (124).

Differences in experience may have given lesbians an edge in terms of the skills and knowledge needed for organising, but gay men had more economic power than lesbians. Economic differences between gay men and lesbians had always existed. It was when gay men began to organise, along with lesbians, against AIDS that those differences showed themselves most blatantly. Where lesbians and feminists had struggled for years to pull together resources for organising, gay men were financially better off with more access to resources. Many lesbians were critical of this situation, and refused to assist gay men in the early years of the AIDS epidemic. Shulman argued in 1985 that lesbians' animosity towards gay men was not simply because men were favoured in terms of power

⁶ Perrow and Guillen (1990) discuss the organizational responses to AIDS in the early 1980s. Gary Kinsman (1992) refers to state inaction and indifference in relation to HIV/AIDS in the early 1980s, and goes on to discuss the development of activist groups in response to this. By the late 1980's state inaction was largely replaced with state regulation, which led to new forms of activism.

and economics, but also because of the men's refusal to work for women's liberation:

Socially, gay men and lesbians have a historically tenuous relationship. Grossly unequal in terms of money and power, lesbians have watched gay men develop their social legitimacy and financial resources. In the meantime there has never been a lesbian play on Broadway, a lesbian newspaper with a paid staff, or an exclusively lesbian bar that wasn't Mafia controlled, overcrowded, and frequently closed down. When women have experienced economic or physical brutality, gay men as a group never really cared. They've had men's money, men's arrogance, and men's self-absorption (1994: 120).

There has been a chasm created between gay men and lesbians based in their differences in social and economic power. Although at first glance it may seem that gay men and lesbians have a common struggle, in fact there have been historical differences which constructed separateness in the lives of lesbians and gay men. There have been many similar social problems; however, because of the social relations of gender, class, and race, gay men's struggles and those of lesbians have taken different shapes during this century.

Responses to AIDS

The entire response to AIDS was, in many ways, different than any previous response to disease.⁷ The so-called "gay and lesbian community" played an

⁷While as a response to disease, AIDS organizing was quite unique, as a social movement it shared common roots and attributes with other types of organizing. Patton tells us that while AIDS organizing was unique in many ways, there were also ways in which feminist and lesbian/gay organizing dovetailed with AIDS organizing (Patton, 1986: 144).

integral and leading role (Patton, 1986:158). The progressive response to AIDS was activist, grassroots, and community-based, while dominant discourses of AIDS tended to focus on the medicalisation and professionalisation of the disease (Kinsman, 1992: 224). There was much work in communities to provide the necessary services, as well as to lobby towards meeting the needs of people infected with HIV. On another level, AIDS activism attempted to undermine the usual way disease is understood, replacing it with new ways (Gamson, 1989:351) .

Women's organising around health issues made a particularly important contribution to AIDS organising. The feminist health movement lent some valuable principles to the AIDS movement (Banzhaf, Morgan, and Ramspacher, 1990; Brownworth, 1990). The feminist health movement, which had developed from the women's liberation movement in the late 60s, had operated on the principle that a woman could and should have control over her health. This position led women to become informed about their bodies and to learn about health maintenance. AIDS organising borrowed the idea that individuals could become active in their own health from the feminist health movement. Where feminists had demonstrated over reproductive rights in the seventies, AIDS activists in the eighties demanded that the needs of those with AIDS be addressed by the state and medical establishments (Banzaf, Morgan, and Ramspacher, 1990: 200). People living with AIDS educated themselves about the illness and wrestled control over their bodies and their health from the so-called medical experts. Rather than "patients," thanks in part to the work that feminists had done before them, and to their own educational and activist work, they came to be experts on their own bodies.

Aside from the response to AIDS from community activists, the response from social institutions had differences as well as similarities to previous responses to disease. Susan Sontag points out that illness is metaphor (1990). In this, AIDS similarly became metaphor. The differences (and similarities) in responses from social institutions were in part organised from the metaphors AIDS came to represent. For example, AIDS has been associated with unsafe behaviour among certain populations. Participation in "dangerous acts" constructs the actor as weak-willed or delinquent. Those people who go on to be diagnosed with AIDS may be thought of as somehow "guilty" for their illness. Others who are seen as so-called "innocent victims" of AIDS are given compassion, while those who are considered blameworthy are afforded little concern. Sontag compares this situation to syphilis, where sexual transmission was also prevalent, and to cancer in that those with this disease are sometimes understood as receiving "punishment for living unhealthy lives" (1990: 113-116).

These metaphors, and much of the meaning and experience of AIDS, are constructed within classist, racist, and heterosexist social relations. Sontag points out that those belonging to "risk groups" have often already been constructed as social pariahs (1990: 113). Patton, discussing the dominance of virologic thinking, explains how a viral metaphor implicitly makes individuals morally culpable for engaging in activities which might result in HIV infection. Not only does this logic construct some people as "guilty" victims of AIDS, it also focuses on the search for a cure, in the short term selling out those who are already infected with HIV (1990: 64).

Perhaps the contours of social power and oppression are even more visible when someone outside the bounds of socially constructed deviance - usually a homosexual or IV drug user in the case of AIDS - is afflicted with HIV. Katie Roiphe describes the case of Alison Gertz, an affluent young American woman who was infected with HIV through intercourse with a male partner. Roiphe argues that while the American public were bombarded in magazines and on television's "Oprah" talk-show with the message that Gertz proved that AIDS could strike anyone, her story actually carried the somehow astonishing message that *even* the rich were not immune to HIV:

Alison's safe sex campaign slogan, "AIDS can happen to anyone," may have had a democratic ring to it, but the point was precisely that Alison wasn't just anyone. In her case "anyone" was a euphemism for "even the rich" (Roiphe, 1997: 43).

The implicit expectation is that AIDS can reasonably only be expected to affect the poor, the uneducated, those who live "dangerous lives." AIDS has been understood as a disease of other people.

Perhaps one of the most significant differences in attitude toward AIDS compared to other diseases was the lack of institutional, especially state, response in the early months and years of the epidemic. Some, such as Patton (1986) and Kinsman (1992), have asserted that governments seemed in no hurry to tackle the many aspects of this new disease. In Canada, the federal government came under harsh criticism from AIDS activists for years of inaction in terms of policy, treatment issues, and meeting the needs of people with AIDS (Kinsman, 1992). This inaction made the response from activists all the more crucial. In fact, government inaction

was one of the key issues that activists organised around in the 1980s. Kinsman says that AIDS activism arose in the early 1980s "in *reaction to state inaction and indifference*, problems with the medical profession, and social discrimination against gays, Haitians, injection drug users, and sex trade workers" (1992: 216, emphasis added).

The work of gay men and lesbians in response to AIDS was pivotal to building a movement around AIDS. Given the lack of concern shown by many social institutions, the organised response to AIDS by activists and community groups helped to meet the needs of many people with AIDS, as well as to force governments to take responsibility for responding to AIDS.

In orchestrating responses to AIDS, gay men and lesbians were working together, at times more closely than they had before. While there were lesbians who had been part of the gay rights movement in the 70s, lesbians also came to the AIDS movement from different political backgrounds. Lesbians were allies for gay men in the early days of the epidemic, and as time went on came to also work for the inclusion of women's concerns into the response to AIDS.

Why lesbians got involved in AIDS organizing

It was, in large part (although not entirely) through a sense of common struggle, or community, that lesbians became involved in the struggle against AIDS early in the HIV epidemic. Cindy Patton (1990: 21) asserts that lesbians who became involved did not do so because they felt any personal threat from AIDS. Rather, she says,

lesbians became involved because they felt their community was under attack. There was a sense of community resistance which had the potential not only to create a strong response to AIDS, but also to bring together lesbians and gay men as a unified force. In an earlier book, Patton points out that for some lesbians (and gay men), AIDS activism was their first foray into organised responses to oppression (1986: 144). So, while some lesbians understood the need to organise when it came time to do something about AIDS because they had been involved in other progressive social movements, some simply experienced AIDS as an immediate attack on their community and rallied to its defense.

Deborah Stone alluded to her sense that she was volunteering because of a commitment to community when she wrote about the reasons why lesbians become involved in AIDS work. Stone says, "I was aware of the devastation AIDS had inflicted on my extended community, the gay community" (1988: 143). Stone was also hopeful that by working together, gay men and lesbians could overcome a history of divisiveness, and forge a (stronger) community.

According to Patton, in the early months of the response to AIDS from activists, there was something more than a sense of a common gay and lesbian community being under attack. Some lesbians also felt a concern for other women in what was shaping up to be an epidemic; they understood that women would be particularly vulnerable to medical maltreatment. Political resistance to an attack on the community of lesbians and gays was, however, certainly a part of the reason lesbians became involved in AIDS work. Rather than acting out of altruism,

concerns for personal safety, or even simple compassion, Patton argues that AIDS activists first organised as a contribution to community self-determination.

Thus, the core of lesbians who became involved early on were active not because they perceived a personal risk of HIV/AIDS, but because they saw their community under assault or saw women as particularly vulnerable to medical maltreatment and the political backlash accompanying AIDS (1990: 21).

Later, institutionalised AIDS non-profit organisations (at least in the US) would come to rely on the altruism of "volunteers." Patton asserts that it is erroneous to attribute the entire early history of AIDS organising to non-profit altruism, but rather, that there was a complex understanding of the political implications AIDS could have for women and other disadvantaged groups (1990: 22).

While there was early grassroots activism, the sense of community resistance eroded, and with it the great hopes that coalitions between various communities could be forged. Instead, Patton describes a social movement that fragmented along lines of color, class, and gender.

