It's not just about HIV: An investigation of the Relationship of HIV Positive
Women to a Northern Ontario AIDS Service Organization

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The philosophers have only interpreted the world in various ways; the point is, to change it.

Karl Marx, "Theses on Feuerbach." In Marx and Engels, <u>Collected Works</u> Vol. 5 Moscow: Progress Publishers, 1976.

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Abstract

This thesis is based on the investigation of the social relationship constructed between women living with HIV/AIDS and a Northern Ontario AIDS Service Organization (ASO). Further, upon review of the literature, this research is considered an important contribution to the existing literature since there has not previously been research conducted on the relationship of HIV positive (HIV+) women to a Northern Ontario ASO.

This research started in November 1998 and the interviews were completed in December 1999. I utilized a feminist, ethnographic approach, namely a Sociology for Women, as developed by Dorothy Smith (1987). This investigation was conducted through open-ended, one-on-one interviews with HIV positive (HIV+) women who currently access a particular Northern Ontario ASO. Staff of the ASO were also interviewed.

The information and analysis presented here is based on interviews with eleven people. Six of the people interviewed were HIV positive (HIV+) women and the rest were staff of the ASO, including a previous Women's Project Coordinator.

One of the major findings as a result of this research was that the socially mediated or mutually constructed character of the HIV positive woman's life is organized through several social relations she participates in throughout her life. This is not only in terms of her HIV status, but also in relation to class, race,

poverty, motherhood, and injection drug use. Thus, the socially mediated character of each woman's life must be considered when providing services for them. The social process of the relationship of positive women to a Northern Ontario ASO becomes "professionalized" in character, and it is this "professionalized" character which can prevent women from accessing the services of the ASO fully, because it marginalizes positive women by creating a "division" between staff and positive women trying to access services. Another research finding is that the social stigma of HIV/AIDS still greatly impacts upon women making use of services creating alienation for the women who feel outside the homosexualized HIV/AIDS programming or activities, and therefore do not often use its services. Finally, the notion of a "good" versus a "bad" client serves to marginalize some positive women in that some women are treated differently from others and may even gain different support because of the identity of "bad" or "good" attributed to the HIV positive woman.

Summary

This thesis is a preliminary investigation of the relationship of women living with HIV infection to a northern Ontario AIDS Service Organization (ASO). The information described and analyzed in this thesis was obtained through interviews with eleven people, six with women living with HIV/AIDS, four with staff, and one with a woman who was the "Women's Project Coordinator" at the ASO approximately five years ago (1994 - 1995).

Most of the HIV+ women interviewed are between the ages of 20-44, unemployed, and experiencing constraints on their ability to access services due to poverty, child-care needs, addictions and drug use, and previous abuse. This thesis focuses attention on the effort and activity HIV+ women develop in order to socially construct their relationship with the ASO. Considerable energy goes into an HIV+ woman socially organizing her relationship with a northern Ontario ASO. The way in which an HIV+ woman organizes her relationship is also required for her ongoing health and survival.

A finding of this research was that HIV+ women definitely had a "relationship" with the ASO but this relationship was indicative of the social location/positioning of these HIV+ women. Thus, the relationship of the HIV+ women accessing the services of the ASO was often mediated through several aspects of her life for instance, class, gender, poverty, level of education, her children, her family, sexual activity, and religion. The relationship is further burdened by the stigma of HIV/AIDS, something which profoundly affects

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women, especially marginalized women (Mykhalovskiy and Smith, 1994: 16).

Therefore, the mediated character of HIV+ women's lives socially organize and inform their lives and their relationship with a northern Ontario ASO.

The use of an institutional ethnographic analysis helps to meld together the broader social analysis and the local analysis of the relationship of HIV+ women to a Northern Ontario ASO by learning from the everyday social experiences of the people interviewed. This research is developed around the notion that the relationship of HIV+ women to a Northern Ontario ASO cannot be analyzed in a closed or cut-off fashion but rather, it must be analyzed in terms of its connection with larger social processes.

Research Findings

- The professionalized character of the ASO can prevent women from accessing services fully, but also becomes taken for granted by the HIV+ women and staff of the ASO.

- The socially mediated character of HIV positive women's life is mutually constructed through several social relations and not just her HIV status. This must be considered when providing services for them. For instance, how do we begin to get HIV+ women to start thinking of their own needs and wants and not those of the significant others in their lives? How can we transform the work we do with HIV+ women to account for the mediated character of their lives?

- The social stigma of HIV/AIDS acts as a barrier for women in fully accessing the ASO and its services and programs.

- The notions of a "good" versus a "bad" client serves to undermine the life experiences of HIV+ women and separates some of the HIV+ women out from others as "bad". Notions of "good" and "bad" are also linked with notions of "responsible" and "irresponsible" clients.

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Recommendations

- Create a more collective nature to the ASO incorporating the experiences of positive women and involving them in the everyday decision making of the ASO (this is elaborated upon in the recommendations section of the thesis).

- Develop and implement a participatory form of needs assessment for positive women in order to develop women's specific programming. A needs assessment of this sort would begin with the experiences of HIV+ women and their involvement should be built in throughout the entire process. A needs assessment of this sort should be by and for HIV+ positive women.

- Create a safe space for women to bring their children and to socialize and mingle or hang out with other HIV+ women and their children. This would include the development of programs and activities which may be useful to their children as well (i.e. a playroom). Along with this there is a need for child-care support funding for parents who are not able to bring their children to the ASO. This space will not only allow these women to be listened to and heard by each other, but also provide a venue to discuss issues of importance to them which are not always directly related to HIV or their HIV status. Most of the women interviewed suggested that they do not always wish to engage in activities which are HIV related, but rather wish to engage, in an informal setting, with other HIV+ women. It is often this informal gathering of HIV+ women which leads to the sharing of information and to their needs and concerns being addressed.

- Provide funding for HIV+ women considering attending social and support groups since most women have other things on their mind and in their daily activities (the mediated character of HIV+ women's lives) which can prevent them from taking part in activities which are beneficial to them. This will also alleviate the stress caused by financial constraints which may prevent HIV+ women from attending or even considering attending programs because they could be earning money or doing something they define as having more priority in their lives at that moment.

- The ASO needs to take up anti-poverty and childcare issues, by creating alliances with groups such as anti-poverty coalitions, or through viewing these issues as a central part of the advocacy work the ASO takes up since these issues are important to the lives of HIV+ women.

i. Introduction

This thesis is an investigation of the relationship of HIV+ women to a northern Ontario AIDS Service Organization (ASO). The thesis was developed around the research question, "How do HIV+ women view their relationship with the local ASO in terms of benefits, positive experiences, limitations, obstacles, barriers, contradictions in outreach and/or accessibility?"

I became involved in work around HIV/AIDS approximately ten years ago when I was working at CJAM, a campus radio station in Windsor, Ontario where I hosted a weekly radio lesbian/gay program called "This Way Out." This was built on the same radio magazine format as that of the National Public Radio Program (in the United States) of the same name. During that time I became involved with the Day Without Art Collective in Windsor, Ontario. As part of my contribution, I decided I would produce 24 hours of radio programming for December 1st, all of which would be about HIV/AIDS. During the first year of the broadcast I produced the entire show, interviewed numerous researchers in the field of HIV/AIDS, and tried to have the lives of Persons Living With HIV/AIDS (PHA) described by themselves on the air. Having HIV+ people talk about their lives on the air was the most difficult because it was hard to have people disclose their HIV status. The World AIDS Day/Day Without Art Programming continued on CJAM Radio for a few years after I left the station to pursue my academic career.

I was also asked to cover the International Conference on AIDS in

Vancouver in 1996 for CJAM Radio. What the international conference did was set the stage for me to develop a more critical awareness of the inequalities that exist in the world of HIV/AIDS. These inequalities and constraints exist for many of the HIV+ women living in northern Ontario. It was my desire to expose how HIV+ women describe the ways in which they socially organize and make sense of their relationship to a northern Ontario AIDS Service Organization (ASO).

During the development of my thesis I was hired by a northern Ontario AIDS Service Organization (ASO) to organize an AIDS conference which included a focus on the needs and concerns of People Living with HIV/AIDS. I was able to develop an understanding of the funding constraints northern ASOs encounter, as well as understand the ways in which HIV+ people living in northern Ontario may socially organize their lives by talking to HIV+ people who came into the ASO, and by talking with them at the conference.

Throughout this thesis I make use of the interviews I have undertaken with HIV+ women and the staff of the ASO. I use some of the excerpts from these conversations a number of times in different sections of the thesis. Some of these conversations are rich and substantial and I feel a number of them must be used more than once in order to exemplify relations and clarify points. In order to protect the anonymity and confidentiality of the people involved, each participant was asked to fill out a confidentiality form (see Appendix II). Along with this all identifying information such as place names, individual names, or the names of agencies or programs, have been removed from this thesis.

In this introductory section of the thesis I outline the research problematic, how the relationship of HIV+ women to an AIDS Service Organization (ASO) is a social process, and my theoretical and methodological perspectives for the thesis.

The Research Problematic

The number of HIV positive women in Canada is steadily increasing. For example, "in the first six months of 1998, women accounted for 20.5% of HIV positive reports; in 1995 they accounted for 19.4%, and in 1985-1994 for 10.1% of positive HIV test reports" (Health Canada, 1998:1). Further, 38.7% or 353 of all HIV positive women live in the province of Ontario (Health Canada, 1998:29). What must also be considered here is the level of under-reporting that is also taking place. There are many more people who have not been tested and thus these numbers can only be seen as estimates or approximate numbers. Given the fact that the province of Ontario has the largest number of positive HIV tests for women in the country (a reported 1,850 women have tested positive as of June 1998), Ontario is an important province in which to explore the relationship of women to AIDS Service Organizations. However, research on the relationship of HIV+ women to a northern Ontario ASO has not yet been conducted. This research is the first of its kind to take place in northern Ontario.

This research is important to the lives of women living in northern Ontario since the prevalence of women sero-converting in this area is increasing. There are approximately 226 cases of HIV+ people living in northeastern Ontario of

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which approximately 40% are women or 90 cases (Murray, 1999). The number of people infected with HIV can only be approximated due to the larger number of people who have not been identified or who have not sought any form of health care.

According to information provided by a northern Ontario ASO, most of their "clients" are under or unemployed and between the ages 20 to 44. As such, the financial constraints, for example of transportation or child care, experienced by these women reduce their ability to access the larger pool of resources in metropolitan cities like Toronto or Montreal. Regionally there are many remote or rural areas of northern Ontario which are without HIV/AIDS related services (Murray, 1999: 25). For instance anonymous testing is only available in Sault Ste. Marie, Mindemoya, Sudbury, North Bay and Thunder Bay. There are many communities in between these city centres in northern Ontario (Murray, 1999:25). Along with this, it has been reported that in terms of AIDS Service Organizations (ASOs) there is an uneven allocation of resources on a racial, sexual, gender, and class basis (Stoller, 1998:9).

The problematic or point of disjuncture that this thesis explores arises out of the everyday experiences of women with HIV/AIDS and their relation to the ASO. An HIV+ Aboriginal woman I talked with describes herself in relationship to race relations, and geographical location, as well as the social process it took for

her to access the services of the ASO in the following way:

> I first connected with the agency through the phone. It wasn't one on one, it was long distance, because of my distance away. I had no one in my area. I wasn't even told about [Person's name] until two weeks later. And she didn't even get in touch with me until a month later. It bothered me. The doctor had to go through her own doctor friends who had AIDS patients...It was four months until I spoke to a PHA [Person Living with HIV/AIDS]. I asked to speak to a PHA who was a native woman. That took six months. Even Voices for Positive Women [in Toronto] couldn't connect me with a native woman.

Although there seems to be a steady rise in the number of Aboriginal women becoming infected with HIV, there still seems to be limited access to resources for Aboriginal women. The route of HIV transmission for Aboriginals seems to be predominately through injection drug use in northern Ontario (Murray, 1999: 49). A disjuncture in experience of Aboriginal women occurs when the social relations they live such as racism, class or poverty, or route of transmission, cease to refer to their social worlds. But rather, the social worlds of these Aboriginal women get transformed in the work of the ASO where the ASO problematizes the Aboriginal women themselves rather than the social relations which impact on these women's lives. Along with this, Aboriginal peoples are further disadvantaged by racial discrimination, isolation, poverty, unemployment, poor health and lower social status and power. Therefore, in order to understand the impact of HIV on Aboriginal women, we have to take into consideration the historical and social process which socially organizes what it is to be Aboriginal in the Canadian context, and how this impacts on an

Aboriginal's HIV status or her relationship to an ASO.

The Aboriginal HIV+ woman interviewed above is exemplifying some of these social inequalities which stand out for Aboriginal peoples, particularly women. As Patton (1998) suggests, "For minority women, or class segments with less access to formal education, they have not acquired the capital or monetary resources to make themselves accessible to research or resources" (Preface XI). The same Aboriginal woman quoted above goes on to describe the isolation she faced and what this meant in terms of her receiving the services she requested. She also describes the way in which agencies and doctors could preserve confidentiality in ways that worked against her. Consequently this meant that she did not have any direct contact with another HIV+ Aboriginal woman until several months later after developing that contact on her own. She requested to be in contact with another Aboriginal woman to fulfil her particular needs, a need which she identified could not be established with the more mainstream HIV/AIDS related avenues.

Some of the HIV+ women interviewed not only socially organize their relationship to the ASO through the mediated[1] character of their lives, but also as a result of the way in which they have also socially constructed what HIV/AIDS means or is associated with. Himani Bannerji (1995) describes the usefulness of mediation and a mediational social analysis in the following way,

> The sole purpose of the concept is to capture the dynamic,
> showing how social relations and forms come into being in and
> through each other, to show how a mode of production is an

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historically and socially concrete formation. This approach ensures that the integrative actuality of social existence is neither conceptually ruptured and presented fragmentarily nor abstracted into empty universalism (83).

Bannerji uses mediational social analysis to explicate the mutually constructed character of relations of class, race and gender in the experiences of women of colour and of all women. In a somewhat similar fashion I find Bannerji's notion of mediation very useful in capturing the multi-layered and mutually constructed character of the lives of the HIV+ women I have spoken to.