In terms of AIDS' effect on the relationship between lesbians and gay men, from the early days until the present there has been the potential for interdependence and understanding to be enhanced. There was a hope early on that in responding to the AIDS epidemic lesbians could come to count on gay men to work on issues that affect the lesbian community and women as a whole. This would not only lend additional personnel to the struggles of lesbians and women, but also enhance the political power behind them since men tend to have more political clout. But by the late 1980s, lesbians recognised that this was not happening. Both Patton and Stone acknowledge that this potential for community

building had gone largely unrecognised (Patton, 1990: 21; Stone: 150). Stone maintains that, while on the whole AIDS did not bring together lesbians and gay men, some individual women and men have been able to resolve their conflicts through working together in the response to AIDS.

The comprehension that gay men as a group have not contributed to women's organising anywhere nearly as much as lesbians have worked to respond to AIDS was one of the factors leading lesbian feminists to question the commitment of lesbians to AIDS organising. Stone writes of one lesbian who didn't understand why lesbians should be involved with AIDS after gay men had done so little for lesbians.

Gay boys have done shit for lesbians, and now we're rushing to their bedsides. We're acting like nurses, like a bunch of mommies. Like women always do (1988:143).

The speaker resents lesbians contributing to the struggle against AIDS, which she sees as gay men's problem. The resentment arose among feminists because they felt that gay men did not contribute to the same degree to the struggles of lesbians (Brownworth, 1990: 44).

Feminists in the late 1980's also began articulating the idea that lesbians' response to AIDS was recreating relations that women have participated in for hundreds of years. That is, that women are caretakers. Stone, responding to this idea, admits that her response could be considered a typical one for women in two ways. Firstly, this role of caregiver is what she calls a "traditional" one for women. Secondly, it is women who are generally the ones to look after other people's needs

without receiving any monetary compensation. That is, not only are we caregivers, but we are also relied upon to be volunteers in this capacity and others.

Women and Work

The unequal distribution of the types of work done by men and women has been the subject of feminist inquiry and thought. On some level every feminism from liberal to radical postulates that there is an imbalance of power between the genders. Liberal feminists would argue, among other things, that there is inequality between women and men in terms of employment. Such feminists have reams of statistical data to show that men's work is more valued than women's. From the fact that men are more often the CEOs of large corporations to the idea that women earn less than men, evidence of gender inequality in the labour market is plentiful. Most feminists would argue that work is one social phenomenon where gender inequality is evidenced (although, depending on the feminist stripe, the rationale behind this inequality and the tactics for transforming it may be very different).

Lesbian feminists who have shown concern about lesbians' involvement in the AIDS epidemic have generally limited the critique to the volunteer work that women have done. While volunteer work has been seen as problematic because the "favour" has generally not been returned by the gay men for whom the work is most often done, there is a broader critique of volunteer work which shows, for example, the social relations which mean women become volunteers more often.

A broader critique may also highlight the paid work that women do in the AIDS epidemic to research whether social relations of gender inequality in the workforce organize women's lower position in AIDS organizing, or what power relations of racism has had on lesbians in AIDS work.

Lesbians' work in the response to AIDS has been subject to the same social power relations which have constrained other women's efforts. Although at times the response to AIDS has been articulated as a movement for social justice, lesbians participating in AIDS organising have faced many of the same problems that other women working in other sectors have faced. At a basic level, in the broader society this includes the under-valuation of their work as made apparent by less pay, less employment, and/or jobs requiring less skill and expertise. The work of lesbians in AIDS organising is inextricably linked to these particular power relations between the genders. Lesbian feminists, while arguing that lesbians' work in the response to AIDS is problematic, have not explored the social relations surrounding that work except to say that it is the type of work that women have always done. Here, by exposing and examining the relations surrounding lesbians' AIDS work, I actually render that work problematic in a more substantive way than lesbian feminists' reactive response to AIDS work has been able to do.

For the purposes of inquiry, I separate the work that lesbians have done in the AIDS epidemic into two kinds: paid work and unpaid (or volunteer) work. The opportunity for monetary compensation for work rendered in responding to AIDS has developed, as women become leaders, educators, administrators, and take on other positions in the AIDS service industry. Distinguishing between this paid work

and volunteer work is important since so much of what lesbians have done in the response to AIDS has been unpaid and the number of women achieving the distinctions of experts and professionals in the AIDS service industry has been disproportionate through its overall history (Patton, 1990: 21).

Women, including lesbians, have made up a large proportion of the volunteer base even in gay-centred organisations. According to Patton, there was an influx during the 1980s into the AIDS epidemic of women with particular profiles: they were white and middle class volunteers (1990: 6). Patton contends that heterosexual white women joined AIDS service organisations because they are "the traditional volunteer reservoir" (1990: 21). Their participation showed the systematic sexism within the organisations, as the division of labour favoured men. White middle class heterosexual men almost never became volunteers but did become the experts and professionals.

Historically, employment for wages and volunteerism have been related. The idea that women should volunteer, and their ability to do so, was supported by the convention that men were to care for women in a financial sense. Thus, women's time was freed up, enabling them to devote volunteer efforts to charitable causes (Gold, 1994: 102). The idea that women should volunteer was a white middle class notion, given that women of the proletariat were forced to seek paid work for sustenance. In fact, such women were often the subject of charitable efforts from the middle and upper classes.

The practice of middle class men providing a family wage reinforced the expectation on middle class women to volunteer. However, while women's

volunteerism may find its roots in this idea, men no longer bring in the sole family wage in the majority of households.⁸ A larger percentage of women in Canada now work outside the home than those who remain homemakers.⁹ For these women, any volunteer work is done in addition to their paid work.

For lesbians and other women without financial attachment to men and whose paid and volunteer work is done without the benefits of the concept of the "family wage" earner, the inequalities in sexuality (not only gender) and in the labour market continue to intersect.¹⁰ Dunne argues that lesbianism "both necessitates and facilitates financial independence" (1997: 2). Yet, lesbians (and all women) in the current and recent historical social contexts do not have the same earning power that men do. So, while the higher earning power of males may continue to be of some dubious indirect use to heterosexual women, lesbians neither have access indirectly (through a male partner) nor directly (through their own work) to the jobs and wages that men on the whole have. Women's work is undervalued, creating a situation where lesbian women will certainly not benefit

⁸ According to Statistics Canada, in 1995 60.5% of husband-wife families were dual earner families. In the same year, the wife earned more than the husband in 14.2% of those families. In 4.9% of husband-wife families in 1995, the wife was the sole earner compared to 17.8% of families where the husband was the sole earner (Statistic Canada, 1997: Catalogue no. 13-215-XPB).

⁹ According to Statistics Canada, 52.2% of women were employed outside of the home in 1997 with 57.4% participating in the Canadian labour force. In Nova Scotia, the number of women working outside the home was less than half at 47.7%, but the majority (53.5%) of women in Nova Scotia were participants in the labour force (Statistics Canada, CANSIM, Matrix 3472).

¹⁰ Adkins (1995) argues in *Gendered Work* that sexuality and the labour market have been analytically separated. She works to explicate what she sees as the intersection of the apparently disparate processes of sexuality and the labour market.

from the higher earnings of a male partner, nor will they enjoy equal access to the jobs and benefits that male counterparts have.

Marxist feminists, such as Hartmann (1981), have argued that the undervaluation of women's work is part of the process of men's control of women's labour. Such control is understood as the "major social site in which the material basis of capitalism is secured" (Adkins, 1995: 22).

Faderman argues that it is because middle class women were participating in work that could be seen as housekeeping on a grand scale that they were able to go out from the home into the public sphere of paid employment in the latter half of the 19th century (1991: 23). Middle class women who worked as teachers or nurses were sometimes able to be self-sufficient, thus living somewhat outside the realm of capitalist reproduction of the family. The work that these women did was not the small scale work of caring for a family, but rather the mass mothering of communities. As teachers, healers, and caregivers, women's domestic skills moved outside the home, allowing women to begin achieving roles of prominence on their own in the new capitalist system.

Lesbian feminists argue that just as women have been limited to small and large scale mothering during the last century and a half, women participating in AIDS work are being limited to caretaking roles. Jackie Winnow argues that lesbians flocked to respond to AIDS because it was a place where the attributes women possess, either by "nature" or through socialisation, could be utilised (Schwartz, 1993: 231).

Lesbian feminism arose from a desire to challenge the male dominated ordering of social relations. According to Carol Anne Douglas, the idea that lesbianism could be part of a political solution for women occurred to those women who saw lesbianism as a choice rather than a genetic predisposition or an effect of early nurturing (1990: 138). Rather than remain a party to the inequitable social relations between men and women, women could create social spaces and social relations on their own. This practice would challenge male domination as women would no longer need to relate to men on an intimate level, and would soon have fewer and fewer reasons to interact with men at all. The notion that women could chose to be lesbians for political reasons was a crucial aspect of lesbian feminism.¹¹

Lesbian feminists were trying to envision a new way of being for women that challenged male-domination. To be(come) a woman over the last one hundred fifty years has meant assimilating those qualities associated with femininity, including the capacity for caregiving. The femininity of women at the same time has not only been a difference between men and women, but has also been relegated to a lesser status. Differences in femininity and masculinity have been socially constructed, and following that, inequality has been based on those differences. For lesbian feminists, becoming lesbian could be a rejection of the feminine ideals. In fact, the notion seemed like such a challenge to the whole concept of

¹¹There were those radical feminists who felt that lesbianism was not a true political choice, but an apolitical stance. By choosing to relate only to other women, Ti-Grace Atkinson once said that, "The lesbian solution to the problem of women is to evade it" (1974: 25).

womanhood that some theorists conceived of "lesbian" as something other than "woman." However, as Rita Mae Brown wrote, all females have been raised to be straight, or in other words, to be women. Those who chose lesbianism for political reasons certainly may challenge the articulation of what woman means. However, through the social relations constructing women, each woman is imbued with the baggage of being women.

With lesbians' response to AIDS, lesbian feminists were disappointed to find that lesbians were behaving just as other women had. It was particularly galling to lesbian feminists that women would respond to an epidemic that affected primarily men, and in so doing would once again perform in their capacity of caretakers. Stone says that she understood the sentiment expressed by lesbians who felt women were acting like nurses and mothers. "My response to the AIDS crisis was very much in the mold of activities considered traditional for women, not only as caregivers but as volunteers working without pay" (Stone, 1988: 143).

However, Stone goes on to attempt an explanation for lesbians' involvement in the AIDS crisis that goes beyond the idea that women were once again simply looking after men. Schwartz also sees a need to develop a more complex understanding of lesbians' involvement.

Whose problem is AIDS?

The question of whose problem AIDS is has surfaced in many places during the AIDS crisis. Early in the epidemic, the media and popular representations of AIDS

constructed it as a gay male phenomenon, largely because of the population where Gay-Related Immune Deficiency (GRID), which became known as AIDS, was first identified (Patton, 1986: 23). Later the so-called general population was targeted by government education initiatives focusing on the idea that anyone could get AIDS. This coalesced with the mid-eighties claim from activists that "AIDS is not a gay issue" (Patton, 1986:145). Activists were attempting to assert not only that everyone could be at risk for HIV, but also that all would be affected by the disease. The hope was that all would take responsibility for stemming the spread of HIV and for looking after those already infected.

The notion that AIDS was a gay men's disease had hindered the achievement of government mobilisation or popular awareness of HIV and AIDS. During the mid 1980s, the Canadian federal government paid disturbingly little attention to the needs of people living with AIDS, who in Canada were largely gay men. While public health initiatives began to push the idea that anyone could get AIDS in the hopes that heterosexual people would feel some urgency about AIDS, AIDS activists themselves began to assert that AIDS was everyone's issue. They had realised that the marginalisation of AIDS could continue if the link to the already peripheral groups AIDS was associated with was not severed.

The organized response to AIDS as a social and political issue in the early 1980s, as well as the late 1980s activism around some of the issues concerning treatment and care for those gay men who were infected, however, did not come from everyone alike. It is now clear that it arose from the gay and lesbian community (Patton, 1986: 145).

Treatment-based activists had some affect on social policy, urging the government to take more action in the late 1980s, and once again presenting insightful thoughts on who was affected by the AIDS issue. At this point, activists wanted governments and everyone else to realise that, in forming policy and procedures, the needs of those most affected by AIDS, those who were living with AIDS, were to be taken into consideration first and foremost. In this activist period, especially in 1989, the lack of treatment strategies and services for gay men began to be addressed under Minister of Health Perrin Beatty, shifting some government attention away from public health, and the "general population" that public health policy guards, and onto the needs of people living with AIDS by the time the National AIDS Strategy was released in June of 1990 (Kinsman, 1992: 218-219).

In the years after the Strategy was released, those participating in AIDS work began to feel that the funding was not allotted properly. While treatment had been raised in the Strategy, seemingly focusing the attentions of AIDS workers on those most affected by AIDS, by the mid-90s community education and development were priorities at many AIDS service organisations. At the 1994 ACAP Regional Meeting in St. John's, Newfoundland, I saw a backlash to funding strategies that had spread money to various targeted populations for education and community development. The identity-based divisions that Cindy Patton (1990: 22) described in the early part of the epidemic - along class, race, and gender lines - were obvious. White, middle-class, gay men wanted to reclaim AIDS, at least in terms of receiving resources. Two men stood up to say that they were the ones being affected by AIDS but that funding for programs for gay men was abysmal,

implying that funding was going to other groups.¹² In fact, a survey of the programs and services offered by the two provincial AIDS organizations, AIDS Nova Scotia and the Nova Scotia Persons with AIDS Coalition, as well as the regionally-based Atlantic First Nations AIDS Task Force shows that resources in Nova Scotia during the early to mid 90s had been divided among different communities, including gay men, First Nations people, black communities, women, and various people living with AIDS.

Early in the epidemic, the "othering" of AIDS had happened even within the ranks of gay men. Patton describes gay men's early reluctance to join in the fight against AIDS, approaching it as a gay and lesbian liberation issue because they had "a feeling that AIDS was affecting those *other* gay men, the non-political ones who had taken advantage of the gains of gay liberation without ever putting in any of the work" (1986: 3).

This social history of AIDS reveals how activists have struggled between themselves consistently over the course of the epidemic. These activists have also had the potential to form coalitions or other collective forms of resistance, and at times have shared knowledge and skills. They have in common that they must all struggle from the margins, with vastly unequal social power compared to the state and the relations of ruling. Sexism, heterosexism, classism, and racism all work to continue to keep these would-be allies separate. The irony is that these are the

¹²Rofes (1996) argues in *Reviving the Tribe* that, in the US situation at least, the decrease in funding for AIDS education for gay men can be blamed on, among others, the AIDS educators. He argues that safe sex education among gay men didn't actually work.

very relations which lesbian feminists, AIDS activists, gay liberationists, and all those who work for progressive social change are trying to transform.

In fact, it is very hopeful that lesbians, gay men, women, and those responding to AIDS have continuously struggled to remake themselves and the world around them. Contesting relations of oppression is a historical process that keeps on. Understanding this history may help those of us who continue to work for social change to make good decisions about our actions.

Chapter 4

Lesbians Responding to AIDS in Nova Scotia

Throughout Nova Scotia lesbians have been among those working to counter the devastating effects of AIDS. The women with whom I spoke for this research were from various areas of the province, including the Annapolis Valley, Northern Nova Scotia, the Sydney-area, and the Halifax region. At the time of the interviews (1995 and 1996), these were the areas where organized responses to AIDS had existed for some time.

Although not all the women continued to be involved in responding to AIDS, each had at one time been very involved in community-based AIDS organizations in some area of Nova Scotia. Two of the women had been paid for their work, the others volunteered their time. In the previous chapter, I discussed the social relations which provided the contexts within which these women began their involvement with AIDS. Now, I will show how these contexts affected the women's actions and how their work contested, remade, or rearticulated the social world.

First, it is important to understand who the research participants were in terms of some of the important social relations not only of gender and sexuality, but also of class and race. As noted in the previous chapter, theorists such as bell hooks have highlighted the need for taking all of these relations into account. Unfortunately, race and class were not very well encompassed in terms of representation among the participants. By virtue of education and current socio-

economic status, if not by family history, all of the women could be considered middle class.

There is some explanation from the literature for this occurrence. The relationship between higher education and lesbianism was explored in Dunne's study of lesbians and work. Dunne contends that access to higher education is influential in causing women to question heterosexuality (1997: 230). Further, she observes that being a lesbian necessitates a level of self-sufficiency leading many lesbians to seek out educational opportunities and to build skills (227).

Only one of the women was not white. Of the white women, two were immigrants to Canada from Europe and the remaining three had been born in Nova Scotia. In searching for research participants, effort was given to finding women of color. However, this search at the time yielded only the Native lesbian woman who participated. Although I did not interview all the lesbians who had worked in the response to AIDS during or prior to 1996, there were no black or working class lesbians that I knew about in Nova Scotia to interview. Had there been, however, their experiences would further the explication of lesbians and AIDS work, as was the case with the one Native woman respondent.

Just the fact that these women were as I've described them is worth noting as it may point toward Nova Scotia trends in volunteerism that have been present in other times and places (Stone, 1988: 148). It may also indicate where the responses to AIDS have arisen or been maintained. Middle class white women were prevalent among those who did AIDS work, especially in a volunteer capacity (Patton, 1990: 6). As we have noted in the previous chapter, in terms of class this

should not be surprising, since this type of work tends to be a middle class phenomenon (Gold, 1994: 102).

Responding to AIDS

The lesbian feminist critique of AIDS work asks, in part, whether AIDS is a lesbian issue at all, since it directly affects comparatively few women and fewer lesbians. Yet, the six lesbians interviewed in this thesis found AIDS was an issue for them (or at least at some point it had been). This is, however, not because they were terribly concerned with the direct impact of AIDS on their own lives or that of other lesbians. The urgency to address AIDS in a lesbian context was not the prime motivator for these women, neither for their becoming involved nor for their ongoing commitment. None of the women indicated that concern for lesbians was a factor in initially getting involved with AIDS work, although some later came to understand the need to teach and support lesbians. For some, even dealing specifically with the concerns of women was not very important in their decisions to do something about AIDS.

Doing work for women in the AIDS movement could be seen as crucial feminist work. Where a large thrust of the lesbian feminist critique of AIDS work is built from the notion that lesbians are doing work for men in the AIDS movement, if they actually focused on women there would be that much less at issue. In describing the first work they did to respond to AIDS, these women talked about their perceptions of AIDS' impact, or that potential, on various different communities

they identified with. At times for some of these women, those communities included what feminists would call the women's community, or lesbian communities. However, there is more evidence that these women were often motivated by concern for other communities.