Often this has meant, at least in terms of the women interviewed for this thesis, that the homosexualized character of HIV/AIDS has meant that they feel left out or alienated from the ASO, its programs or activities. What is meant by "homosexualized character" is that HIV and AIDS were first constructed around the notion of AIDS being a "gay disease." As Deborah Brock (1998) suggests, "By the mid 1980's the emergence of HIV (Human Immunodeficiency Virus), the virus believed to cause AIDS (Acquired Immune Deficiency Syndrome), was transforming our social and sexual landscape ...This prevalence coalesced with pervasive homophobia" (p.84). What is now called AIDS was given the name GRID or Gay Related Immune Deficiency Syndrome which clearly identified the disease as gay related. Much of the stigma and fear still attached to the disease is a result of the way in which the disease was first constructed as being a gay disease which has also informed the response by ASOs.

This homosexualization[2] of AIDS also came to shape the ways in which

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ASOs have responded to AIDS including the establishment of programs and support groups. As one HIV+ woman tells us about the programs of the ASO and her concerns:

> No. Everything is geared to gay/bi men, transgendered/transsexuals. There are not enough support groups for hetero couples, singles, families, family members. Myself I only shared needles three times. The only support group was only drug users. I didn't understand the lingo [language]. What about straights or raped victims. You feel like you are pushed into one group.

Some of the HIV+ women interviewed argue that the way in which AIDS has been constructed around particular issues, or identities, such as: intravenous drug use or gay men, has meant that their issues or ways of identifying have been difficult to address causing them to feel that they have to join, or identify with a particular group to get their needs met.

These conversations with HIV+ women, as seen above, also describe the ways in which the social stigma[3] of HIV/AIDS has emerged when interviewing people who are not gay. These quotes and others throughout this thesis, illustrate the ways that the stigma of HIV/AIDS shapes the ways in which HIV+ women utilize services of the ASO. For instance Mykhalovskiy and Smith (1994) suggest the stigma of HIV/AIDS is carried even in talk about HIV transmission (p.6). My conversations with HIV+ women point out how the stigma of HIV/AIDS is established and reproduced in the language used by the HIV+ women themselves. Further, the description of HIV/AIDS used in this thesis by the HIV+

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women suggests how the stigma of HIV/AIDS is socially organized.

Conversations with HIV+ women describe the ways in which the stigma of

HIV/AIDS has shaped the relationship women have to the ASO.

Since the start of the AIDS epidemic it has become quite evident that for

HIV+ women, there are great inequalities in access to medical treatment, drugs,

early intervention, and the ability to care for oneself and/or partner (Christensen,

1990).

As another HIV positive woman suggests:

> But I did have a doctor who told me outright I couldn't have a
> hysterectomy in [a community in northern Ontario] because they
> weren't doing them here. He wasn't, he didn't have the training to
> do a hysterectomy on someone who is HIV positive. And the
> operating rooms were not set up for it. And my answer was you
> know I am HIV positive, you could do a hysterectomy on someone
> who is HIV positive and never know if they are positive. Universal
> precautions are supposed to be taken, it is no different here.
> Maybe you want to take a little extra sew up inside but I mean there
> is no difference there and ah, I went through laser surgery twice
> with him. I was going to go to Toronto to see if I could see a
> gynecologist and then they said for me to try this. This other doctor
> [I] seen him for two weeks. Within a month I was in having a
> hysterectomy. When I was at [mentions a particular agency's
> name] looking at my report they had taken out my uterus and all of
> my cervix and it was all cancerous so if I hadn't been the type of
> person that would speak out, that says I know my body and I know
> something is wrong and pushed I still would be going through laser
> surgery and my uterus was cancerous. That is why I would really
> like to get the women together because you go and you see your
> doctor and they tell you it has nothing to do with HIV, it has nothing
> to do with your illness. Then you go to a meeting with all positive
> women and we are all sitting around chatting away and ah all of a
> sudden you find out nine out of ten of you are all having the same
> symptoms, on the same medication.

What this HIV+ woman describes when telling her story, is that the

personal becomes political. As HIV+ women engage in conversations with each other and share experiences and knowledge they realize that they are the experts on their lives. These women realize they do know more about their bodies in comparison to the medical establishment which undermines their experiences, suggesting that some of the physical problems they are facing are all in their minds or do not exist because medically it has not been proven.

In the 1970's a second wave of feminism rallied under the banner of the "personal is political." By the 1980's the notion of the 'personal is political' began to strain coalitions formed in the 1970's mostly through the crisis of identity politics (Patton, 1998: preface). AIDS organizing, like its gay liberation precursor, and through the influence of feminism, has valued the knowledge gained from demystifying the oppressive labeling of the medical system (Patton, 1998: preface X).

Other PHAs may do much the same thing as HIV+ women, that is, share information through informal conversations with each other. The way in which this differs from the medical establishment informing someone about medical treatment is that it maintains the agency and subjectivity of the persons involved. The HIV+ women, without articulating it this way, make their realities political because they are speaking out against what the medical establishment has informed them to be the "truth." Further, these women have made the personal political in that they are sharing their everyday realities and experiences with other women. These women therefore, put theory into practice by becoming

actors who produce knowledge through conversations with one another and make it organizationally actionable.

The staff of the ASO also advocate for women in situations like the one described above. But, without the availability of women's specific programs or forms of support, it is often difficult for HIV+ women to gain full support, share medical information or share their concerns. Therefore, in order for the impact of the HIV/AIDS epidemic on women to be better understood there is a need for a description of where women in northern Ontario locate themselves and are located in reference to HIV/AIDS. A woman's relationship in terms of access to resources, public attention and even power in relation to HIV/AIDS will impact on how a woman will fare in the epidemic (Christensen, 1990:5). Given this, a qualitative evaluation which utilizes a reflexive, mutually determined approach to describing the social character of the relationship of women to a local northern Ontario ASO, one which learns from HIV+ women themselves is important.

My reflexive approach to the investigation of HIV+ women's relationship to a northern Ontario ASO is social in character. The following section will investigate this relationship as a social process.

The Relationship of Women to an ASO as a Social Process

Often we think of a relationship as a connection between two people. This thesis examines the notion of relationship as a social process. Specifically, this thesis identifies that there is a human element to the development of the relationship, a social construction created by people and transformed by people.

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In the context of HIV/AIDS, the relationship is developed and interpreted by women with HIV/AIDS and the staff of the ASO within the constraints of state funding and regulation. This linkage is a social relation in which HIV+ women's everyday experiences are socially organized through institutional processes located outside their everyday experience. Conversations with HIV+ women reveal how these processes socially organize their lives.

HIV+ women do not develop their relationship with the ASO in a universal way but rather there is a socially mediated character to the relationship. Mediated character refers to a need to challenge binary oppositional relations and instead to look at social relations and forms and how they come into being in and through each other. For instance, women interviewed were dealing with several social relations, such as drug use or 'addiction' issues, class, gender, sexuality, children and family, the homosexualization of AIDS and HIV stigma. Thus, when they access the services of the ASO all of these other issues or concerns have to be taken into consideration. Therefore, the notion of relationship will be constructed around the social organization of a relationship brought into view by these women talking about their experiences. For instance an HIV+ woman describes an aspect of her relationship in the following way, "I use it for counseling [the ASO]. I use it or let it use me to go talk to nursing students, kids, schools, that type of thing for addiction and HIV."

Other women describe aspects of their relationship to the ASO as follows:

Well actually I approached [the ASO] for specific services [Ligaya-

to help with moving, food vouchers, transportation] which were unavailable and then I approached other agencies to access specific services that were unavailable through [the ASO].

I'm still shocked that there is not a woman available at [the ASO] to speak to. I find it difficult that the counselor that is available also is HIV negative. I am trying to find some group support which is also not available at [the ASO] at this time. I also approached [the ASO] for some help for living things, furnishings, and unfortunately that wasn't available and actually I approached them to help me move to [a community in northern Ontario].

Some of the HIV+ women interviewed felt that their needs could not be met by the ASO staff because of the staff's inability to relate to their experiences in a way which made sense to them. What I mean by this is that the women were treated in a universal fashion based upon the strategies which had been developed earlier in the AIDS crisis to assist white, often middle class, gay men. These same strategies do not necessarily work for these HIV+, straight, women. The staff addressed HIV+ women in a more pathologized fashion rather than in a mediated fashion and often this meant that aspects of an HIV+ woman's life experiences or needs may be overlooked. In the case of the HIV+ women noted above they thought it only made sense to approach the ASO, for help in terms of furnishing their homes or moving to a community located in northern Ontario. Both women quoted above felt they could only approach the ASO for some things and not others. For instance, they could approach the ASO for counseling but not for any items they needed to live. This exemplifies the way in which women's mediated lives are not considered by the ASO. It also suggests that only providing one avenue of help, the counseling, and not thinking holistically,

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does not always help the HIV+ woman.

Conversations with HIV+ women exemplify the constraints which impact on the types of services HIV+ women are provided with, and those HIV+ women are not provided with. Due to funding constraints and time limits, staff of the ASO may only be able to deal with one aspect of an HIV+ woman's life rather than all of the issues or concerns which impact on her life. It is easier and more 'efficient' to have an HIV+ woman come in and the agency only has to deal with what it has been directly funded to deal with such as counseling. The agency can refer the woman to another service agency which may have been funded to fulfil her other needs such as housing or furniture. But, for some of the HIV+ women, it has taken them so long to even ask for help, or come into the agency at all. By not providing a "one stop shopping" setting it becomes problematic for HIV+ women as they try to awkwardly manoeuvre through the social services system.

The HIV+ women also make visible other limitations of the ASO by stating,

> Well the number one glaring thing is that as a human being, you feel more comfortable connecting to someone else who shares your experiences, who can put themselves in your shoes. I do not feel that a gay man who is HIV negative can have a comprehension of what my life is like because he will not share any of my life experiences.

> I think without question, they have to look at getting another counselor available of another sex, female. I don't see how they can possibly continue with the infection rates being what they are, I mean there are so many women now that are testing positive and there is nobody available to deal specifically, I mean the issues that

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gay men have are different from the issues that a mother has, or
that a child has or that, it's a different set of issues.

These quotes illustrate some of the strategies HIV+ women engage in to make

use of the ASO. These quotes also illustrate some of the needs HIV+ women

have, as well as the specificity or uniqueness of their needs. These

conversations with HIV+ women also outline proposals these women have for

change at the ASO. As some of the HIV+ women suggest, there is a need for a

female counselor, one who can relate to these HIV+ women on their level. This

means understanding child care issues, parenting issues, the social inequalities

women face as women, and the violence which has an impact on some of these

women's lives in a way which makes it difficult for them to develop relationships

with men let alone seek their help as a counselor.

This leads me to make a number of recommendations for change at the

end of this thesis. These include: creating a more collective character in the

ASO which would help to create more direct involvement of HIV+ women in the

work of the ASO; developing a participatory needs assessment for HIV positive

women in order to develop women's specific programming; creating a safer

space for women to socialize and bring their children; funding for HIV+ women to

attend support groups and other activities; and the taking up of anti-poverty and

childcare issues as important work of the ASO.

These perspectives and developing analysis, set the stage for outlining

more specifically the theoretical perspectives and methodology used in this

inquiry. The next section of my thesis will address the theoretical perspectives that I have used to inform my research. The perspectives I use when engaging in my research are feminist ethnography, and a standpoint for women.

Ethnography and the Standpoint of Women

This research makes use of a feminist ethnographic approach to the study of women and their relationship to a northern Ontario ASO. The reason for utilizing this research approach was to get at the social relations/organization of the relationship HIV+ women have to the ASO which cannot always be quantified. This approach allowed women to express, in their own words, how the relationship between themselves and the ASO came about, and the type of relationship that exists between them and the ASO. It allowed them to voice their emotions, concerns and feelings about the relationship, but more importantly it allowed me to learn how HIV+ women socially organize their relationship with the ASO. Conversations with HIV+ women make visible the social organization of their relationship to the ASO, therefore, this thesis is not only reporting the accounts of HIV+ women but is also learning from their experiences to build a social analysis.

One of the main organizations which has been set up to meet the needs of people living with HIV/AIDS have been ASOs. But even within ASOs constructions of gender, race, class and sexuality were and are reproduced in the world and work of HIV/AIDS, particularly in terms of the financial constraints placed on the ASO by funding agencies. For instance, government funders will

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outline specifically in funding guideline booklets, such as the booklet for the Ontario HIV Treatment Network's (OHTN) (1999/2000) Capacity Building Grant, what they will or will not fund. Inside the booklet are the areas they define as fundable projects. Along with this, the Ontario HIV Treatment Network (OHTN), like many funders, will provide a guideline of the types of information and documents they require in your application for funds in order to make a decision on whether or not to fund your project.

Now the difficulty with this is, if you have a particular need among the people who normally approach your agency, but this need does not meet the funding criteria, then you cannot apply for funds. The other issue is that staff of the ASO must have the skills to write a grant proposal. These skills are lacking in many non-profits, and also in many ASOs. In larger urban centres such as Toronto, the AIDS Committee of Toronto may have a larger pool of 'experts' to draw from when writing a proposal and may be able to ask these 'experts' for their assistance in writing grant proposals.

Some of the specific skills required to write a proposal, for instance for OHTN, would be knowledge of the research, or program the agency wishes to undertake. There would also have to be some knowledge in regards to how to go about research, and the steps which may be considered. This knowledge would include, but not be exclusive to: the types of research to be conducted (whether qualitative or quantitative); the sound knowledge of financial questions such as the development of budgets and the maintenance of financial records;

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the knowledge of the language being used by the funder in order to answer the questions of the funder in a manner which makes sense to them. These are just some of the skills required when developing a proposal for such a funding body.

Further, the HIV+ women are not present in the development of policy or programming. Often times HIV+ women are not even present on the government funding committees who choose which proposals should and should not get funding. As for "core" program funding, again there was little, if any, specific addressing of women's needs or concerns but rather a more universal or generalist approach where the funding made services available to all persons living with HIV/AIDS. It is quite clear that women's needs and concerns are specific and cannot be addressed in merely a generalist fashion.

Given the inequalities that exist for women in terms of access to resources, and given the increasing number of women contracting HIV today, an evaluation of the relationship of women to the ASO provides insight into how to begin to address the needs and concerns of women.

Sociologists, and more particularly feminists, have been tackling the problem of the invisibility of women in sociological inquiry for a long time (Roberts, 1981). What we do know is that all knowledge is gendered in character. There is an interconnectedness between power, knowledge and gender within social life which has prompted many feminist researchers to begin to challenge these inequalities. Feminist research has served to challenge and transform the androcentric character of sociological study.

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This thesis makes use of a feminist, ethnographic approach. The theoretical framework adopted for this thesis is one which views the everyday social worlds as produced by people and recovers the social character of language by talking to people and learning from their experiences. As well, conversations with HIV+ women reveal the ways in which they socially organize their relationship with the ASO. The everyday world of women living with HIV/AIDS is investigated through an analysis of these social relations which they participate in producing, especially the relation between PHA women and the ASO. More specifically this thesis learned from the standpoint of HIV+ women about the relationship which exists, starting from their everyday experiences.

I use a reflexive, or mutually determined between the people interviewed and myself, approach which is a fully social ethnographical approach in order to get at an understanding of how HIV+ women make sense of their everyday social worlds in terms of HIV/AIDS and the local ASO. This thesis is one that strives to maintain the agency of the HIV+ women by using conversations with these women to build a social analysis. Further, this thesis is interested in how the women interviewed participated in helping to produce their social worlds.

I believe that the approach to research developed by Dorothy Smith (Smith, D., 1987), which starts with the actual experiences of women, is useful in trying to begin to understand the relationship which exists between women and the ASO. This research method has been identified by Dorothy Smith (1986) as institutional ethnography. Further, this thesis while making use of the insights of

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institutional ethnography (Smith, D., 1987) is not able to be a full institutional

ethnography of the relations of the ASO because of a lack of access to textual

materials such as documents pertaining to a Women's Project, and funding

documents and proposals.

Institutional ethnography is an approach which examines social

experiences organized as part of broader social relations. This approach

explores institutional relations from the standpoints of those who often

experience problems within these institutional relations. This is an approach

which is a sociology for the oppressed. The institutional ethnographic method

investigates the social world from the standpoint of the organization of work from

those who produce it (Mykhalovskiy and Smith, 1994: 3 note 1). It is the

development of an exploration of the everyday world articulated through social

relations (Smith, D., 1987).

Therefore, for this thesis I am interested in the institutional ethnographic

look at how HIV+ women socially organize their relationship to the ASO, and

how the staff of the ASO also socially organize their relationship with HIV+

women. In order to accomplish this, a sociological study must begin from the

standpoint of women in terms of where we have been, and where we still are in

our everyday worlds, often outside of the ruling relations of our society (Smith,

D., 1987). Through an institutional ethnographic exploration, this research

attempts to "map a terrain" (Smith, D., 1987: 12) in which the aim is to "explicate

the actual social processes and practices organizing people's everyday

experience from a standpoint in the everyday world" (Smith, D., 1987:151).

Starting from the standpoint of women (in this case HIV+ women) does not mean that the social standpoint is the same for all women. There is no unitary women's standpoint. The social standpoints of HIV+ women are varied and diverse in relation to the mediated character of their social worlds.

For women living with HIV/AIDS, institutional ethnography seeks to describe the extended social relations involved in the production of local activities. Therefore, this is a sociology which preserves the subjectivity of HIV+ women by maintaining the agency of HIV+ women through the use of their words as a basis for building a social analysis, rather than transforming the individual into an object (Smith, D., 1987). This research therefore starts from the standpoint of the women living with HIV/AIDS.

The interviews were conducted with HIV+ women first in order to gain an understanding of how they socially organize their relationship with the ASO. The interviews with HIV+ women then served to inform and orient the interviews with staff members. In following this method of analysis the agency of the HIV+ women is maintained through the use of conversations with these same women as the means of building a social analysis and orienting the interviews with the staff of the ASO. Further, this method serves to maintain a reflexive approach in that the human sensuous character of HIV+ women's everyday experiences is not abstracted and turned into something other than the analysis of the social character of their everyday lives.

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The relationship of HIV+ women with the ASO can be described as a social relation. The relationship is made up of the activities, needs, concerns, issues and problems of the HIV+ women in interaction with the ASO as they are known reflexively or in a mutually determined way (Smith, G., 1990). The problematic or point of disjuncture (Smith, D., 1987) for the inquiry, arises out of the everyday experiences of women with HIV/AIDS or women who are seeking access to an ASO, as well as needs that are not met by the ASO. Questions for inquiry and analysis come out of the social organization that their accounts make visible. This reflexive ethnographic approach is developed through open-ended, one-on-one interviews with HIV+ women starting with their actual experiences in terms of their relationship with a northern Ontario ASO.

In trying to understand how the standpoint of women is important to an understanding of how HIV+ women socially organize their relationship to a northern Ontario ASO, the next section addresses feminism, a sociology for women, and starting from the standpoint of HIV+ women living in northern Ontario.

Feminism, Sociology for Women, Starting from the Standpoint of Women

With all the inequalities women face, an adoption of a feminist way of theorizing about the social world will be used to learn about how HIV+ women in northern Ontario socially organize their relationship to the ASO and how this relationship is socially put together. Feminist theoretical perspectives thus serve

to challenge the patriarchal ideologies and patriarchal way of looking at the social.

When women with HIV infection, who have some connection with the ASO, begin to talk about their lives, they are making visible the social organization of their relationship to the ASO. We can recover this given that language has a social character to it. Therefore, it is not just personal and idiosyncratic, but social and systematic. The method of theorizing about the social, which will be utilized in this research starts from the ground up and is based on a critical investigation of the social organization of knowledge. This research starts from the actual accounts of the social world through the voices of HIV+ women, and then moves to the ASO staff. Then, this research moves from these accounts of the participants to theorizing about the social world, so that the participant's experiences become the basis for the development of theory. This research is based on the recognition that all knowledge is social in character and produced by people.

Knowledge is produced by people, and power is also produced by people, thus this research attempts to maintain the agency of women in the relations of the ASO. This research does not treat women as passive "clients" of the ASO, but rather this research sees women and staff as active agents in producing the relationship between themselves and the ASO. This research is interested in a social analysis, in the mapping out, of social relations or locations and relations to social power. Therefore, the everyday world of the women in relation to the

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ASO will be investigated through an initial analysis of these social relations.

The goal here is to maintain the standpoint of the women interviewed (Smith, 1987: 183). This research is specifically interested in the relationship of women to the ASO and how their relationship comes to be organized, and how the women participate in organizing their relationship. Therefore, this research begins by talking with women living with HIV/AIDS, and their accounts of their relationship to the ASO.

I begin to learn from the experiences of these women's everyday lives and draw upon their standpoints. Therefore, I use Dorothy Smith's (1987) "standpoint of women" approach as a means of understanding the relationship between women and the ASO. The standpoint of women as proposed by Smith (1987) does not depend on universalistic epistemologies of feminist theorizing, but rather it seeks to explicate women's experiences from their standpoint, and outside of a pre-established theoretical position. As Campbell and Manicom (1995) suggest, "what is significant about Dorothy Smith's work is that by focusing on how things happen to us, it reaches outside academia" (p. XIV). When people, and in this case women, tell us about their lives they are telling us about the social organization and the social character of their experiences and lives, both of which help describe the relationship of women to the ASO. Thus, what this type of theorizing provides, is a method for the researchers to work with women as subjects not as objects (Campbell and Manicom, 1995: XIV).

The standpoint of women is a theoretical perspective which starts from the

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standpoint of the women interviewed in their social worlds, and these women are often located outside of the ruling relations of society. It is through the women's everyday experiences or standpoint that I have developed an analysis of how the relationship between women and the ASO is socially organized. Therefore, this research does not begin in the world of sociological or political theorizing, but begins in the everyday world and experiences of the women who participated in the study. I learn as I investigate the relationship of women to the ASO and from the women who produce this setting. This is a reflexive approach.

The alternative way of doing sociology as proposed by Dorothy Smith (1987) provides us, as researchers, with a method for critically approaching the social organization of knowledge, particularly as this relates to ideology. All knowledge is gendered, but Smith (1987) further suggests that the standpoint of men has marginalised women through objectification and modes of ruling. Medical and political policies, for instance, govern women's lives and control our bodies and sexuality. The ideological constructions of women in relation to the AIDS crisis constructs women as vessels of transmission and as vectors of transmission of the HIV virus (Gorna; 1996; Patton, 1987). What the terms vessels and vectors do are reduce women to something which is to be regulated and controlled. This research critically analyzes the ideological practices which create problems of access to services, or inadequate programming for women accessing the ASO.

Feminists have critically analyzed the invisibility of women's experiences

through sociological accounts of women's experiences. What is more, feminists

have been most critical of the ways in which research has served to hide the

patriarchal standpoint as a means of making sense of women's experiences.

Feminists have been searching for a sociology that learns from its research

subjects. Smith (1987) suggests sociology must take an anti-reified approach

which refuses to convert the social relations between people into relations

between things. This anti-reified approach attempts to recapture human

sensuous practices. Bannerji (1995) extends the notion of agency, or an anti-

reified approach, even further when she states that there is a need to maintain

the active agency of the people we wish to learn from and in this case, HIV+

women. Therefore, Smith (1987) suggests our research must become active

and work as a means of capturing social processes between people and social

relations or organization, and more specifically, for this thesis, the women and

their relationship to the ASO through learning from these HIV+ women about

their everyday social worlds.

In trying to maintain the active agency of HIV+ women, I epistemologically

ground my research in feminist ethnography, the standpoint of women,

reflexivity, and active agency. Feminist ethnographers reject the positivist

approach because of the separation between subject and object, researcher and

researched, the political and the personal. Feminist ethnographers are

interested in an integrative, inter-disciplinary approach to knowledge which

grounds itself theoretically in the experiences of women's everyday lives (Smith,

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1989). Smith (1987) makes a poignant statement which summarizes why a feminist ethnographic study is best suited to women when she explains, "the standpoint of women is distinctive and has distinctive applications for the practice of sociology as a systematically developed consciousness of society" (p.107).

Problems in using ethnographical approaches arise when we as researchers, transform our research to meld into the rules and regulations of traditional sociological inquiry and research. According to Smith (1989) in order to avoid these ethnographic problems we should try to maintain the agency, and the indexical and reflexive character of the subjects' worlds. In other words, we learn what we can from the experiences of HIV+ women, regarding the social organization of their everyday social world, and what this makes visible for us about the more extended and broader social relations. Then we can begin to apply this to a theoretical understanding of social relations.

It is believed by this researcher that a feminist ethnographic approach is one way of unpacking and developing themes which women in northern Ontario, and in particular women with HIV/AIDS describe as the relationship between a specific ASO and themselves in terms of woman-centred outreach and services, and programming. The only way to begin to understand these relationships is by talking to the women themselves about how they construct and view their social world. Beginning from the standpoint of women is the needed starting point. It is from this point that I begin to trace out the broader social relations of these women's social worlds.

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Another means of working against some of the limitations of standard sociological procedures in using an ethnographic approach is to ensure that the research is always grounded in the social practices of people while subverting ideological practices (Smith, 1989). What this means is that there is a need to try and maintain the active agency of the HIV+ women by learning about their everyday social worlds, from the ways in which they come to socially organize and make sense of their social worlds and the broader social relations of their relationship with the ASO.

Himani Bannerji (1995) suggests the crucial aspect of evaluating mainstream knowledge is to develop an active sense of agency, viewing knowledge as transformative in nature, and to develop a mediational analysis. Bannerji stresses a relational approach which moves beyond dichotomies of subjective and objective and examines the interconnectedness of social organization and social relations. Further, Bannerji sees the social world as constructed by people, and even though we lose control of our everyday social world we can change it because of the social character of our everyday activities. This research makes visible some of the institutional relations which come to shape this everyday world of women with HIV/AIDS. Thus, Bannerji (1995) uses the example of the social relations of class as a means of suggesting how a mediational analysis moves beyond a narrow, and abstract political economy notion of class in order to create active agency when she states,

Class as an abstraction would cease to refer to the social, being

gutted of its practical, everyday relations and content of consciousness ... But a concrete organization of class is impossible minus historical, cultural, sexual, and political relations. Without these social mediations, formative moments, or converging determinations, the concrete organization of class as a historical and social form would not be possible (p.31).

Himani Bannerji (1995) goes on to describe the mediated character of race, class and gender when she says,

How to think of "race" and class in terms of what is called 'intersectionality,' that is, in terms of their interactiveness, their ways of mutually constructing or reinforcing each other, is a project that is still in the process of being worked out. Somehow, we know almost instinctively that these oppressions, separately named sexism, racism and class exploitation are intimately connected (p. 121).

Bannerji's (1995) work in relation to mediational analysis informs this research by suggesting that women living with HIV/AIDS also live their lives in relation to poverty, disempowerment, class, sexism, ability, parenting, and race. Thus, mediational analysis suggests that these women's lives are mutually constructed through a number of social relations and this researcher must realize that the women involved in the study are not only women living with HIV/AIDS, but women whose lives are always socially mediated in character.

For instance, in her interview with McNally (1995), Bannerji states, "To me class is not an experience in and of itself. A class experience is an experience of a multiple set of social relations through which class is organized" (p.14). Bannerji's use of mediational theorizing is quite important to research on women and AIDS. Feminism has often approached women in a universalistic manner

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focusing only on gender, violently abstracted from race, class or sexuality. So too has AIDS research approached women in the same manner by suggesting all women are the same or react the same in terms of treatment. These universalistic notions of women have silenced women's lived experiences, differences and lives without recognizing the differences amongst women in terms of class, education, race, age and sexuality.

Bannerji's use of mediational analysis will help to inform this research by developing an understanding of women's relations not only to the ASO but HIV/AIDS programming, education and advocacy, while recognizing that women with HIV/AIDS live this differently in relation to class, race, drug-use, whether they are single parents, looking after a partner, or are sex workers.

Along with an analysis of the social character of HIV+ women's lives, institutional ethnography uses a textual analysis as a means to critically examine how, in this case, HIV+ women socially organize their relationship to a northern Ontario ASO.

Critical Textual Analysis

The task of a critical textual analysis would be to describe how and what effect relations of ruling, such as grant guideline booklets put out by funding agents like the Ontario HIV Treatment Network, have and how they have been used by the ASO. As Gary Kinsman (1997) suggests, "an analysis of textually mediated social organization points us towards how texts such as government documents and policies play an important part in the organization of the ruling of

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this society" (p.216).