Lee's involvement with AIDS work was spurred on by a desire to educate her peers. She began with an education campaign aimed at university students while she was still studying in 1989. This was before she was even out as a lesbian. So, her initial work did not have much to do with being a lesbian or with concern for the lesbian community. Even three years after she began her involvement with AIDS work, a time when she called herself a lesbian, she remained focused on educational aspects, although the target became her geographical community rather than students.

During this phase of her involvement, Lee said that she did see the importance of including information particular to women's needs in educational efforts. It wasn't until sometime later that she began to realize the impact that much of the education was having on lesbians. In particular, there were safer sex campaigns that did not utilize an understanding of AIDS specifically in terms of lesbian lives. The message was the same as for gay men when it came to safer sex: wear more latex. Lee points out that lesbians were already sex-phobic and that this message may have caused a setback in her community. It is an important point to note the role that understanding lesbian history and the development of

that community plays when speaking to these women about their practices.¹ As Pat Califia points out, given the fact that lesbians and other women have given so much time to AIDS work, we should be able to expect some AIDS information that speaks to our lives (1995: 214).

Here, Lee includes herself in the lesbian community and is also able to relate AIDS to lesbian lives. However, she goes so far as to say that AIDS is not a lesbian disease. She makes that assertion on the basis that there is a distinction between the lesbian community and that of gay men, and that AIDS has primarily affected the latter:

I would get things from my grandmother that because I was a lesbian I was at higher risk for HIV. Our education should not confuse the two communities. If we want to talk about AIDS and homophobia, of course homophobia is something that affects us all. But, let's not present AIDS as a gay and lesbian disease. It is not.

Yet, Lee does not completely dismiss the importance of AIDS as an issue, if not a priority, for lesbians. This arises from a belief that lesbians have a responsibility to other women. She says that since there are certain women whom AIDS is hitting hard, it should be a concern for lesbians. Lee does see AIDS affecting women, and feels that she is helping to address women's concerns. However, the focus of her educational efforts was not specifically women but schools and other groups in her geographical community.

¹In a 1995 article, "Slipping," which was anthologized in *Lesbian Words: State of the Art*, Pat Califia discusses the fact that lesbians cannot find safe sex information, even from AIDS organizations who are supposed to be disseminating it. Califia quotes Sarah Schulman's 1992 Bay Area Reporter interview in which Schulman says there has been no research on the efficacy of dental dams, but that dental dams became the fad because they fit into lesbians shame about their sexuality. Schulman contended that there was no evidence that oral sex could transmit HIV (Califia, 1995: 212-213).

Like Lee, Maggie began her work with AIDS through educating others. Maggie taught in high schools where she began incorporating AIDS into sex education programs. Education continued to be the main focus of what she did while working with AIDS groups. It has included teaching children and adults about AIDS in educational settings, but also a broader focus on teaching the people in her area of Nova Scotia. She says that she is the only lesbian involved in AIDS organizing in her area of the province.

It was out of concern for her geographical community that Agnes got involved with an AIDS group. In particular, she was concerned about the lack of community support that the families of those with AIDS were receiving in her area. This motivated Agnes to organize a workshop which eventually led to a support group for the families of those with AIDS.

In 1990, Jan attended that workshop. Jan said that she got involved "out of concern for a lot of people I had known and things that had happened." She says that she had a bit of a social conscience which contributed to her taking action on her concern for gay men. Jan was concerned, too, about her geographical community. But she says that the fact that she was a lesbian probably contributed "indirectly" to her involvement at that time and place. "Over time that had led me to meet so many of these people who were later to die," Jan says, indicating that she might not have even known these people were she not a lesbian.

Jan is unique among those interviewed in that she indicated that she had known gay men with AIDS prior to her involvement with the work. She says that that fact may have motivated her. While involved, she worked to organize a group

that would respond to the needs of her geographical community. This work was behind the scenes, and did not include any direct work with people living with AIDS. In fact, there were very few gay men in the group, and little outreach to gay men while Jan was involved.

From her involvement with women at high risk for HIV, Sue developed a concern for women around AIDS. She is the only one among the six women interviewed for this thesis to identify a commitment to women as the motivating factor in her continued involvement with AIDS work. Several of the other women were involved in women's organizations before or during their AIDS work, said they were feminists, tried to educate women, or attempted to be involved in working with HIV positive women. However, only Sue began her involvement with AIDS through her work with women.

Violet had worked with women's organizations before beginning her work for a Native AIDS group. Working for the betterment of women is important to her, but it has been in the context of contributing to the growth and health of Native communities. Violet has worked only for Native women's organizations. Despite her involvement with the community development of Native women, Violet does not identify herself as a feminist. She says she does not see feminists dealing with the issues important to Native women:

That's just coming from being a Native woman and coming from my community. It seems that any issues that we have, they never get addressed. . . . We're already at the bottom of the totem pole. Anytime we get involved with any of the organizations like those, we don't get anything from them.

Although the lesbian feminist critique may suggest that lesbians should be addressing those concerns more relevant to women, it seems quite unlikely that Violet would be working in an organization she felt was "feminist" given that what she is identifying within such groups could be called racism. According to the logic of the lesbian feminists, there may be a suggestion that she put her energy toward those issues which affect Native women specifically, which she has previously done. However, Violet said that she found homophobia within the Native women's groups. To further complicate matters, she has also seen sexism in the male-dominated Native organizations. The conflict in community work abounds.

Violet came to AIDS work through her commitment to the health and growth of Native communities. She said that while she saw AIDS as a disease that did not impact on her community, she didn't care about addressing it. When AIDS first started to take its toll, she said she thought, "As long as it's white guys, what the hell. The less the better." This reveals the fact that Violet did not perceive herself as being in community with white gay men. Once she saw the potential for HIV to devastate Native communities, she began to work to educate Native communities in the Atlantic region about AIDS.

While lesbian feminists decry the idea that lesbians are doing work "for men" in the HIV epidemic, the reasons and motivations that these women became involved in the response to AIDS are much more complex than this gender analysis would lead us to believe. In fact, there is little evidence to support that these six women were thinking much at all about the impact that AIDS was having on the gay men in their lives. As is demonstrated below, there were very few gay men in

their lives prior to their AIDS work. Rather, the lesbians that I spoke to expressed concern for people in the area where they lived and a desire to spread information about this disease. They felt the need to heal and to care, but not specifically for men.

Neither did they feel the need to care specifically for women. The lesbian feminist critique may have been less harsh were lesbians seen to be attending to the needs of other lesbians and women in the AIDS crisis. All of these women expressed concern for women's needs, but only one of them had regular contact with HIV positive women. In terms of education, women-specific information was seen as necessary, but that was within the context of more general audiences. Two of the women had been part of a woman-specific response to AIDS, but did not continue that involvement even while they remained involved in AIDS work. Given this lack of focus on women, with the one exception, I would not say that these lesbians were doing this work "for women."

Let this not sound like a criticism of the work that these women did. The work may not have been for women, but it was not specifically for men, either. Before concluding that the work must have been for a small group of transgendered people, examine the scope of the terms within which this attempted analysis occurs. These women's experiences have been discussed from the lesbian feminist analytical framework of gender. From this point, the critique has been able to explicate historical relations and social power struggles between the genders which problematize AIDS work for lesbians. It has not been able to illuminate other intersections of social power relations, such as race and class. Nor is it able to

account for the multiple commitments and motivations that these lesbians faced, such as their desire to participate in creating healthy communities wherever it was that they found community. Asking these women how it is that they came to be workers in the AIDS crisis shows that their work and their lives are accomplished within the context of many social relations, not only those of gender. Of course, these women had varied foci for their labours.

Violet's example demonstrates this desire for creating a nurturing community at the same time that it shows how women of color were beyond the scope of the lesbian feminist critique of AIDS work. The AIDS phenomenon had the power to highlight social problems of poverty, racism, and heterosexism in North America. Within the Native communities in Nova Scotia, Violet says after she had been involved for a time she realized that AIDS had helped to bring on-going problems to the fore:

We have to start healing our communities. . . . And, now when I look at the scope of it, the scope of HIV and AIDS in our community, I see more than just that. I see all those other things that have to do with alcohol and drugs, family violence, and how our communities are so affected by it, all those things. It seems that our communities are so much at risk because of all of those things.

For Violet, AIDS is only part of what is at issue in the context of "her community." She also sees the opportunity for education, dialogue, and action on other problems. Although she is a lesbian, Violet identifies with the needs of Native communities in Nova Scotia.

The lesbians that I spoke to all expressed commitment to what they understood as their communities. In contrast to what lesbian feminism suggests, this did not necessarily translate into simply to the "lesbian community," nor the

"gay and lesbian community," nor even the larger community that feminists are most concerned with: the community of women. This stance came through most clearly in my discussion with Violet, who said during our conversation, "The only ones that can speak for us are our own." She was referring not to women nor to lesbians but to other Native people. Whenever Violet used personal pronouns referring to a group to which she belonged, it was a group based on Native identity. While lesbian feminists try to lay absolute claim to these lesbians based on their sexuality and gender, race is crucial for Violet's life and work.

The feminist critique narrows its focus to lesbians doing AIDS work. An individual woman is assessed in terms of her commitment to issues which affect women, or perhaps even those which are of concern to lesbians specifically. She is understood as "a lesbian" only. This has the effect of excluding other aspects of the individual's social existence. One of the women interviewed, Sue, provided a parallel example of this problem while she was explaining that people identify who their own peers are. That group may not be the same ones that someone else would see as that person's peers. Sue said, "Some people based on their understanding of what a peer is, some people will speak for or represent a whole group of people that they may not represent." What I am getting at here is not that feminists don't represent the concerns of lesbians. Whether they do or not is a matter which may be debated elsewhere. What is important here is that those lesbian feminists who question AIDS work are conceptualizing lesbians as *only* their peers without examining what other community affiliations, motivations, or conflicting identities they have. The understanding that the lesbian committed to

AIDS work has of who her peers are, or who her community is, is not examined within the lesbian feminist critique. This failure is based on what Phelan (1989) calls the totalising tendency of lesbian feminism. The centrality of gender in this analysis eclipses all other social relations so that everything is explained through the analysis of the relations between men and women.

Aside from the lesbian feminist theoretical inability to deal with difference, there is a second problem with lesbian feminism as it relates to this thesis which has to do with methodology. Ironically, it is one of the most promising methodological innovations of feminism which I now turn to in explanation of how it is that the feminist analysis of lesbians and AIDS appears in some cases far removed from the lives of the lesbians in this study. In this thesis I have been researching from the feminist methods suggested by Smith (1987), Aptheker (1989), Phelan(1989), and others whereby I begin from the standpoint of those on the margins. Any theory, including lesbian feminism or the critique expounded upon here, is to be tested against the experiences of women. Such reflective knowledge building was limited to white urban lesbians among those critical of lesbians doing AIDS work in the literature (Stone, 1988; Schwartz, 1993). Even those who were sympathetic or defensive of the work that lesbians have done in the AIDS crisis had not spoken to women like the ones represented in this thesis: Native women and women living in small communities. Perhaps it is in part because of this limit that the lesbian feminist critique was able to ignore the complexity of identities that all women live within.

While the lesbian feminist critique was grounded in the experiences of some lesbians, these experiences should not be transferred to stand in as truth for any woman that identifies herself as a lesbian. It is probably true, as Patton observes, that many lesbians began their involvement with AIDS work as caregivers. However, a problem arose when lesbian feminism mistook this to mean that, therefore, lesbians are caregivers in this epidemic. A test of this idea against the lives of the women in this research shows that it is not universally the case, and certainly has not been the experience among those lesbians working and volunteering in the response to AIDS in Nova Scotia.²

In the last chapter I described how when women started to move out of the home to work, the two occupations open to them were ones which their housekeeping had prepared them for: teaching and nursing. Lesbian feminists charge that lesbians ran to the bedsides of gay men, as women had always done for men, to nurse them (Stone, 1988: 143). This was not the case with the women interviewed here. None of these women regularly cared for gay men, or anyone else, with AIDS. Sue said that she made personal choices about when she would offer personal care to the people she knew with AIDS who were ill. None of the other women participated in caregiving. Even Agnes who had worked in palliative

²This thesis is limited to those who participated in AIDS groups in Nova Scotia. There certainly have been lesbians outside of these organized responses who personally cared for those dying with AIDS. However, the literature has also been primarily based on the experiences of lesbians involved in organized responses. Therefore, the comparison we are making between what Nova Scotia lesbians have done and what lesbians in other parts of North America have done is on the same basis.

care before coming to AIDS work remained an organizer and did not make care part of her work.

At the same time, teaching and the more broad notion of support were certainly things which these women did. While lesbian feminists have been critical of lesbians as caregivers, much less has been said about lesbians as teachers. All six participated in educating in some way about AIDS, whether it was about the disease itself or about safer sex. Five of the women were trained as teachers or had worked in the profession. Here is where a gender-based analysis of AIDS work does contribute to our understanding of the experiences of the women in this thesis. The theoretical and methodological problems with the feminist critique of AIDS work acknowledged, it is crucial to continue to construct an understanding of the ways relations of gender conflict and impact on the lives of different women.

Winnow says that the attributes women possess, either by "nature" or through socialization, could be utilized in AIDS work (Schwartz, 1993: 231). Schwartz states that "from nursing, women branched out into the fields of social work, teaching, and counseling - all professions compatible with an image of woman as nurturer" (Schwartz, 1993: 231). These six women, then, were not using terribly different skills than their mothers and grandmothers may have used to work both inside and outside the home.

Two of the women suggested that they understood they were using skills that women are taught, and even that these attributes could be strategically used by AIDS educators. Violet suggested that AIDS education initiatives should utilize women's ability to teach the people around them:

I think as women, as Native women, we have to be the ones to educate them. And, that's what we're doing. We are the teachers, we are the ones that have to tell our kids and educate our communities. The women have to get educated first. Once the women are educated, they can go home and educate their kids. We can go back and educate our communities. But, it is the women that are the major factor, I find, in Native communities when it comes to teaching about sex and sexuality.

Violet is suggesting that women are leaders when it comes to informing and developing their communities.

Sue echoes that idea:

Really effective work is going to happen in the community with women who are active in their community. Women have been doing health education, sex education, and support work for years. It's just to try to get them involved with HIV.

Agnes also noticed that women are usually involved in teaching, but was more critical of it. She suggested that the women in AIDS groups are the educators, but have little decision-making power. In contradiction to the notion that lesbians have little power in AIDS groups, it was Agnes and others who formed one of Nova Scotia's rural AIDS response groups, which gave her significant decision-making power in its formative stages.

Teaching, and support work as well, are skills and abilities which women have been expected to possess. They have been nurtured in women, yet, are not solely feminine attributes. However, for these six women, the desire and ability to educate motivated and shaped their contributions to AIDS work. Lee said, "I tried to keep my activities geared toward education and advocacy rather than in home support." What is more, Sue and Violet suggest that AIDS education and community development efforts should utilize women's positions in communities as teachers, counselors, and organizers.

Community involvement

I am arguing that these women were coming to AIDS work out of perceptions that AIDS was affecting their communities, or at least that they intended to ensure that it did not devastate them. Given this, let us look at the different areas and people with whom they were concerned. I have already shown that a lesbian community was not necessarily at the forefront of their motivational identifications. The Native community was central to Violet's concerns and actions. Some of the other women showed concern for their geographical communities or for other women. None of the women with whom I spoke said that AIDS had touched them in much of a personal way before their involvement, although two said that, prior to their AIDS work, friends had passed away from complications due to AIDS.

The idea that some lesbians became involved in AIDS work because they felt that they belonged to a gay and lesbian community under attack has caused some to point out that such a community barely existed before AIDS (Shulman, 1994: 216). In fact, Sue says that she still does not see a lesbian and gay community in Nova Scotia. She points out that since gay men and lesbians are not in community together, it is not logical to expect lesbians to do more for people with AIDS, or to look for gay men to work on lesbian health issues like breast cancer. We need to build community between lesbians and gay men to encourage such mutual support, she argues. However, despite the fact that she does not see a mutually nurturing community, Sue admits that gay men have been an important part of her continued involvement. This work is important in her life not only

because it is about creating healthier communities. She is also participating because she has met a lot of gay male friends who have HIV, some of whom have died. So, while the community may not be very developed, she has been able to find bases for friendship with gay men over the years getting to know many of these men through AIDS work.

Although Jan is the only one to observe that her lesbianism contributed to her involvement with AIDS, Sue's relationships with gay men have influenced her ongoing commitment. It might seem to be common-sense that the other women had a better idea of the impact that AIDS could have because their sexual identities had brought them closer to gay men. Yet, this is not necessarily the case with the women interviewed. Faderman has shown how gay men and women organized in the 60s and 70s for sexual liberation. However, before their involvement with AIDS work, these women did not do much in the way of political organizing with gay men despite the fact that the six women are each fairly group. While living as lesbians may have made these women aware of homophobia and heterosexism, there is little indication that these women felt that they were in community with gay men *before* their involvement with AIDS work.

It is complicated to speak of a "before AIDS" for some of the younger lesbians with whom I talked. For Lee, AIDS has always been a fact of her life as a lesbian because she came out after AIDS. She believes that this has given her and other lesbians an opportunity to get to know gay men that otherwise would not have existed:

When I first came out, I didn't know any gay men. AIDS work and AIDS organizations have provided a way for lesbians and gay men to work side by side. I think we'd be pretty much camped in our own little communities if AIDS hadn't happened.

So, involvement with mixed gender organization may have come through AIDS work, but there is not much of a "before" and "after" to compare for younger lesbians.

There have even been aspersions cast on the notion that AIDS could bring gay men and lesbians closer together. Patton argues that AIDS had the potential to create stronger community links between lesbians and gay men, but that it did not happen. Also, Stone argues that AIDS brought together individual lesbians and gay men, but she concludes on the whole the lesbian and gay communities were not able to resolve differences. Beth Elliot wrote an article in 1992 in which she argued that lesbians have been pressured to identify with AIDS as a way to "replace lesbian feminism with a forcibly integrated community in which lesbians play the traditional female role" (quoted in Califia, 1995: 224). The women interviewed did not do much political organizing with gay men beyond the scope of their AIDS work, although they sometimes socialized together. Lee was involved in quite a lot of community organizing with gay men, but all of it was *after* she became involved in AIDS work. Lee does indicate that she considered herself to be connected to gay men in a "sisterhood/brotherhood, community sense."

The gay and lesbian communities in Nova Scotia have had opportunities for political organizing together, such as the Gay and Lesbian Association (GALA) and,

most recently, the Nova Scotia Rainbow Action Project (NSRAP).³ There have also been community-oriented projects and gatherings such as *Wayves Magazine*. However, these groups have had small memberships and have often been centred in Halifax, leaving those outside the city to organize their own groups. Such groups have existed outside the Metro area of Nova Scotia. However, the women interviewed did not indicate that they had participated in these types of political organizing alongside gay men before they became involved in AIDS work.