Ruling texts and discourse provide an ideological knowledge for social relations which Smith (1987) argues perpetuate inequality. A connection between starting with the accounts of women living with HIV/AIDS and developing a broader social and institutional analysis allows us to move beyond the limitations of ideological knowledge. Therefore, this thesis is interested in how ideology operates and is used in particular settings and tied to definite social relations, in other words how it is relational and social in character (Campbell and Manicom, 1995: xi).

According to Gary Kinsman (1997) regulatory relations have been put in place which inform state practices of regulating AIDS groups. Government texts, like the National AIDS Strategy, become ways in which the government regulates and organizes social policies regarding HIV/AIDS. These texts inform funding, programming, and management of women living with HIV/AIDS. Given this we know that such texts actively regulate individual's lives. For instance, the analysis of textually mediated social organization suggests how government documents which regulate how funding will be distributed and for what purpose, play a part in the organization of the ruling in our society (Kinsman, 1997: 216).

Further, it is these forms of ruling relations that impact and direct ASO funding, programming and management. ASOs are confined by government regulation and funding guidelines thereby, limiting the ASOs ability to fully perform and meet the needs of their service users, specifically the distinct needs

of women.

For this research I wanted to develop a critical look at the texts used by the ASO, but unfortunately a critical analysis of texts did not occur. Texts provided by the ASO could have provided insight into government funding, or the lack thereof, of women's programs, as well as government guidelines for programming initiatives. The ASO did not provide me with any documents or printed materials that made a critical analysis of texts impossible. Should I have been provided with such materials an analysis may have been helpful in terms of the development of recommendations or looking at ways of changing or improving aspects of the relationship between HIV+ women and the ASO.

Furthermore, a critical textual analysis could have also served to inform the ASO and HIV+ women of ways they could actively advocate for their needs to be met by government funding agencies. What can be initially stated without a specific examination of these textual materials is that the ASO has been regulated, predominately via funding constraints, in terms of the programs and activities it undertakes.

Within funding documents I received through my employment with an ASO, it is clear that the OHTN (Ontario HIV Treatment Network), for instance, clearly indicates which programs their grants will fund. Although the programs are broad in definition meaning, they are programs which could be used by both men and women, there is nothing specific to women. Comparatively, there are still programs and funds specific to men for instance the "men who have sex with

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men" or MSM studies or programs. These constraints have also meant that HIV+ women do not currently have programs or services developed specifically for them. But a textual analysis may indicate more thoroughly and concretely how this is socially constructed.

If I was not able to implement a critical textual analysis then how did I go about my research? The next section of my thesis outlines the research strategy I used and the ethical considerations I gave to the work I engaged in.

Research Strategy

The major reason for making use of an ethnographic approach to the study of women and HIV/AIDS is to develop a qualitative analysis which cannot always be uncovered through a survey or quantified method. This type of approach moves the research from the local interactional world of the HIV+ women and their interactions with the ASO, to a broader social world where theory is produced by tracing out more extended social relations. The social character of language becomes fundamental to the research strategy.

A sociology for women which uses insights from institutional ethnography, focuses on a mutually determined exploration of the social world of women, one which is determined by the women interviewed and the researcher in a reflexive process. Roxana Ng (1996) defines institutional ethnography in the following way, "institutional ethnography closes this gap (between micro and macro) by locating the dynamics of a local setting in the complex institutional relations that penetrate local settings" (p.10). Therefore, the relationship of HIV+ women to a

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northern Ontario ASO could not be analyzed in a closed or cut off fashion, but it must be analyzed in terms of its connection with larger social processes. This thesis does not fully make use of an institutional ethnographic approach because of the lack of textual analysis, but is informed by its epistemological and ontological ways of understanding the social.

Within this methodological framework, I interviewed eleven people using open ended questions in one-on-one interviews (see Appendix I) which ran about one hour in length. The HIV+ women interviewed were women the ASO had direct contact with and who identified as being HIV positive. Also interviewed were staff (past and present) who worked with the women who used the services of the ASO (see Appendix IA). My investigation is grounded in the accounts of the experiences of HIV+ women. I learn from them first how this relation is put in place. My investigation of the staff and their participation in this relation is based on what I have already learned from the HIV+ women.

When engaging in research with human subjects, particularly around an issue such as AIDS, which has so much stigma attached to it, it was important to gain formal consent from all participants in this research. As such I discuss the ethical considerations I undertook for this investigation in the following section.

Ethical Considerations

In order to protect the confidentiality, anonymity, and safety of the women interviewed for this study, as well as the ASO, the name of the ASO has been removed from this research. In keeping with issues of confidentiality, no given

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names of the HIV+ women interviewed, nor the names of the staff have been used. Finally, all identifying information such as place names, and the names of friends or relatives have been removed from any of the quotes in order to protect the identity of the participants.

Since this research makes use of an open-ended interview schedule, the easiest method of documenting the interviews was through the use of a tape recorder. All the interviews took place in closed rooms in which only the participant and the researcher were present. Consent (see Appendix II) was asked of each participant prior to the tape recorder being turned on. Following the interview, the cassettes were transcribed by the researcher. Once the transcription was complete the cassettes were destroyed. A new cassette was used for each interview.

In chapter two I begin to illustrate the ways in which gender, social power and AIDS are interrelated. I then outline the ways in which the taken for granted social relations of professionalism, ruling relations, and state regulation of ASOs have an impact upon the relationship of HIV+ women and the ASO.

ii. Gender, Power, and AIDS

Gender, and the Social Construction of AIDS

There is little research or knowledge available in relation to women and HIV/AIDS, especially, in terms of transmission, disease course, treatment, psycho-social factors and intervention efforts (Herdt, 1991 and Christensen, 1990). The types of research which are specific to women are changing and improving in quantity but it is still lacking overall. It is this lack of knowledge which has slowed or prevented the development of programs, treatment, education, and services for women. In order to have programs tailored to fit the needs of women, an ethnographic approach to the evaluation of the relationship between HIV+ women and a northern Ontario ASO has been used. I use this method in order to try to develop an understanding of the specific needs, concerns and issues which impact upon the lives of HIV positive women living in Northern Ontario and accessing the services of their local ASO.

Constructions of gender, race, class and sexuality were and are reproduced in the world of work around HIV/AIDS. The oppression that faces women more generally is also apparent in AIDS work, ASOs and treatment. As one woman interviewed suggested, "I've met a lot of native women and, you know like, it's really hard for them they say because there's, you know either it's gay or it's for men, you know, they don't fit anywhere." What continually occurs is that women are viewed in a universal fashion that serves to silence their differentiated lived experiences. Further, there is an unequal distribution of

resources often again based on gender, race and sexuality (Stoller, 1998: 8). Those who are the leaders of the ASO are the ones who determine the programming, policy, and agency response to gender, race, class, and sexuality. But often this is constrained by government funders only allocating funds to particular programs and not others therefore, legitimizing some concerns and not others, or prioritizing some issues and not others.

Initially women in the context of the AIDS crisis were thought not to be at risk, but now women are seroconverting at an increasing rate (Hankins, 1990; Gorna, 1996). Due to women's inferior positioning in society in relation to men, particularly in terms of gender, class, poverty, education, sexism, and heterosexism, services have been poor to women. Consequently, risk practices that affect women have been poorly understood.

Moreover, the social organization of gender enters into shaping the AIDS crisis, where the gendered character of social relations defines us as, "vectors or vessels of transmission," (Patton, 1987; Herdt, 1991; Denenberg, 1990; and Gorna, 1996) rather than defining us as a distinct group of people who have special needs, approaches and knowledge in relation to HIV/AIDS. Women are considered vessels of transmission through reproduction to the fetus and baby, and vectors of transmission through vaginal or anal intercourse with men. Vessels of transmission refers to the fact that women are the recipients of infected fluids. Thus, the woman as the dangerous container of this fluid can potentially harm her "innocent" fetus/baby. Along with this, as the recipient of

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seminal fluid, the female "vessel" becomes transformed into a being without agency or desire in regards to sex (Gorna, 1996: 167). Women are often only viewed as incubators in terms of their childbearing capabilities. According to Gorna (1996) "the reality is that, in sexual contexts, women with HIV are far less likely to transmit the virus than men with HIV" (p.168).

Vectors of transmission, on the other hand, refers to women as being the carrier of the HIV virus from one person to another (Gorna, 1996: 214). Women are viewed as the link in a chain of infection in which the infection passes, a vector (Gorna, 1996: 214). The irony behind this type of definition of women as vectors of transmission is that a vector is often defined as having both magnitude and direction, a form of power. Yet, women are rarely in a position of sexual power, particularly some of the women interviewed for this thesis. In fact, some of the women interviewed suggest that they were sexually abused or have a lack of trust for men because of rape or previous abuse. It is interesting that HIV+ women have been socially constructed as vectors of transmission. This definition would suggest that we are sexual beings who possess control and power in our sexual relationships yet, other constructions of what it is to be female define us as sexually passive, or non-sexual beings. The terms vectors and vessels blame women, and construct women as a threat rather than examining the need for women to discuss how they can become empowered in their sexual relationships and discuss strategies for communication and transformation within those relationships. The identification of women as either vectors or vessels of

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transmission prevents or dismisses the agency, autonomy and integrity of women with HIV/AIDS (Gorna, 1997: 146).

The power dynamics in our society integrally affect women's vulnerability and susceptibility to HIV/AIDS. Women often find themselves located in an inferior bargaining position in terms of safer sex. This is complicated further still, with the lack of communication skills, or language to describe sex and sexuality in women's terms (Patton, 1994: 95). Women become what Cindy Patton (1994) identifies as the last served. Being recognized as "last served" suggests that there are social relations preventing women from exercising power within our health care system but also their personal lives in relation to HIV.

The androcentrism and patriarchy which exist more generally in our everyday social relations as women, are found within the social relations of the health care system, medicine and sexuality. The 'traditional' approaches to women's health care have been androcentric in focus, where the male-view is considered the norm and the female becomes an abstract form associated with having physically based deficiencies or differences. A patriarchal society perpetuates and maintains the inequalities found in female/male relationships. The framework of patriarchy is characterized by gendered defined power inequalities, and these inequalities are embedded in our society so much that they become commonsensical in character, they become perceived as the "norm."

It is within the context of the unequal power relations that women are

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required to take preventative and protective actions towards minimizing their risk

of HIV infection, yet women are rarely provided with or taught the skills to enact

the power or control required to minimize their risk of infection. Social

constructions of female sexuality only serve to disempower women because they

do not address transforming sexual practices and sexual relationships.

Patriarchal power inequalities form the basis of 'traditional' female/male

relationships and therefore, isolate women from the ability to control their lives.

The gendered character of our society that privileges men, makes it

almost impossible for women to gain their fair share of resources. Women in

relation to HIV/AIDS have little access to HIV control or planning processes even

if women are the major providers of education and primary health care (Patton,

1994: 95). Further, lack of access to social institutions such as education, paid

employment and property silence the voices of women often preventing us from

gaining the needed skills to be heard.

HIV prevention, detection or treatment is hindered by the established view

of male as the norm that has informed standard medical and scientific research.

Women are often absent or invisible to medical research. This distinction

between male as the norm and female as outside the "norm" is further exercised

as the predominately male medical establishment controls the female body,

apparently protecting us, but in actuality controlling reproduction. Christensen

(1990) explains this further when she says, "women are often treated as potential

fetus incubators whose reproductive capacities are more valued than our lives"
(p.5).

Women may also delay seeking medical intervention because of a lack of resources, the burden of child care or family care, and the discrimination or the threat that our symptomology is an apparition, or conjured up in our mind (Patton, 1994:95). As one of the women interviewed stated, "if I hadn't been the type of person that says I know my body and I know something is wrong and pushed I would still be going through laser surgery and my uterus was cancerous. He wouldn't even do a biopsy." Thus, this power imbalance between women and the medical establishment has often meant misdiagnosis and lack of available treatments. Women's lack of control over their bodies has further meant major difficulty for most women to effect health promotion plans or strategies (Patton, 1994: 95).

Women also fare poorly due to our economic and social inequality. We earn less than men, but are often responsible for more dependents (Christensen, 1990; Patton, 1994). Women are often financially dependent on men or are relegated to a life of poverty. Further, we bear the double day burden of waged work and unwaged domestic work. This double day burden often means as women we compromise our own needs, health or even safety. For HIV+ women this double day can significantly reduce their life expectancy. As Cindy Patton (1994) suggests, "HIV+ women, when denied access to many of the activities which promote a sense of self worth, develop skills, and provide information

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about mental and physical health, these women frequently do not even see the importance of their own well being" (p.95). Due to the mediated character of women's lives, many will prioritize aspects of their lives and health in favor of the significant others in their lives, or other aspects of their lives such as work. The mediated character of HIV+ women's lives is further exemplified when one of the staff of the ASO describes the character of the female clients she sees by sharing this general statement,

> I'm finding especially with the clients that we're taking in now that I guess it's the way that I personally look at HIV. HIV is not most of the clients big issue. And the more and more I work with HIV the more I realize the issues surrounding HIV now are practically as minuscule as the virus itself. It is that when you are dealing with IDU [Injection Drug Use], or that you are dealing with women who have gone through past addictions or alcoholism you're dealing with so many of the basic fundamentals of what happens to women who have sort of been running amuck lately of the law or something and you start going back into their childhood and youth and you're dealing with all the issues surrounding sexual, physical, mental abuse, neglect, etcetera.

Thus, what the staff person is suggesting is that the women's lives are mediated in character and often lead to the lack of self nurturing or caring that is often required to advocate on behalf of one's self or one's life. But these forms of discourse also construct the HIV+ women as a particular type of problem. As Cindy Patton (1990) suggests, "addiction and ways of otherizing HIV+ women seek to change the individual rather than examining the social implications of why women may take drugs or become defined as a criminal" (p.11). Professional/medical labels like 'addict' or 'alcoholic' re-articulates the HIV+

woman's identification from being, for instance, an injection drug user who is living in conditions of poverty, into being an "irresponsible addict" or "alcoholic." This professional and medicalized labeling focuses on the individual as the "problem" and not on the social context and relations that produce problems in the life of this HIV+ woman. It seems women living with HIV become pathologized or reduced to a bio-medical model, where the disease stands in for the women within medicalized and professionalized discourses. Even HIV+ women may take this labeling up and reduce themselves to the definition of "I'm HIV," or "I'm an addict." The social relations of class and poverty are not even considered in the description of the HIV+ woman by the staff member above. This omission of the broader social context tends to place the "blame" on the HIV+ woman rather than looking at the social relations of an HIV+ woman's life. By taking up the standpoint of HIV+ women in my research, I am learning about the meanings HIV+ women give to their relationship to the ASO and how their relationship with the ASO is socially organized.

In terms of gender, power and AIDS, it is rare that women will belong to a community where others are visibly experiencing the same health crisis as they are. Usually, it is isolation and invisibility which unite women living with HIV. This is very different for gay men who have been living in an urban setting. For gay men, HIV/AIDS has had a terrible impact on their already pre-existing communities, in that friends and lovers are also infected or have died, and where grieving or activism is common-place. For gay men there has been the

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possibility of peer support and a shared cultural identity, this is not the case for women. In fact the women interviewed shared a view that there was a homosexualization of AIDS and a stigma attached to AIDS.

All of the HIV+ women interviewed for this thesis identified as heterosexual, but it is also through the conversations with these HIV+ women that the stigma of HIV is carried on through talk about the transmission of HIV. What the conversations with HIV+ women suggest are the ways in which the stigma of HIV is established and reproduced in the language used by these women, and through the ways they describe how the stigma has been socially created and organized in their lives.

The social organization of the AIDS stigma was originally put together through the work of health professionals in their work to prevent the transmission of HIV. Initially it was the ways in which the medical establishment labeled the disease as a gay disease. What is now referred to as AIDS or Aquired Immune Deficiency Syndrome was called GRID or Gay Related Immune Deficiency. This homosexualization of AIDS was then taken up and amplified in mass media coverage. The disease was further attributed to a "lifestyle" which was constructed around 'promiscuous' sex and drug abuse. The stigmatization of AIDS was further supported through the ways in which the construction of "risk" groups was developed. Risk was identified as particular groups or individuals responsible for the spread of HIV. These groups, homosexuals, drug users, prostitutes, hemophiliacs and Haitians, were already socially oppressed

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(Mykhalovskiy and Smith, 1994: 24).

Typically, stigma has been associated with shame, fear or other factors which emerge and serve to separate or set people apart. What is important about notions of stigma and the homosexualization of AIDS are the ways in which stigma and homosexualization become a part of the relationship HIV+ women have with the ASO. What becomes apparent in my conversations with HIV+ women is the ways in which stigma and the homosexualization of HIV have shaped the ways in which HIV+ women develop their relationship with the ASO. The relationship of HIV+ women to the ASO is also shaped by the professionalized character of the ASO, ruling relations, and the state regulation of ASOs.

The Taken for Granted Social Practices of Professionalism, Ruling Relations and State Regulations of ASOs

The practices of professionalism are said to be analogous to bureaucracy in that they involve personal detachment, specialized technical expertise and 'rational' decision making (Blau, 1967: 455). In this thesis I am addressing professionalism specifically in relationship to how it is facilitated and supported through the state regulation and funding of ASOs. When I use the term professionalized, I am not referring to credentials required of some professions in order to work but rather, professionalized relations are distinct from bureaucratized relations in that professionalized relations infer a 'professional' distance between the staff person and the 'client.' Furthermore, even where the

staff of the ASO may not have professional credentials, they certainly have the specialized skills and knowledge. Professionalized relations differ from bureaucratic ones in that bureaucratic relations are more in keeping with aspects of the day to day work required by the staff such as proposal and grant writing or report writing. Professionalism takes place within a bureaucratic context and can be specified in relation to state funding and regulations, as well as the replication of certain forms of corporate and professional organization such as Boards of Directors, Executive Directors, a hierarchy with staff, and professional work practices. Professional practices are organized through the social processes of bureaucratization, including the professional transformation and individualization of people in all their complexities into 'cases,' 'clients,' or 'service users' in professional discourse and practice.

As Morgan (1981) argues, "bureaucratization creates false categories of social relations; individualization fetishizes[4] them; and professionalism keeps the control of these fetishized relations in the hands of the state" (p.19). In other words, what bureaucratization, individualization and professionalization do, are to transform actual social, political and economic relations into individualized problems without a social character, absent of human sensual activity. We come to give supernatural power to forms of bureaucracy and professionalism. We come to ignore the human element of bureaucratic and professionalized relations. Therefore mistakenly, what occurs is the social relations, which are bureaucratic or professionalized in character, are viewed as autonomous from

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human sensuous activity and viewed as governing rather than dependent on the social relations. Professionalized and bureaucratic relations are fetishized in that they are given powers which force all human relationships or experiences to become treated as "things." The underlying social relations become hidden from our perception and we come to build an understanding of the social relations based solely upon the appearances of professionalized or bureaucratic relations.

All ASOs are non-profit organizations. Once a non-profit organization takes on aspects of bureaucracy and professionalism these become so ingrained that they are part of the taken for granted world of the non-profit. This leads to the needs and wants of the HIV+ women who use the services being neglected. This occurs because staff are bogged down in the bureaucratic everyday aspect of their work, making meeting the needs of the HIV+ women not always a priority. Social relations become abstract in character as bureaucratic forms absorb the demands from below or in this case the staff of the ASO (Morgan, 1981: 19). This is not necessarily a reflection of the staff, but a result of the constraints placed on the staff by government funding bodies who outline and direct what the ASO offers and how. As Davies and Shragge (1990) state, "funds from the State become available for specific functions, thus limiting groups in the establishment of their own agenda and practices" (p.138).

Thus, what professionalism does is that it organizes the work of the ASO in a hierarchically stratified manner through the use (and misuse) of skill or knowledge or technology not readily available to HIV+ women. Therefore, social

processes such as the ability to determine one's health, or one's needs or one's social welfare, or the fulfilment of one's needs becomes the property and mandate of state agencies and are funneled through community agencies such as ASOs rather than becoming an integral part of the community (Morgan, 1981: 19).

Staff of the ASO are also aware that they need these institutions or government funding bodies and the services they provide, even while they may be pursuing community based projects in a language and style familiar to HIV+ women. In order to explain programs or advocate changes in policy or law, it is necessary for the ASO to at least partially adopt the concepts and premises of these government institutions (Patton, 1994:6). In other words, the methods used to address the needs or concerns of HIV+ women become compatible with capitalist, bureaucratic, professionalized social relations rather than challenging them or threatening them (Morgan, 1981: 19), or the government funding agency offers "support" to community organizations. Often the trade off becomes one in which the ASO has to sacrifice their autonomy. The problematic then becomes one in which ASOs find themselves working in partnership with the State, while the State has neutralized the ASO as an effective oppositional voice (Davies and Shragge, 1990: 138).

As one woman interviewed suggested, "Going with one counselor. If he's not available... [Ligaya-You're out of luck?] Yup. One [staff person] is for condoms, one [another staff person] is for research ... If I go in on Monday and

he's [the support counselor] not there I have to go the next day because he's my counselor." This quote begins to describe how professionalism becomes taken for granted within the ASO, and makes the bureaucratic and professional regulation of the lives of HIV+ women more visible.

For instance, each staff member has a particular role to play, a particular job within the ASO which helps to maintain its 'efficiency' because HIV+ women can be directed to a particular individual for a particular need or concern. 'Efficiency' becomes defined by the funding body in that they want to know statistically how many people have been served and for what purpose. What I mean here is, if the ASO is funded to have a men who have sex with men (MSM) program the funding body will want to know how many men the program has served and what types of services the men have requested such as condom use or educational pamphlets.

In the eyes of the funding agency 'efficiency' is the ability to provide a service in a quick and 'useful' manner. This eliminates the possibility of more than one person engaging in the same work through the maintenance of a professionalized division of labour as well as maintaining the bureaucratic or professional character by suggesting that each staff person possesses a particular skill or expertise which they bring to their particular position within the agency.

Along with this, 'efficiency' ensures that there is no overlap in service provision and that each person is designated to a particular task or role. We

must always keep in mind that 'efficiency' for the government or for the staff of the ASO is not necessarily 'efficiency' for persons living with HIV/AIDS. Thus, 'efficiency' comes to be defined by state organizations, and is maintained through the work of the staff at the ASO. 'Efficiency' is also defined by the staff because if they are not 'efficient' they could not see as many clients as they do, as well as meet all the requirements and report writing required of them by funders in order to justify their existence.

As an organization grows and develops its bureaucratic form, inevitably it is committed to internal organizational goals rather than social change or even the needs of its 'service users.' The way in which this happens is that the staff of non-profits come to fetishize bureaucratized social relations. This occurs as staff continue to develop particular skills for their job, along with possessing particular knowledge which is not readily accessible to HIV+ women. For instance, knowledge of when conferences are being held or when positions on boards such as the Ontario AIDS Network (OAN) become available. The types of services or the ways in which the services are provided also become professionalized in character, since statistics have to be maintained to justify a programs existence to a funding body. Or as I suggested earlier, a professionalized division of labour plays a particular role within the agency which also means each staff person possesses a particular skill, or expertise which they bring to their job. HIV+ women have to approach a particular staff member in order to have a particular need met.

Although the organization may be interested in an egalitarian way of functioning, often this equality is displaced in favor of other organizational concerns. If this is the case, the concerns of the HIV+ women who use the services of the ASO may also become displaced when organizational concerns outweigh the needs of the HIV+ women as was suggested in an ASO newsletter,

> ... when we think of those changes we have to wonder whether they have been good changes. From a grassroots organization to a modern "Internet connected" agency, have the changes been for the better? Now that we have our new professional looking office and reception area have we lost that 'come on in and chat' atmosphere.

What is interesting about the quote above is that the previous "drop-in centre" atmosphere of the ASO has been lost as it tries to conform to the professionalized character it has been regulated to follow as a result of funding constraints. But not only is this produced through funding constraints, it is also shaped through the fetishization of bureaucratic social relations and professionalized social relations. What was once viewed as grassroots organizing has become transformed into agencies used to assist in the strategies of public health regulation (Kinsman, 1996: 398). For instance, the push for people to get tested, the promotion of safer sex strategies, or moral regulation around issues of disclosure to possible sexual partners. People now walk into the centre and a desk stands between them and the people providing services to them. Staff then ask in what way they can be helped and depending upon their request they will be directed to a particular staff person, or given a pamphle, or

condoms and then sent on their way. There is no longer a "drop-in centre" feel

to the agency since the removal of a large meeting room in the front as you walk

in. Although technology is now required in many places of employment,

particularly computers or the Internet, these forms of technology should never

come before those we are here to serve. What has occurred is that many

agencies feel regulated or mandated to pursue these forms of technology in

order not to be seen as an agency behind the times or illegitimate in character

because of their lack of modern technological tools often associated with what is

considered a professionalized organization.

> As one HIV+ woman said:

> [Ligaya-So what do you think is needed to make people feel more
> comfortable?] I don't know I really don't know. Like the smoking I
> think would be a start okay because instead of just coming in and
> leaving. If there is a room where people can go and have a coffee
> and start smoking then they are automatically going to start talking.
> And then you start connecting but you know if everybody is in a big
> rush to come in and go and aren't going to stick around you are not
> going to get that connection.

What is important about the quote from this HIV+ woman is not so much the

suggestion of smoking, but rather the need she articulates to have a more

inviting and safe space for PHAs to sit around and begin to develop friendships

and conversations about their lives.

Non-profit organizations are those which are organized without making a

profit, but instead raise funds through grants, government funding, or fund

raising activities. Since for profit organizations are often geared towards making

money the organization becomes one which uses its levels of power, rules, and membership to run 'efficiently' all in the name of profit. Non-profit organizations often end up following the same tactics as for profit companies because of the pressure to maintain a service, deal with funding constraints, and advocate on behalf of their clients. Non-profits are often not able to critically analyze state intervention and its role in maintaining and reproducing ruling relations. For the ASO this occurs with the development of the Boards of Directors who follow a hierarchical order in terms of their make up and rules of conduct (Robert's Rules of Order), volunteers who have to go through a volunteer form and meet the requirements or needs of the ASO, staff who have to adhere to funding regulations, and 'clients' who have to be able to understand how this all works or the language being used in order to not fall through the cracks or not have their needs met.

What is occurring therefore, is a bureaucratized social relation which serves to fragment the needs of HIV+ people who access the ASO. In the case of HIV+ women, these women lose their social character and become individualized, abstracted and segmented into aspects of the bureaucratic social relation, where their needs and concerns are addressed in a universal fashion as women with HIV/AIDS. What occurs then is that the agency and needs of the HIV+ women become abstract in character as they are separated from the class, race and gender realities of these women's lives and they are reconstituted into false categories of social relations.

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Non-profits and ASOs, once they start utilizing state funds, find they often get caught up in a process of 'trade-offs'. A 'trade-off' occurs when what the ASO wishes to do is traded off for what they are mandated to do by the funding agent. This leads to a loss of autonomy, the limiting of an oppositional voice, and difficulties for many ASOs to establish their own agendas. It just becomes taken for granted that following the bureaucratic social relations is easier to do than work against them because the repercussions of not doing so could mean a reduction in the programming the ASO already offers. Also when having to fill out reports in order to justify the funds the agency has received, it is easier to have been following the bureaucratic relations in order to fill out the paper work. For instance, the funding body wants to know who they can talk to if they have questions about funding applications so they would need to know who the President or the Executive Director of the ASO who is applying for funds is.

Further, the Ontario government requires that non-profits establish a hierarchical form of governance within the agency, thus, when the agency is filling out their annual incorporation forms they have to identify who the President, Vice-President and Secretary are. In order to maintain a charitable status the same type of governance must be established. When the state agencies enforce these types of regulatory practices it is often difficult or too time consuming to actually make your day to day work different from this type of structure.

As Renalt (1994) suggests, "collectivist models are difficult to sustain

because they require that the collective agree, as well external pressures from funding sources require collectives to adopt traditional organizational structures" (p.686), which work against collective forms of organization. The 'efficient' and effective manner in which the organization operates is analogous with what it means to be professional. The 'efficiency' and effectiveness of an organization are defined by the staff of the ASO following state regulations. These are also defined by the government who determine 'efficiency' and effectiveness by the number of 'clients' an ASO see in a year or how many they service in a day. Along with this, the government will also decide who will get funded and who will not.