On the social front, the six lesbians had some interaction with gay men, although most of their friends are other lesbians. Agnes says that while she has some gay friends, in the area that she lives (which is outside Metro) gay men and lesbians seem very segregated. "I have gay men friends, and when I go to their house [my partner] and I are the only lesbians. I don't know why they invite us." Maggie said that most of her friends were lesbians.

The women's involvement with AIDS has changed their personal relationships with friends in some cases. Lee feels alienated from her gay male friends because she feels that gay men would not be there for a lesbian health crisis:

Sometimes I have this almost resentment because if a virus tomorrow came out that only targeted lesbian women, even though that's not possible, I don't think the gay men would be there for us, and I don't think the straight

³ The Gay and Lesbian Association of Nova Scotia (GALA) no longer exists. During its functioning, GALA had a board of directors consisting of gay men and lesbians. The organisation ran a nightclub and also responded to issues affecting gay men and lesbians in Nova Scotia. In 1996, a new provincial organisation was formed called the Nova Scotia Rainbow Action Coalition. Its membership includes gay, lesbian, and bisexual people, and is open to anyone who wishes to be involved with political organising on issues affecting non-heterosexual people.

women would be there for us. . . . So, sometimes I really get into thinking about, well, let's look at what's killing most of our community.

She says that it is through her involvement with AIDS work that she has become aware of this problem of the lack of support for lesbian health concerns. Breast cancer comes up for her as "the biggest" current health issue for lesbians. This is consistent with what other lesbians have insisted about lesbian health. In 1990, Victoria Brownworth declared in *The Advocate* that "the statistics about women's health are staggering" (p.44). She went on to illustrate with the American statistical information that 110 000 women died of breast and gynecological cancer in 1989, which was more than the entire toll of AIDS during all the years of the epidemic in that country.

It is interesting to note that Lee does not feel that straight women have been as supportive of lesbians as they could have been. Violet also experienced some perceived problems with straight women's organizing, or what she called feminist groups.

Most of Sue's friends are people who also do AIDS work:

HIV and AIDS work, I believe for you to be able to do it means looking at yourself all the time. Like taking care of yourself, learning how to deal with change, loss. . . . So, I try to keep people around me who don't question that. We are being with people as they get sick and as they die. And, being with their friends and family. It's really important to me personally that when I'm socializing or chilling out or being with people that that's not questioned.

While this does include gay men, Sue's group of friends is not centred around sexuality as much as it seems to be focused on people who can empathize with her position.

Heterosexism and sexism

The process of coming out was of varying degrees of importance to these lesbians. They all reported being "out" to some extent in the work that they did around AIDS. For Agnes, Sue, and Jan, being out in the work was not an active process. They did not make a point of establishing their sexual orientation, nor did they go through any elaborate measures to hide it.

AIDS work is one place where lesbians have come to the work expecting that, at least within the group, they would not have to face the problems of homophobia and heterosexism as in other work. Shulman contends "ACTUP was the only movement I could agitate in that permitted me to affirm my homosexuality" (1994: 216). Indeed, AIDS work is one of few places where lesbians and gay men were seen to have necessary knowledge and would be paid for that insight and for their work. However, while the perceived homophobia may have been less within AIDS groups, it is not the case in Nova Scotia that there has always been affirmation for lesbians.

Within the Nova Scotia groups, there was a mixture of people. Lee observes that, since it was AIDS, they all had some idea that they would be working alongside gay men, if not lesbians. However, she also says that people were at "different stages of dealing with their own heterosexism." One of the group members who participated in educational efforts was very supportive of the gay men in the organization. Yet, not cognizant of her heterosexist approach, she told classes of young people to "wait until you're married" before having sex.

One of the women said that she had encountered homophobia from HIV positive heterosexual women that she worked with. She thought that "a lot of them just haven't been, that they know of, around gays or lesbians before." These women exhibited their discomfort by ignoring her personal life and relationships.

Agnes was more aware of sexism within the group than of homophobia. At one point while she was working with the AIDS group, she felt that the men took over. That was problematic for her not only because the men did it, but also because the women did not put up a struggle. Agnes says that women are held or forced back from positions of power in the AIDS organizations. With the ongoing problems with sexism, she says, "We aren't closer together in any of this."

While she observes that women in her group thought "that the group was being taken over by the men," Lee remembers perceptions that the women felt as if they were doing all of the work. She says that the women did not feel as if they were being listened to in meetings. After an open discussion about this problem within the group, she was satisfied that the difficulty was with two men in particular, who had been the first gay men to get involved.

Sue recognized resistance from gay men to women's programs getting funding and support:

When other groups started to get funding and started to want room to do advocacy to become really active member of the AIDS movement, I think there was real resistance there. I've certainly heard people who do women and AIDS work or targeted work across the country talk about that; a real resistance and resentment from gay men in particular.

The focus on the need for AIDS groups to address homophobia was well understood by the time women's groups, Native organizations, and Black-focused

projects began to point out the needs to address sexism and racism. Sue says gay men as a group did not lend their support to organizing these types of initiatives.

Sue also identified some of the sexist comments that women hear while working in a fairly male-oriented environment. The examples she gave included comments from the men about being "on the rag" if she was in a bad mood. She also observed that many of the men had impressions about women as a group that were inaccurate. Within the work, Sue wanted to see "more opportunities for people to reflect on that stuff and how their attitudes affect other people."

Outside of the groups that these women worked with, homophobia and heterosexism were more frequently encountered as these were some of the issues tackled in educational programs. Violet found it important to come out to the people being educated because this made them confront their own negative perceptions about gays and lesbians. Once when the group was asked to attend a community event, Lee recalls that the organizers reminded her group "this is a family event." She also finds that as "heterosexuals are getting scared that their little white heterosexual middle-class kids are going to get AIDS" they are volunteering for AIDS groups and bringing their heterosexism in with them.

In organizing an annual AIDS walk as a fund- and profile-raiser in one area of Nova Scotia, I encountered this problem myself. A heterosexual woman who was newly involved made a comment. She was adamant that there should be no gay-oriented material in the walk because, as I so clearly remember her putting it, "AIDS is everyone's disease."

Two of the women report problems with being out as lesbians in other work. Like Lee, Violet reports homophobia in other work situations. Violet says that she left the Native Women's Association because they were certainly not able to affirm her sexuality: "What happened with that is I found they were too homophobic, the national organization, and I sort of got disillusioned with them." Lee found that co-workers and supervisors in a previous government job had problems with her sexual orientation. Both women were satisfied that there were less problems with homophobia in their AIDS work.

Learning

Despite the difficulties between lesbians and gay men in AIDS organizing, the women that I talked to did recognize some learning that had been able to happen because of their participation. Many of their new insights came from simply being in a crisis situation, where so many people are dying and there continues to be inadequate state action. Being closer to gay men also allowed these women to actually see how the men lived in a greater detail than had perhaps been available before.

There is a sense of how emotionally challenging the situation may be. One of the women who has been employed by an AIDS group talked about how the people involved in this work learn to deal with change because so many people are dying. Among the knowledge she has gained that she did not have before her

involvement she counts learning how to put a funeral on before she was thirty years old.

Agnes feels no better equipped to deal with the change. She says that despite the work that she has done, "I'm not any better at dealing with it than I ever was, so it's not like I've learned how to deal with it. But," she continues, "I think I learned lots of things about the system, about inequality and sexism and homophobia."

In contrast, Jan does not think she learned much about these relations in her AIDS work, not because they were not part of the work, but because she had encountered sexism, racism, homophobia and these other inequalities in our society in other work that she had done.

Along with the learning that lesbians have done, there seems to be room to continue to promote the learning of gay men from lesbians in AIDS work. Sue perceives that as long as the gay men she worked alongside would refer to the lesbians as "fucking dykes," there is room for more understanding between gay men and lesbians.

To stay or go?

At the time that we spoke, the two women who were paid to do AIDS work were continuing their involvement as did one of the volunteer women. The reasons that the other three women gave for leaving the work hinged around feeling that their part was done. Those who remained in the work felt that AIDS was as crucial as

ever among those with whom they worked. They continued to see their contributions as important.

Violet is paid for the work that she does. She says that if she were not paid, she would still be doing the same kinds of things: educating people about sex and sexuality and counseling them. She did not expect to feel such a commitment, but over the course of her involvement she has grown increasingly concerned that people in the Native communities know what to do when AIDS comes to their part of the world.

Jan felt that an increase in the number of men changed the nature of the group so much that she no longer wanted to participate: "The nature of the group, I felt, changed a lot. I felt after a couple of years I didn't have much to offer the group. It didn't seem relevant to me anymore. I had a conflict of ideas with the way things should be done." Jan left when some of the squabbles within the group started to be more than she wanted to deal with. She indicates that she felt the group would be fine and did not need her anymore.

The change within the group was partly from a focus on support for families of those living with HIV to support for people living with the disease. The educational component of the group's mandate seems to have grown up in there as well. Three of the women felt that men began to take over in the group they worked with. It is possible that the men, who were gay, were concerned with provision of services to other gay men who were HIV positive.

Lee supports this idea in her discussion of the two gay men who were causing struggles within her group:

It was a big issue for them and their community. Even though they weren't HIV positive, they knew people who were. The group was, at that point, meeting and looking at videos. They really wanted to make it do something: have an office, have a phone line, have business cards, staff it. And, they moved fast.

The gay men saw an urgency and a way to address it in this fairly new community group in which they quickly became members.