To a certain extent the non-profit must also take on aspects of bureaucratic organization and/or the social relations of professionalism to fully make use of funds. To be socially viewed as legitimate they must at least partially adopt bureaucratic and professionalized social relations through the use of state or funder's concepts or premises. Roxana Ng (1996) defines this more concretely in her study of the transformation of an employment agency for immigrant women when she states, "Professionalization is the process which transforms non-capitalist forms of organization into hierarchical ones, as in the evolution of the employment agency [that she examined] from a collective structure into a bureaucratic and hierarchical one" (p.28).

Therefore, the definition of social needs and the methods used to address them become compatible with the bureaucratic and professionalized social

relations rather than critically challenging or threatening their existence (Morgan, 1981: 19).

An example of this occurred during one of the interviews with staff. When the staff person was asked what kinds of support do you provide, one of her responses was, "I've always thought that I see a lot of clients. They come back, and they [say] I'm very date oriented. One of my clients now has a date books and I think, oh my goodness, did that wear off?" This example is not one which constructs the PHA as unorganized but that the staff of the ASO may wish the PHA to be organized in a fashion which is in keeping with the professionalized mainstream and fits with the needs of the staff of the ASO. This type of professionalized way of organizing can also suggest the way in which meeting times are imposed as part of socially regimenting HIV+ women's lives. Finally, due to the high level of emotional stress of working in an ASO, and dealing constantly with sickness and dying, a professional distancing from 'clients' is one of the ways through which staff can maintain their emotional stability.

With the growth of the public sector, state and bureaucratic forms, non-profits are forced to follow suit and develop their own administrative and bureaucratic control strategies in order to 'effectively' make use of what is available to them, as well as access resources, such as funding, which it needs to survive and meet the needs of those who utilize its services. To do anything other than try and fit into the mainstream leads to worker burnout, is too time consuming, or emotionally intense (Renalt, 1994; Freeman, 1995). The

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alternative for a non-profit is to develop its own organizational system, unique to the mainstream organization, which is able to transform rational bureaucratic forms to one which is based around people who utilize the services of the ASO, for instance the development of a collective model. We must consider though that due to the fetishization of bureaucratic and professionalized social regulations a collective model within an ASO may be difficult to establish but not impossible.

A transformation of bureaucracy and professionalism within non-profit organizations can take place because bureaucracy and professionalism are social in character. Women and feminists are part of the social organization, we contribute to its consciousness, creation, and work, but continue to often stand outside of these forms of social relations also because we are women and often still get excluded and marginalised. These same sorts of inequalities occur for the HIV+ women who use the services of the ASO. Thus, all social relations are gendered. Only by acknowledging that social relations have not only a gendered character, but a power differential to them, can we begin to address organizational processes in different ways and change them to become more empowering to the 'service user'. We can begin to develop organizational perspectives and theories for the oppressed by linking the personal with the political. This means that, not only should individual services be provided, but that they be linked to political and social change.

Power/Knowledge Relations

One way political and social change which addresses the concerns of HIV+ women can be activated is by having HIV+ women actively involved in the collective decision making and the day to day operations of the ASO. This would mean that there would also be the need to hire and train some of these women to work within the agency rather than employing people with training or a knowledge of the bureaucratic social relations. This would help to de-mystify the knowledge of staff of the ASO and help to empower HIV+ women. Some of this training could even take place without any cost to the agency by sending HIV+ women to attend meetings with the Ontario HIV Treatment Network, or the Ontario AIDS Network, or the Canadian AIDS Society. At these meetings the HIV+ women will begin to get an understanding of how the bureaucratic relations are constructed and put in place.

According to Foucault "knowledge is power" (Simon, 1996: 316). More significantly he looks at power/knowledge relations. What is meant by this, is that Foucault sees knowledge as productive in character (Roth and Hogan, 1998: 17). Therefore, in the case of ASOs a power knowledge relationship occurs as we examine how the relationship between HIV+ women and the ASO is organized and what cultural and historical effects of domination these power/knowledge relations have(Roth and Hogan, 1998: 17). For instance, the social relations of professionalism and bureaucracy act as forms of power over the 'service user.' The way in which the staff of the ASO interact with the

'service user' becomes a way in which the staff regulate the 'service user's' health, access to information, and resources.

As one woman interviewed suggests, she is feeling a little overwhelmed by the way in which the health professional's wish to direct her treatment and that the medical model is the one she should follow when she states,

> On the negative side about the physician that agreed to take on my case, because I was referred by [the ASO], is a strong advocate of drug therapies and so that may present itself to be a problem that remains unseen and through this doctor I was referred to the clinic and in one visit I had made there my impression is that they, as well, are quite strong drug advocates.

This HIV+ woman interviewed was a strong advocate of alternative therapies. She was feeling very healthy, in fact, her viral load was undetectable and she had never been on a drug treatment regime yet. A person's viral load is a measure of the amount of HIV in their blood. You therefore always want your viral load to be low and your T-cell count or CD4 to be high. Your T-cells are the cells which fight off infection such as HIV. This same woman further felt that if she started to use one of the drug regimes, this would undermine her current state of health, yet none of the health professionals were willing to listen to her side of the story. The use of alternative therapies is especially difficult now with the medical and researcher's consensus that treating HIV+ people with a good drug treatment plan such as a "drug cocktail" or combination of drugs is useful (CATIE, June 1998: 14). As advocates for the PHAs, the ASO failed this woman since they seemed to support the use of drug therapies rather than alternative

forms of therapy.

What Foucault's (Simon, 1996: 316) work disregards and my work tries to build on, is the social relations of agency of the HIV+ women who use the services of the ASO. Foucault does not account for the fact that professionalism and bureaucracy are social in character and as such are made and changed by people. Since people have the capacity to change the social relations they participate in, they can transform professionalism and bureaucracy.

In an effort to try and maintain the agency of HIV+ women, I adopt the use of Dorothy Smith's work. Smith's approach is not a subjective one, but rather a social epistemology, reflexive in character and an ontology, which recognizes that objective knowledge produced through media, texts and policies removes the perceptions and agency of the participants. Epistemologically, my research is interested in making as visible as possible the active agency of the HIV+ women and their relationship to an ASO, and also in how they can assist the ASO in transforming the social relations of professionalism and bureaucracy. Himani Bannerji suggests that maintaining an individual's and group's agency is vital to theorizing when she states in an interview with David McNally (1998),

> I cannot dismiss the need for people to have an agency. People
> who need an agency cannot but do it under a certain name; people
> need to have some kind of concrete content to what their agency is
> going to be, and that can only come from the kinds of social
> relations, ideologies, and atmosphere that people encounter (p.12).

Epistemologically, this thesis uses a reflexive, indexical approach based on the actual experiences of women. Harold Garfinkel (1967) developed

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ethnomethodology or the study of people's methods, as a means of

understanding how the social world is produced. Dorothy Smith (1987) took this

notion of people's methods further when she utilized a reflexive and indexical

means of understanding the social from the standpoint of people and learning

from their everyday experiences and connecting them to broader social relations.

Reflexivity is a process of mutual determination, a social epistemology. This

process of mutual determination using the standpoint of women living with

HIV/AIDS is based on the standpoint of women as developed by Dorothy Smith

(1987). Smith's (1987) approach is one which refuses to participate in

converting participants into objects of study, but rather strives to maintain the

indexical/reflexive character of the social world of the participants.

Ontologically, my research is centred around the notion that the social

world is constructed by people. Even though people often lose control of their

everyday social world, they can change it. My research is further interested in

the everyday social worlds of women which are produced by women and

recovered by talking to women, as well as learning from them. Ontologically, this

research realizes that people are the producers of the social world we live in, yet

people often find themselves constrained by the ruling relations of the world we

live in. As Marx and Engels (1973) suggest,

> Individuals always started, and always start, from themselves.
> Their relations are the relations of their real life. How does this
> happen that their relations assume an independent existence over
> against them? And that the forces of their own life overpower
> them? (p.30).

In trying to understand how HIV+ women may socially organize their relationship with a northern Ontario ASO, we need to have a general understanding of the social location of these women. In chapter three, I begin to outline what northern Ontario has to offer in terms of HIV/AIDS services and how HIV+ women construct their relationship with the ASO. From here I outline the ethnography and agency of HIV+ women living in northern Ontario.

iii. History and Ethnography of HIV+ Women and the ASO

Northern Ontario, the History of the ASO and The Social Dynamic of Women and HIV/AIDS in Northern Ontario

Northern Ontario is vast but sparsely populated. This geographical area stretches from Parry Sound right up to James Bay, and from Mattawa on the Ottawa River in the east, to the Manitoba border in the west. Northern Ontario includes 8% of the province's population. In order to gain a perspective on the size of Northern Ontario, it is a large geographical area, larger than Alberta, but with a sparse population distributed throughout remote geographical areas. (This data on northern Ontario comes from Glen Murray and Associates, 1999: 12). In terms of HIV/AIDS it has been difficult to determine the actual number of individuals living in northern Ontario who are HIV positive. Robert Remis' 1998 report suggested that there were 134 cases of AIDS in Northern Ontario with an estimated number of 345 persons infected with HIV (Murray, 1999:12). This thesis is not investigating HIV+ women in northern Ontario more generally, but is exploring the particular relationship between HIV+ women and one specific ASO which is located in a northern Ontario community.

ASOs were generally started by gay men, and sometimes lesbians and health workers informed by the feminist movement, who needed to create awareness, provide support, and do early safe sex education when so many of their friends, even themselves were becoming infected or ill. Further, ASOs were established in order to try and dispel some myths around HIV. ASOs

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started from the ground up as grassroots, gay positive organizations. Women and lesbians were often involved through the friendships they had with gay men who organized the ASO. The way in which ASOs initially addressed the concerns of women was as friends or family of the PHA (Stoller, 1998: 17). It was not until later that the specific needs of women became apparent. What has still not been addressed is the distinct character of women's needs in comparison to those of men. Further, the needs and concerns of women are made invisible when excluded from drug trials and treatments (Patton, 1994: 12).

The ASO I am investigating was started, as were many ASOs, by gay men who were infected and affected by the HIV virus. For the particular ASO I investigated for this thesis, a gay man whose brother had passed away from AIDS related disorders mobilized together with friends to develop education and awareness about HIV/AIDS. The ASO was never intended to be a long-term organization but was intended to be a short term temporary aid to help the community. There were also heterosexual women, as well as a few lesbians, involved with the ASO from the time of inception, assisting their friends in developing programs or aspects of the ASO. Unlike some ASOs this ASO did not really emerge out of activism or even the gay community in a broader sense. It emerged out of a need which founding members thought would be short term. The way in which this ASO emerged makes it different from ASOs located in larger urban centres such as Toronto which emerged much more out of gay men's activist networks. One staff member describes this history,

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His brother passed away. [He] was active in the gay community and felt that if this was happening everywhere in Canada, it has to be happening here. He called upon, he put together a really interesting group of people. There wasn't the crisis in terms of HIV as it was in Toronto or Vancouver. It was still very much underground. So he brought together for example, the medical officer of health, directors of nursing of hospitals, he had a physician, he had a priest, nuns, people from the gay community, an HIV positive man and these people formed an advisory committee. A proposal was written provincially for funding. That was enough funding to hire an ED [executive director] and part-time administration person.

Unlike many other ASOs I have been in contact with, there were no HIV positive people who were regular staff persons at the ASO, not even in a limited capacity, during the period of this study. All of the staff are from northern Ontario and several of them have direct connections to HIV/AIDS, even if they may be HIV negative themselves. In my experience with ASOs to date, these organizations have also had a direct connection to the Gay/Lesbian communities, because the disease, initially, was thought to be a gay disease. Some ASOs still have their offices located within the Gay/Lesbian communities of some urban settings. Two of the staff disclosed to me that they were members of the Gay/Lesbian community, while the rest identified as straight. Just prior to beginning my research there was one person on staff who disclosed to me their HIV status, but since my work began, there have been no HIV+ people working as full-time or part-time employee. There are Persons Living With HIV/AIDS (PHAs) who are representatives at the Board of Directors level and these same PHAs provide possible representation for the ASO on other

governmental bodies or boards, but that is the extent of it.

The first female PHA to use the services of the ASO was in the early 1990's. One staff person describes her contact with the first female PHA as follows,

> Our first female client that I was in contact with, was a young woman who came in on a Friday afternoon about 3:30 in the afternoon weighed about 85 pounds who had completed a number of 8-balls of cocaine in a suicide attempt and had gone to her GP of many years and he'd said go directly across [the street name] that's where you need help from and that's when we were on the street. She walked in and that was the first time actually we'd been in contact with an IDU [Intravenous Drug User].

The ASO gains its funding provincially and federally for most of its core programming. For instance the ASO will receive some funding from the Ministry of Health-AIDS Bureau, as well as the Ontario HIV Treatment Network and Health Canada. The ASO, like many others, must also raise its own funds through fund-raising activities like the AIDS Walk. These types of funds are not provided by the government but are charitable donations made by public or corporate donations. This type of funding is important because it is this type of funding which goes directly towards programs and activities for persons living with HIV/AIDS, which are not provided by state funding, therefore these types of funds are not used for administrative purposes.

In 1999 Glen Murray and Associates conducted an assessment of access to HIV treatment in Northern Ontario. In their study they found that women in Northern Ontario, especially Aboriginal women, were not having their issues or

concerns addressed. In fact, women reported that they were overwhelmed by the multiple issues which affected their lives. Glen Murray and Associates (1999) state in their report,

> Practical issues of importance to women such as the lack of translation services for native language speaking women from remote reserves and child care provisions for attending appointments, have not been addressed well. Women diagnosed with HIV/AIDS in Northern Ontario have not been able to form any lasting support groups. At the 1998 Opening Doors Conference women listed the following special problems: confidentiality, non-availability of local testing, lack of support and counseling in their home community (p.51).

Therefore, the lack of available resources, as well as the needs and concerns of HIV+ women needing to be addressed, make this exploration of the relationship of HIV+ women to an ASO unique and instrumental in having the standpoint of HIV+ women expressed. The following section looks specifically at the social character of the relationship HIV+ women develop with an ASO.

The Ethnography of the Relationship of HIV+ Women to the ASO

The needs and experiences of women in relation to HIV have not been easily uncovered or analyzed. The desire to understand the specific needs of women who are HIV positive living in northern Ontario has meant that a critical analysis of the relationship between HIV+ women and a northern Ontario ASO is an important undertaking. Because institutional ethnographic analysis helps to bring together the more extended, broader social relations and the local interactional world of the relationship of women to a northern Ontario ASO, the research connects the broader aspects of the relationship of HIV+ women to a

northern Ontario ASO and the analysis of this relationship together through face to face interactions with HIV+ women.