Further to accounting for why she no longer participates in AIDS work, Lee explains that she felt her contributions were not being well-used. According to her own analysis, that was because the group she worked with had become focused on the immediate needs for care and support of people with HIV who were not well. She explains her choice to re-focus her energy on less crisis driven work in this way:

Because in the end, nobody dies if your job doesn't get done. It takes a certain kind of person to deal with death that much, and I don't think that I'm that kind of person. If I don't feel like I can contribute on the educational forefront or on the political forefront, which I didn't feel like [that group] was allowing me to do, then I didn't feel like I had a lot to contribute. When you've got someone dying or someone who needs medication, or need to raise money in able to be able to exist, you lose the rest of that as your focus. That becomes your focus.

Lee was not interested in participating in such a support aspect. While she understood the immediacy of the need for care and support, Lee was not interested in doing these things herself.

At the same time, others involved in responding to AIDS in Nova Scotia have seen support as crucial and been eager to organize these types of responses. Agnes originally became involved to provide support to the families of people with AIDS. While she was no longer involved in the group when we spoke, she

continues to be concerned that people with AIDS or other terminal illnesses and their families get support and care.

Caring for communities

The reasons that these lesbians became involved with AIDS and their experiences contradict the lesbian feminist critique of AIDS work, show that it was a limited view of these women's lives, and show how, nevertheless, it is necessary to understand the problems associated with the work. Whether similar or disparate, the lives of the six lesbians interviewed here as well as my own are more complex than the critique of AIDS work could explicate.

The critique itself postulated that women were running to the bedsides of gay men to take care of them. In direct contradiction to the presupposition that lesbians were acting as women always have, as caregivers, none of the lesbians represented in this thesis participated in the care of people living with AIDS. These women did, however, participate in community education. The teaching on AIDS that these women do has been directed at the communities that they have been concerned about: the community in which they live including the children that live there: Native communities which need to heal from years of social problems, and women who have particular concerns and needs when it comes to HIV and AIDS. Although teaching has also been considered a female pursuit, at least for the last century, the lesbian feminist notion that these women have been doing this work "for men" does not hold true in this case.

There have been suggestions that lesbians may come to AIDS work through personal attachment to the issues. The idea that lesbians as a group experienced some personal threat from AIDS never really took hold, although some outspoken lesbians such as Pat Califia (1995) insisted that the risk should not be underestimated. When lesbian feminists have spoken about personal attachment, it has meant having friends living, and dying, with AIDS. Such personal impact was not prominent in the lives of the women interviewed for this thesis. It is possible that lesbians and gay men in Nova Scotia over the last two decades did not have enough contact, either in political organizing or in socializing, to develop close relationships.

Many of these women had histories of social activism which gave them an understanding of some of the social relations linked to AIDS. They had already tackled heterosexism, racism, and sexism in other places. AIDS was another area of social struggle where homophobia and heterosexism needed to be tackled, where women's poverty and other signifiers of sexism demonstrated themselves, and where racism was remade in the form of inadequate responses in communities of color. In their AIDS work, these women were at the forefront of working with these problems in their communities.

These women became involved in AIDS work because they perceived that their communities were in danger. Some of the women had seen community members and their families devastated by the syndrome. They wanted to work with these people to build better supports. Through their education and community

mobilization these women worked to prevent and relieve hardship, sadness, and turmoil.

Chapter 5

Conclusion

The HIV epidemic highlights contradictory commitments among the social and political relations of race, class, sexuality, and gender. It challenges social activists to cross boundaries of community and identity, with the hope of resisting racism, classism, heterosexism, and sexism. A progressive response to AIDS must grapple with these social power imbalances.

The feminist critique of AIDS work is part of this struggle for radical social change. By highlighting the historical and social inequity between the genders in terms of the division of labour and, more recently, the public and private spheres of life, some lesbian feminists have been able to reveal some of the social organizing that constructs responses to AIDS.

The lesbian feminist critique is a part of this ongoing re-creation of the social relations of AIDS and the work that is needed to care for those who are affected and infected. The assertion of systemic sexism within AIDS work leads to struggles within the AIDS movement. Such crises are, of course, necessary among those committed to a process of dealing with the social relations of inequity.

However, Patton points out that such a "process of mutual critique among potential allies" has consistently failed to lead to coalitions between those who would seem well suited to collective effort (1990: 6). While there are lesbian feminists who would argue that lesbians and gay men are not suited to be allies at

all when it comes to AIDS organizing, I would argue that they must work together at some points. For example, the social inequities which are re-articulated in the AIDS crisis are of concern to lesbians, gay men, and all those who participate in progressive social change.

The lesbian feminist critique of AIDS work describes some important problems with lesbians' involvement in the response to AIDS. All those involved must confront within the work these sorts of socially organized problems. How will lesbians and gay men, as well as others in Nova Scotia such as the Native community or women's networks, be able to form meaningful collective actions in the face of powerful and important critique such as that which lesbian feminism created? Such critique is necessary. The question is whether it may be constructive to allies engaged in related aspects of progressive social action.

The problem is not that the goals of lesbian feminism are at fundamental odds with AIDS organizing. Both must act on the social relations which constitute sexism, racism, heterosexism, and the inability to effectively respond to AIDS. In the end, their political goals must be the same. The problem is with the articulation of the lesbian feminist critique. Understanding lesbians who participate in the response to AIDS only in terms of their sexual identity or gender limits the scope of what is seen to be relevant for their lives and for their liberation. Even the overarching social problems which activists have been struggling against for some time are rearticulated through AIDS - things like poverty, racism, and classism - are not made visible when the focus is on only a part of women's lives.

Sarah Schulman explains that during the mid-eighties, activists moved away from organizing with overarching political ideas (1994:5). Identity politics shifted the focus of activism away from being ideologically based to being ethnically based. There was a notion that one had to make a commitment to the community which gave rise to her identity, as if identity were a simple phenomenon. Thus, the lesbian feminist critique of AIDS work sought to steer lesbians to work on those issues obviously related to their sexual identity.

At the political level, lesbian feminism utilizes the notion of the lesbian community to speak of that group of women who share a lesbian identity as well as common history. However, on the personal level the six women who participated in this research show various allegiances and commitments. They have identities that are complex and varied. Sometimes, as in the problems that the critique of AIDS work highlights, these identities conflict. When lesbians who are doing AIDS work to create a healthier community must face sexism, there is conflict. While the lesbian feminist critique is based on the political assumption that the lesbian community is a totality, in the everyday and personal lives of lesbian women it is but one social identity.

The effect that the lesbian feminist critique of AIDS work has is to undermine cross-community work that lesbians are able to do. It does so by negating the range of identities that these women have in favour of supporting the political agenda of one. There is no accounting for these women's differences in terms of their histories and commitments. Only the sexual identity is recognized as an arena

for political and personal action. Thus, personal action that takes the form of AIDS work is understood as unrelated to the political priorities of lesbians.

Some feminist theorists have come to realize that people have multiple identities. These women are not just "lesbians" but mothers, sisters, members of a geographical community, white, Native, middle-class, teachers, and more. As Pat Califia says:

It's confusing. It would be so much simpler to think about these issues if women would just be consistent, have simple identities, and stop behaving in complex ways that are affected by their culture and their need to survive. What we need is a little more monogamy and purity and all the other virtues of the middle class. Including the money (1995: 226).

What is more, these identities are not constant. The lesbians represented in this research were challenged by their participation in the response to AIDS to redefine their identities and their community allegiances. Some are no longer participating in AIDS work, having chosen other priorities. Some are no longer lesbians.

Violet's example shows that the lesbian feminist critique of AIDS work, constructed as a totality, was racist. For her, a Native lesbian, the reasons to fight AIDS might have more to do with being a Native person. She is working for the sake of Native communities and people. Although relations of gender are part of this work, relations of race have a prominent role. These social relations involving race were not evident in the lesbian feminist critique. As bell hooks (1988) pointed out: feminists can be very white in the way in which they view the politics of gender.

Violet's assertion that as long as AIDS was affecting white men, it was not a concern to her also illustrates that these women were not becoming involved with AIDS to look after men. This was one of the points put forward by those such as

Stone (1988) and Schwartz (1993) . The lesbian feminist critique narrowly postulated that lesbians were caring for gay men. This may have been the case for some. However, for the six represented in this research, it was not. While Sue says that she makes choices about when she will assist with care, the vast majority of what she does has little to do with men at all. Agnes is involved with organizing people to do caregiving, but does not do it herself. The perception that AIDS was a concern for Native people helped to motivate Violet to action. None of them were even working solely with gay men, although they all included gay men in their work. Personal care for men was not a prime part of their work.

When moving out of the home into the sphere of work, Faderman tells us that women became nurses and teachers (1991). These women were educators in their communities, but they were not caregivers. They were teachers and also were community developers, organizers and administrators.

These women do not see AIDS as a gay man's disease, as the lesbian feminist critique assumes. Although the numbers may be found mostly with gay men in Canada, what these women see is the disease's impact, or possible impact on their communities. Again, the communities they define as the one(s) they care most about are not necessarily lesbian communities, but the place where they live, the people that they know. Others concerned themselves with families and loved ones of those living with AIDS. All participated in educating their communities.

Despite its problems, however, I cannot dismiss the lesbian feminist critique. Lesbian feminists have been justifiably critical, especially in terms of the amount of volunteer commitment, about the work lesbians do in the response to AIDS.