The Agency of HIV+ Women and Learning From HIV+ Women

The HIV+ women I have talked to are active agents in their relationship to the northern Ontario ASO. Their experiences are described in the following section. Their experiences with the ASO have been socially organized through various relational sites. Accounts from HIV+ women help to reinforce, recognize and illustrate how their relationship with the ASO is socially organized and constructed. HIV+ women have an active relation to the world and the ASO. Through the agency of these HIV+ women, the women themselves come to illuminate some of the research findings and recommendations for change within the ASO. These findings and recommendations are based on the social organization of the relationship between these HIV+ women and the ASO.

All of the HIV+ women interviewed have led lives which have been mediated through the various social relations they live. All of the women have little formal education, most did not finish high school or grade school, and most are unemployed. All of the women were mothers whether their children were teenagers or newborns, living with them or not. All of the women depended on some form of social assistance to survive. Two women identified as Aboriginal, while the rest could be characterized as "white." All the women were between the ages 22-40 and identified as straight. Three out of the six women became infected through the unsafe use of intravenous drugs. One HIV+ woman stated

that, "I was doing a lot of coke and my skin was grey. I was the first woman diagnosed in [name of a community]." Two of the women were still using drugs while also using some form of HIV treatment. One of them described the women who utilize the services of the ASO as, "most of the women who come are all like me, we are all ex-users or in the process of quitting. But it all revolves around drugs. We have all taken drugs pretty well."

The HIV+ women themselves describe their relationship to a northern Ontario ASO in the following ways. Many of the women utilize the service to gain food vouchers to buy food for themselves and their families or bus tickets for transportation around town and in order to hook up to services they require to survive. But the women do little else in terms of making use of the ASO in other ways.

According to Mykhalovskiy and Smith (1994) hooking up to social services is not easy and straight forward. It involves a great deal of energy and work on the part of the PHA (p.6). HIV+ women, because of their differing social locations may hook up with the ASO or other social services at different times in their lives depending on their needs. Mykhalovskiy and Smith (1994) reiterate this process of hooking up when they state,

> PHAs enter the work of hooking up from a myriad of social locations. Depending on their circumstances, they must deal with different social service needs at different times and with different resources. Often they must manage access to more than one social service at a time. All of this renders the description of their work in hooking up to social services difficult (Mykhalovskiy and Smith, 1994: 6).

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There are three institutional settings in which HIV+ people can access

services in the community in which I conducted my research. There is a medical

centre in which most of the work is developed around HIV treatments and

medical diagnosis. There is a drop in centre utilized predominately by the

intravenous drug community, although many of the women interviewed who may

not engage with drugs at all also use the drop in centre as a means of support

and gaining friendships. Although I am only able to explore the relationship of

HIV+ women to the ASO, some of their needs are met in these other two

locations and thus it is important to identify these other social locations. But what

is clear is that hooking up to any social service is a difficult process. Lastly, there

is the ASO in the community that meets specific needs of the women, particularly

in the form of food vouchers, bus tickets, and counseling. When I asked one

HIV+ woman why she uses the ASO her response was,

> For the fifteen dollar food vouchers which I began getting in May of
> 1999. And recently I had also been advised that 50% of
> reimbursement of my transportation, bus costs from my home to
> the city would be reimbursed so I used [the ASO] for that purpose
> as well. There are other services that I had hoped would be
> available that at this point in time unfortunately are not.

> [Ligaya- how is the drop in centre different from the ASO?] I guess
> cause there is no agenda. [Ligaya - what do you mean by
> agenda?] There is no mandate. I guess that is what I mean. They
> are not there as a function for anything they are there as support.
> [Ligaya-function refers to the ASO, and support refers to the other
> agency] Like the AIDS Committee has a mandate to blah, blah,
> blah well the [agency name] doesn't. It is just there and they are
> there for the HIV positive people more than anywhere they really
> go out on a limb for you.

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The HIV+ woman uses the term mandate, a term she has learned through her interaction and relationship with the ASO. Language like the term 'mandate' is part of the ASO discourse. The usage of this type of language comes in part from forms of state/professional regulation whereby these terms become actively organized within the worlds of the official discourse within the ASO. This form of discourse becomes a point of disjuncture between the experiences of HIV+ women and the organization of regulatory practices of the state through professionalism. This rupture between HIV+ women and the social organization of their relationship with the ASO is organized through social relations of marginalization that is rooted in the state and in the professionalized regulations and terms or concepts used by the state and ASO (Kinsman, 1997: 81).

The HIV+ women continue to describe their perception of the ASO as follows:

> They have more important things to do. They are busier. [Ligaya-you mean the ASO] [staff name at drop in centre] she has important things to do too but she rarely gets too busy for a client. You can call her and say can you do something on a certain time of day. She will find the time. So she is not as busy as [the ASO].

Some women describe the ASO as being too busy to meet their needs. Some women even describe the daily work of the ASO as so important that it may even take away from their needs being met. It is true that the staff of the ASO are probably overworked and the ASO may be understaffed, again a reflection of the constraints which impact on the services HIV+ women receive or

do not receive. This is not necessarily a reflection of the staff but rather a reflection of the lack of adequate government funding for core programming which also self-regulates the staff, whereby this regulation constrains and regulates the work of the staff. It is a reflection of the constraints placed on ASO staff by the government to prove and justify their work and existence.

But this perception of "importance" creates a delineation between staff and the women who utilize the services of the ASO, it creates a point of disjuncture. The ASO does not feel like it belongs to these women. HIV+ women are constructed as 'clients' and 'service users' and they actively use the ASO to try and get services or needs met. There is a point of disjuncture where the experiences of HIV+ women indicate that the "important" work of the ASO is more relevant than the needs of HIV+ women. A point of rupture occurs whereby the needs of HIV+ women become organized through social relations of marginalization of HIV+ women, in which the "important" work of the ASO means that the ASO holds the power in terms of when the HIV+ women's needs will be met, if ever. But they also hold power because they are perceived to possess the required knowledge which makes their job so "important."

This level of "importance" also determines how information is shared in the ASO between the HIV+ women and the ASO staff. For instance an HIV+ woman states, "they don't tell me about other conferences. [The ASO] doesn't tell me until it is too late to apply. Like [a city in northern Ontario] knows about Ontario AIDS Network (OAN), Ontario HIV Treatment Network (OHTN). I was

never told by [the ASO]." Further, HIV+ women's experiences and knowledge are undermined when they are not listened to by the staff or medical establishment in terms of how they chose to go through treatment or not. An HIV+ woman in conversation with me states, for example, "[Ligaya-they (the ASO) have totally bought into the medical model and are not willing to question the model.] The medical model put forth by the pharmaceutical companies who are making absolute billions of dollars worth of profit."

The power/knowledge relationship which seems to exist between the HIV+ women and the staff of the ASO is that the HIV+ women have a mediated character to their lives which impacts upon how their relationship with the ASO exists or comes about. For instance Cindy Patton (1990) states, "for a poor, urban, single mother, AIDS may feel like more of the same; her experience of AIDS may not easily be rendered in the rhetoric of 'living with AIDS', or from the often referenced reorganization of life priorities which comes from distress of diagnosis" (p.9). This mediated character often is socially organized around the relationship an HIV+ woman may have with the ASO. The following quotes help to illustrate the way in which these HIV+ women socially organize themselves in relation to others and the ASO.

> I myself am a woman who has not had a charmed life and it would
> make me feel more comfortable if we had a woman available [at
> the ASO] who had the same life experience [as that of]
> marginalized peoples because I identify as a marginalized person.

The way in which the HIV+ woman makes this distinction between herself and

the staff of the ASO serves to help me recognize the importance that her life experience plays in her utilizing services of the ASO. She feels the utility of the service is inhibited because of the staffs' inability to relate to her or even put themselves in her shoes. This type of problem can prevent women from using the services of the ASO at all, it delegitimizes their experiences and further makes invisible, the multilayered and socially mediated character of HIV+ women's lives, by creating distinctions between themselves and the staff and ASO.

For HIV+ women this mediated character of their lives also means that they will access the services of the ASO only when it is convenient and when it does not impinge on the other aspects or relations in their lives such as the needs of children or family. Further it may mean that they will access the services of the ASO for others in their life before having their own needs met. The ASO must be able to address these needs. In other words, HIV+ women are not always, if ever, utilizing the services of the ASO for HIV related matters but for other aspects, problems, issues or concerns in their lives. Therefore, we should not assume that women come to the ASO or even develop a relationship with the ASO simply because of HIV or their HIV status. Rather, they access the ASO as a means of dealing with other aspects of their lives which ultimately impact upon their overall health and HIV. As one HIV+ woman comments,

> I'm trying to deal with a lot of issues in my life right now, child
> sexual abuse, a lot of other abuse issues all wrapped into one and
> it has been, I have been here six months, it has taken me six

months to be able to go in there [into the ASO] because he's a man [the counselor at the ASO]. He's a man no matter what way you want to cut it he's a man, he's got a penis, he's a threat. But it's taken me six months to feel safe enough and it shouldn't be that way. You should not have to go through all that.

Some women have become empowered through the realization that their life experiences are not occurring in isolation but that there are other women out there with similar experiences. When women get together and begin to define themselves and voice descriptions about themselves they are validating their experiences. What this also means is that each woman comes to develop a relationship with the ASO in her own unique way and that there is no universal recipe for how this relationship occurs or is socially organized. Further the mediated character of HIV+ women must be taken into consideration when developing an intake form or a program for women, or when beginning to work with an HIV+ woman who is coming into the ASO for the first time. As I mentioned earlier an HIV+ woman may approach the ASO for the needs of significant others in her life before accessing services for her own needs. Another HIV+ woman describes herself as,

> I've led an incredibly isolated life and I heard this term, it was a term 'women at risk.' And when I just heard that term I thought it was the most wonderful thing I had ever heard because I realized that that's what I was, a woman at risk and I'm not talking about HIV woman at risk, IV drug user, I'm talking about being raised in abusive circumstances, became victimized by society ... I'm not an IV drug user, I'm not a prostitute, but I've definitely, I've been a woman at risk, I've survived an abusive childhood and have been victimized by men.

Certain experiences in an HIV+ woman's life are central to the different starting points from which HIV+ women will begin to hook up with services. Women enter the work of hooking up from various social locations, and depending on their needs, will have to deal with several agencies in order to have their needs met. The work that HIV+ women do to hook up also reveals the complexities and disparities they encounter in the process of utilizing services available to them. Hooking up is central to changing the circumstances of an HIV+ woman's daily life (Mykhalovskiy and Smith, 1994:6) predominately by improving their health and meeting their needs.

Many women, and people more generally, living in the north fear the stigma of HIV more so than getting any form of assistance or help. This fear can reduce the length of life or even the ability to live a somewhat healthier or improved life. The fear can also mean that you live your life as HIV+ in isolation. One HIV+ woman describes her experience with the stigma of HIV in relationship to a friend of hers when she shares the following story.

> I know a fella that died a couple of years ago and it wasn't from AIDS that killed him. And he used to do drugs with me and he went for a while two or three years I using drugs with him and he never once told me he was infected. He never once. The only way I knew he was he got the same vouchers that I got but I didn't know if they were given out at other places. It was just a guess on my part that he was getting from [the ASO]. Of all the years I was there, there was a guy there that he was HIV positive. So it really bothered me why he would go to his grave and not tell somebody that he had HIV. He chose to die without sharing that. That really bothered me.

Finally, some of the HIV+ women describe themselves in ways which

problematize their activities or themselves rather than examining the reasons

which socially contribute to a woman taking drugs or becoming HIV+ or being a

sex trade worker. Some of the terms which have been used are "I'm HIV,"

"addict," and "client from hell." Adam and Sears (1996) suggest that, "these

discursive disjunctures in the organization of experiences around AIDS are in

turn taken up by social institutions, frequently transformed and recontextualized

by them, and then purveyed back to new seropositives - who employ the

reworked narratives in making sense of their own experiences with HIV disease"

(p.50).

Therefore, negative ways of identifying oneself for instance as a "client

from hell," do not begin to address the social implications but rather creates a

scenario where the HIV+ woman herself is seen as problematic. The negative

description of an HIV+ woman used by the staff can be contrasted to the notion

of 'good' clients or 'normal' clients, also used by the staff, who are managed

through forms of self-regulation (being "good" means access to services) as well

as professional governance over their lives (Kinsman, 1996: 394).

During a guest appearance, one of the staff members of the ASO referred

to some clients, particularly those who are injection drug users as "clients from

hell," in contrast to 'clients' of the past. This description of the HIV+ women is

contrasted with the 'good' client the ASO used to see. What is meant by this is

that the 'good' clients were not necessarily injection drug users or problematic in

any way they just came in and got what they needed and left. What this further

illustrates is that the 'good' client was constructed as white, gay, and middle-class in character, and not a 'problematic' injection drug user. A 'client from hell' means that the HIV+ woman gets constructed as a problem client, an irresponsible 'client.'

'Client from hell' is a term which has obviously been used to describe HIV+ women who utilize the services of the ASO. An HIV+ woman who identified herself as a "client from hell" during an interview had this to say,

> [Ligaya-you were just telling me about the buddy program, and that you thought it was pairing people up. A volunteer and a PHA and that never happened.] That never happened to me. I am known as a client from hell at [the ASO]. [Ligaya-Why is that? Have you been told that?] Cause I go through these periods of where I will be straight and then I will go back out and I become quite a problem. I am a challenge. When I am using I am very much a challenge. So I am the one who is a client from hell. So I can see that when I am using they would not want to pair me up with anyone because I am so spinney.

The HIV+ woman does not use the term 'client from hell' in the same way that it has been used by the staff member of the ASO. The staff member is describing a group of 'clients' who are problems to deal with in relation to 'better' clients that the ASO supposedly used to have. The HIV+ woman is taking up this designation in part, but she is also shifting it in the context of problematizing her own drug use practices when she is not 'straight.' She is problematizing some of her social practices but not herself in general as a 'client.' Her injection drug use becomes a problem and therefore she becomes a problem, a 'client from hell.' This form of moral regulation is then used by the ASO to deny her access to

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services such as the buddy program.