Although, gender inequity is not at all peculiar to AIDS organizing, if AIDS organizing is constructed as a movement for social justice, gender inequity must certainly be targeted for change. In other arenas of social struggle, I would not suggest that women stop struggling for equality. There is no reason not to continue to work against power relations of gender within AIDS organizing.

What has been highlighted is the complexity of lesbian lives. From country to country, or woman to woman, the social relations that arise from her life are multiple. If she says she is a lesbian, something is known about her. The lesbian feminist critique argues that we know about the sexism that she faces in AIDS work. But, as the limits of the lesbian feminist critique have shown, we cannot know everything. We know little about the web of social relations she lives within: where she lives, whether she is rich or poor, whether she is a woman of color or white, whether she is a caregiver or an administrator, etc. To be lesbian does not represent the totality of her existence.

Instead of being unable to act because we do not know all there is to know about lesbians involved in AIDS work, this should be viewed as a process where lesbians continuously build knowledge through examining people's lives and relating that to what is already known. The lesbian feminism I have discussed here knew some things about lesbians who respond to AIDS. In keeping with feminist theoretical and methodological principles, I have weighed that knowledge against the experiences of lesbians. This understanding does not provide a grand theory of what lesbians live, or even what these six Nova Scotia lesbians live. That is, it does not explain every facet of their lives only through one identity. However, it

does present us with a more complex representation of the multiple and conflicting identities that lesbians live, a representation that may be closer to explicating the social relations which intersect in what these women actually experience on a day to day basis.

One of the women I spoke with who was very committed to AIDS work seemed to understand the complexity that the people responding to AIDS live. Sue held out hope that people could continue to work together despite the fact that there were so many differences among us. That hope arose because she felt that "we are all doing this together. We all experience it differently depending on our HIV status, our age, our state of health, all kinds of things. It's something about a shared commitment to the vision and to the responsibility."

It is more useful to understand that, although each person's experiences are different, what we share are some commitments and some goals than to see the similarities of a group giving it a community status whose imperatives are disparate from other such constructed groups. Agnes illustrates that when the differences of people are brought together and it works, it can be quite powerful:

Everybody was committed to that group. We had the same commitment. It wasn't depending on me or anybody else. When I went, the group didn't fall apart. And, when other people went, it didn't fall apart. It had an energy of its own. In the beginning it was really something because there were all these diverse people that you would never have thought would have come together. . . . It was really special. I don't see it anymore, that specialness, because it's gone now. But, at the time I couldn't believe that I could help initiate something that would run off on its own so quickly and that everybody would make a role in.

Lee echoes the idea that the experience of working in a diverse group was a rewarding one:

We did have people who were HIV positive, those who were gay, those who had had partners die from HIV, who were injection drug users, who were old, who were, young, who were students. The diversity I thought was quite good. There were people who didn't have a lot of money, people who had a lot of money. I always find those sorts of experiences quite positive.

This diverse group was able to come together to address problems that they all understood. For a time, they were able to see each other as allies.

In the face of crisis, perhaps it has been difficult to remember that there are all-too familiar social problems, each illuminated in the AIDS epidemic, that we all must fight. Sexism, heterosexism, racism, classism, and all the relations of power are, at once, what we struggle to overcome and what creates the conflicts among us. The ideology of difference that is imbedded within identity politics has highlighted how these social problems demarcate our lines of separation. We cannot allow these common problems to lead to our separation from each other. As I have shown, this is one of the effects of identity politics as it is articulated in the lesbian feminist critique of AIDS work.

Were we to find a way to honour and address our differences and work with each other, struggling together, we would be as close to our goal as we have ever been. Whether the goal of liberation is too far off, too radical, or too broad to imagine, it does not play the integral role in the lesbian feminist critique of AIDS work that is necessary were it to focus lesbians' and gay men's attention as a common goal. However, when we see difference being handled, if only for a time, among diverse groups of people working in the response to AIDS, there is still a chance that we can struggle together with a shared vision to achieve a common goal.

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Table 2.1

Question guide for lesbians who have done AIDS work

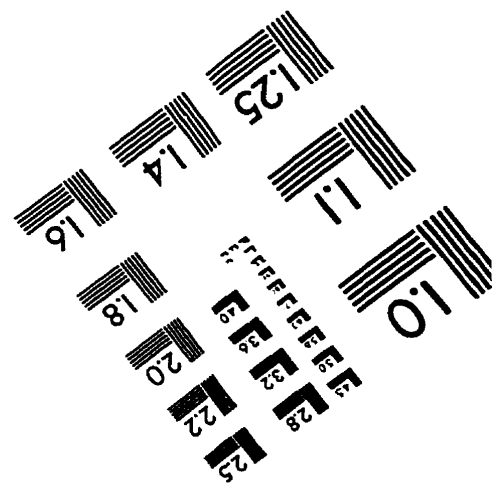
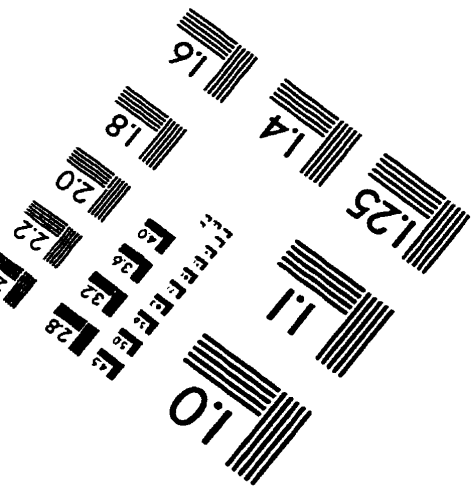
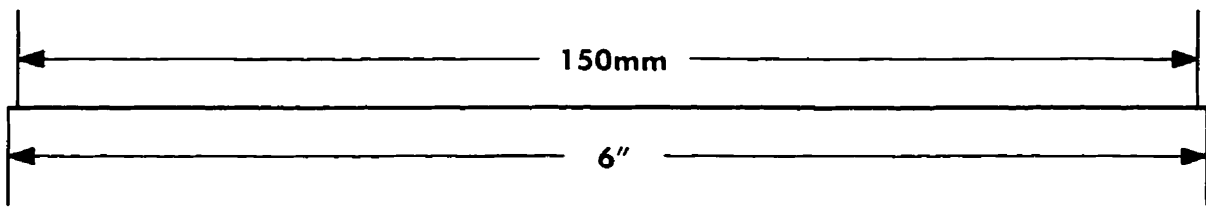
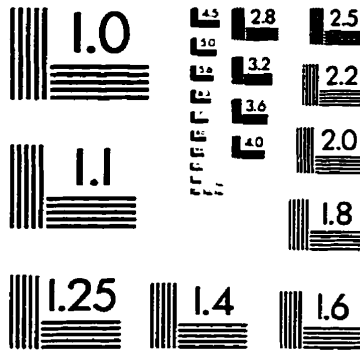
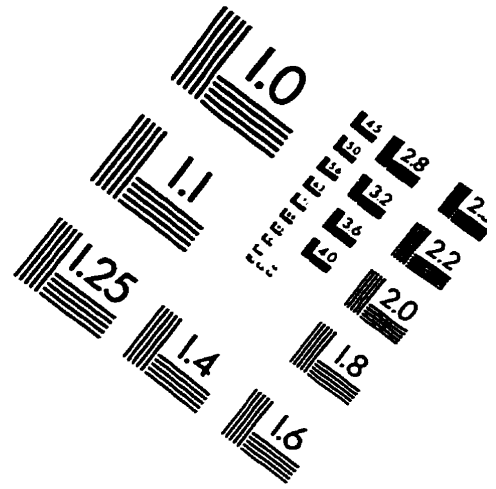
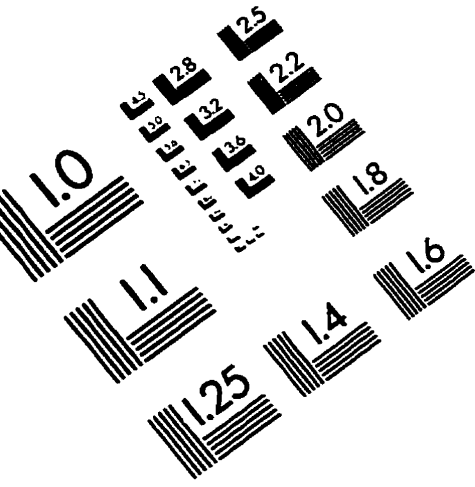
A. Demographics: where does respondent live now, where did she grow up - on-reserve or off, black community, rural, urban, size of community. Age. Coming out history - when, to herself, to others, past and present colleagues, who knows now, what were consequences.

B. Description of her work: story of her first becoming involved with AIDS work, how she came to present work. Responsibilities, everyday tasks, specific work. Ongoing involvement, leaving an AIDS organization.

C. Personal history: Other work before involvement with AIDS, gay communities, caregiving, women's communities, nature of the work, specific duties. How long doing this work? Education. Relationships with other women. Other work while responding to AIDS - volunteer, paid. Leisure activities - lesbian, gay, socializing. Affect of being lesbian on work choices and experiences.

D. Insights into the work: Demographic characteristics of people she worked with - gay, lesbian, straight, women, people of color, poor, HIV+. Atmosphere at the organization - conflict, comradery, personalities. Difficulties faced. Benefits, assets in the work. Who else worked there? Sexism, heterosexism, homophobia, racism. Key issues during her involvement, key issues now. AIDS an issue for whom - women, lesbians, Native people, black communities, poor? Learnings from the work.

IMAGE EVALUATION TEST TARGET (QA-3)



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