Creating this type of label for women who utilize the services of the ASO creates this distinction between "good" and "bad" clients. This can be related to the social construction of broader social distinctions between 'innocent' and 'guilty' PHAs. These forms of labeling construct those who still use drugs or are sex trade workers or are somehow living their lives in a "deviant" manner as being HIV+ as a result of their own practices. These negative labels construct some PHAs as 'irresponsible' people and the cause of the spread of HIV/AIDS. Constructing the isolated individuals as the problem removes the responsibility from the ASO, government or public health agencies who do not provide the adequate resources for these HIV+ women (Kinsman, 1996: 397). Those 'good' clients who try to stay on their treatment regime, or become active as 'volunteers' in the ASO will receive access to services, as well as be recommended to represent the agency on Provincial or Federal Boards or ASO functions.

Those who are viewed as the 'clients from hell' become viewed as problematic. The broader social context is not looked at. One needs to examine what socially leads people to live their lives in a certain way, for instance poverty, class, poor education, and unemployment. Labeling HIV+ women in this fashion also prevents them from utilizing the services provided by the ASO. The HIV+ woman goes on to further describe her relationship with the ASO in terms of the buddy program as,

> Well I like the buddy program. [Ligaya-Tell me about the buddy

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program.] I don't know much about it I just spoke to them [the ASO] about it. I thought it was to match volunteers up with clients that's what I thought it was but then that never happened. It could be because I was using.

Inevitably it means a certain level of support is not being provided for these women because of the ways in which particular HIV+ women have been constructed as problematic (i.e. the 'client from hell'). In this case the HIV+ woman was denied access to the Buddy Program. The Buddy Program was a program set up by the ASO to pair volunteers with a person living with HIV/AIDS, to show them support, take them on outings or just to socialize with the PHA. As far as I know the Buddy program does not exist at the ASO at this time although it is still advertised in its agency pamphlets.

The ways in which HIV+ women have socially organized their relationship with the ASO suggests that their needs are specific and different from those of the men who access the ASO. What also seems quite clear is that the mediated character of these women's lives must also be considered when examining how their relationship with the ASO becomes socially constructed. This is not to say that mediation does not exist in HIV+ men's lives but that its social character is different. Given the mediated character of the HIV+ women's lives, and the need to meet the specific character of their needs many of the HIV+ women interviewed spoke about the types of programs they would like to see at the ASO.

More information with help for children being positive, family counseling.

Make it more family involvement. Make it more straight. When I go to hear about these meetings I am like oh that is good but it is always gay.

More family, more children's groups or activities. They have a craft group once every 3 months. It is with PHAs not with family. There are no kids things like painting, dot to dot they [the children] could go in another room and learn. Need more female counselors. There is only one [counselor, a male]. If I didn't get along with him [the counselor] where would I go. If I was a straight/heterosexual male and I felt uncomfortable where would I be.

These quotes help to solidify the idea that HIV+ women utilize services not only for themselves but for significant others in their lives. At times, the needs of the significant others outweigh their own.

Some HIV+ women are so keen on meeting and talking with other women that they will try anything to do it. One of the HIV+ women interviewed suggested this by stating, "Like the Internet I could have used that to speak to other women but they [the ASO] never told me." Or another woman suggests that she goes to the ASO not really for anything except as a means of possibly hooking up with another HIV+ female to start to develop a friendship or mutual understanding. She says, "Sometimes I go to [the ASO] to see other clients instead of a worker. I sneak in to see if I can meet another woman."

Other HIV women have suggested that currently the ASO is unable to meet their needs because of the lack of women's specific programming and the

lack of a woman's friendly space. What is meant by women's friendly space is that it is often difficult for women to even utilize the space or service of the ASO because of familial constraints such as the lack of child care. Describing the work that HIV+ women do in developing their relationship with the ASO reveals the disparities and inequalities they face in the process. This work varies depending on the social location of HIV+ women. HIV+ women will follow different courses of action or have different barriers to overcome depending on relations of class, race, and gender (Mykhalovskiy and Smith, 1994: 62). Often, women have many other issues or concerns that they are dealing with which they prioritize as more important than going to the ASO. Many of the HIV+ women spoke about how they socially organized their relationship to the ASO as follows:

> Well the number one glaring thing is that is as a human being you feel more comfortable connecting with someone who shares your experiences, who can put themselves in your shoes. And I do not feel that a gay male who is HIV negative can have a comprehension of what my life is like because he will not share any of my life experiences.

In this case the HIV+ woman is outlining how she would feel more comfortable sharing her feelings with someone who could relate to her experiences, needs or concerns. This does not necessarily have to be a staff person, the development of even a women's peer support network could be helpful for this woman. She wants to be able to have someone relate to her and her needs, not necessarily just be empathetic with her.

Being friendly to a woman and being women friendly is two different statements. They (the ASO) are friendly to women, but I don't find their services to be, they don't offer direct services to women by women with women's needs in mind.

I think without question they have to look at getting another counselor available of another sex, female. I don't see how they can possibly continue with the infection rates being what they are, I mean there are so many women now testing positive and there are so many children that are testing positive and there is nobody available to deal specifically. I mean the issues that gay men have are different from the issues that a mother has or that a child has.

There should be women specific counseling. There should be a holistic approach to care.

[Ligaya-Do you see the use in the development of a women's specific program?] I think it is imperative.

In all of these cases, HIV+ women suggest that there may be services available within the agency but they are not necessarily women friendly, nor do they have the concerns of women in mind. In the second quote the HIV+ woman suggests that she would like to have activities developed not only for her but for her children as well. This indicates how the mediated character of these women's lives comes into play and is important when developing a relationship with them.

I would really like to get women together because you go to your doctor and they tell you (your illness) it has nothing to do with HIV. It has nothing to do with your illness. Then you go to a meeting with all positive women and we are all sitting around chatting away and ah all of a sudden you find out nine out of ten of you are all having the same symptoms so you know it is HIV in your body but there is not much study about women and HIV and drugs that they are taking.

This HIV+ woman identifies the way in which these women are the best experts

on their lives and how the personal becomes political. She takes her personal

issues and politicizes them with other women through their sharing of information

which in turn has challenged what doctors and state authorities have informed

her to be "true."

One staff person said:

> Their [women's] needs are different, their physical needs are
> different. I see women especially who have children with them as
> really complex and really threatening, obviously. The system was
> designed for men, and the intake system was designed for men,
> the medical system has been designed for men.

This staff person also acknowledges that the needs of HIV+ women are unique

or specific in character. She is aware that women have many other concerns or

issues which are important in their lives, and at times these concerns outweigh

their own needs. Further, the staff member recognizes that the system which

has been established to assist HIV+ women is problematic in that it was

designed for men. The intake system was designed for men because initially it

was men who were contracting the HIV virus at an alarming rate. But, obviously

this process has not changed and should be transformed to reflect the diverse

client base accessing services from ASOs today.

HIV+ women have clearly identified that they wish to have a women's

specific program at the ASO. Approximately five years ago there was a women's

project. It was funded by what was then called a "Section-25 Grant," through the

Ontario Government. A Section-25 is a grant program for people who are

unemployed seeking employment. The grant boosts the amount they would

normally receive on unemployment insurance (now called Employment

Insurance or EI) while allowing them to work and possibly enhance some of their

skills. A woman was hired to start a women's project but the ASO was aware

that the outcome of such a project would be time limited because of the time

limits of the Section-25. The role of the women's project coordinator was to

liaise with various women's organizations or agencies which offer direct service

to women, and network with these groups and build relationships. Further, the

Women's Project Coordinator conducted some educational work in the

community through public speaks and outreach in some of the bars (both straight

and gay).

> It was a short term contract. It was not renewed. I was hired to do outreach for women. I did some work with the [drop in centre], the [name of a women's association], [name of a women's association], and other agencies. I was upset it wasn't renewed. There was a lot of work which needed to be done ... I did outreach in the gay bars and in [names of several bars].

> [Ligaya-Do you think the project was successful?] Yes , but not long enough to get people fully aware of it.

A current staff members said:

> There was [a project] about 5 years ago. It was a short term funding for about 4 or 5 months. It was funded through a work, you know one of those work related projects. I can't remember what they are called [Ligaya-Okay so like Section 25 or something] Okay. It was 16 to 20 weeks. She really made inroads. She went around and introduced the agency to an awful lot of agencies that we hadn't thought of. The project, the contacts all got turned over to me but we haven't had anything specific since.

> Yes, we had a woman that worked here for a while, that was quite

a few years ago. And she did a lot of work in terms of trying to get women connected, in terms of, look at women's services. And although it was really good, um I think it probably would be better now because of the increase of women that we've seen.

As a result of the women's project some networking was accomplished. But the only educational work which occurred was some outreach work in the gay bars and some of the straight bars frequented by people in their twenties. Since all of the HIV+ women interviewed identified as straight, outreach in a gay bar to these particular women was of no use, but was of some educational use to the community more generally. When I approached the staff for any printed materials about this previous project none was provided to me which made the development of a critical textual analysis of this project impossible. The only forms of recovery which I could utilize was in speaking to the staff and the previous coordinator of the women's project. Given that funds for the women's project were not sustained this also meant that the project was not viewed as important or central by the ASO. It is clear that the make up of the people who currently use the services of the ASO is now different and that many of the women using the services wish to have their specific needs met through a women's program.

HIV+ women's needs and the social character of their relationship can be investigated through links with staff of the ASO. The following section investigates the relationship from the standpoint of the staff of the ASO.

The Relationship of the Staff of the ASO to HIV+ Women and the Links to HIV+ Women's Lives from the Standpoint of the Staff

The majority of the staff of the ASO have been with the ASO since its inception over 10 years ago. The Safer Sex worker has been with the ASO for at least five years and the Outreach worker for less than a year. All of the staff interviewed work directly with clients and in the case of this research, directly with the HIV+ women interviewed. In fact, it was the staff who put me directly in contact with the HIV+ women that they each work with.

In this section of the thesis, are accounts of the ways in which staff socially organize their relationship with HIV+ women. These accounts are the relational processes between the staff of the ASO and their relationship with the HIV+ women who utilize the services they provide as staff, but also the services of the ASO more generally. Learning from the accounts of staff about how this relation is socially organized, helps to maintain their agency and helps to illustrate their role in terms of the relationship which takes place between them and the HIV+ women.

In order to understand how the staff socially construct their relationship with HIV+ women who access the services of the ASO, it is helpful to read the ways in which the staff describe the women and how they try and make sense of the realities of these women's lives. Initially, HIV+ women must approach the ASO and then, with a staff member, go through an intake form. This intake form is designed to get pertinent information about the potential 'client.' Information

is documented such as viral load, CD4 count, a record of their positive test results in order that they can become eligible for some financial programs at the ASO, if they are on any drugs, where they live, and their family doctor's name. But this intake process is somewhat different for women but not documented as such within the ASO. This is identified in my conversation with a staff member, "[Ligaya-Is it possible to outline the questions that you ask women?] They are [all in your mind - the staff member points to his head] Yeah!" The way in which the staff construct and describe HIV+ women helps to further inform their work and their relationship with the women. The staff describe the women in the following ways:

> I'm starting to see women that are younger than before in terms of being newly diagnosed. But for the most part, the most obvious I think, in terms of comparing them to working with men, is the issue of childcare and whether or not they are thinking of being pregnant or not.

> Right now I'm seeing women a lot younger than they were previously. By younger I would mean in their early 20's as opposed to later 30's. And because they are in that age group there are more issues around children and pregnancy. I mean we've had 8 I think this year or something [Ligaya-8 new clients?] no 8 women who gave birth. So that was very different from years gone by.

What is obvious is that the staff person realizes that an HIV+ woman is not going to approach the ASO with herself in mind first, but rather approach the staff with other concerns in mind as well as her HIV status. Her other concerns may outweigh those of her HIV status and this must be considered when working with HIV+ women. By not clearly identifying these unique concerns or issues for

women in an intake form, this does not outline their concerns or issues which may be quite different for men and further discounts their lived experiences.

> When I work with men, as surprised as they are or not, about becoming infected, women are much more surprised. So I think there is even, they have even farther to go kind of thing, before there is any kind of acceptance about the fact that they are HIV positive. For the most part because they got this disease through their partners you know so it's not necessarily that the women were injecting drugs or whatever.

> The only thing I think I want to add is that in my experience working with women, is that it takes a lot longer for women to come forward to begin with. And I think the process of working with an individual is that a lot more patience needs to be involved. You know those kinds of things, where I try to work from a feminist perspective, you know and taking the women where they are and going by that. So I find the difference is that it's usually a little slower. There is almost a feeling of guilt about accessing the services. Like they should be able to take care of themselves or that kind of thing.

Women carry with them numerous social relations, like that of wife, mother, caregiver and nurturer. As a result, women may take longer to utilize the services of the ASO because of the mediated character of their lives. All of these social relations take away from the HIV+ woman putting her needs and concerns first.

Therefore, a counselor may have to deal with those other needs first because that is what the HIV+ woman is willing to deal with first, or perhaps wants to deal with first because she needs to. A counselor must be patient and work on what the HIV+ woman defines as important at that particular point in time. What also seems quite clear to the staff of the ASO, is that women, due to the multi-layered character of their lives, will take longer to get the help they

need. The fear or surprise of becoming HIV+ can also prevent a woman from coming forward and seeking the help or information she needs. The ratio of women to men infected has shifted as pointed out by one staff member who says, "We have more women than we used to. We are probably operating at about 60/40, 60% male and 40% female. It's increased and I see that continuing." There has been a growing increase in the number of women who are utilizing the services of the ASO. With this growth in the number of HIV+ women there will be an increased need to meet their specific needs, issues and concerns.

The staff of the ASO also recognize that there is a mediated character to the lives of these HIV+ women. This awareness of the mediated character of women's lives is exemplified through the following quotes from staff:

> Women are caregivers and so the fact that they have to ask for something is often difficult because often they would be asking for their family or for their children or whatever the case may be. But now they are actually having to ask for themselves.

> I find that it is harder, it's a lot more difficult to get women to connect. They see it almost like well I've got other things to do, I've got families to take care of, or I'm working. There is a lot more issues involved in terms of reasons why they [women] can't come [to support groups] versus reasons why they can come.

> I'm finding with the clients we are taking in now that I guess it's the way that I personally look at HIV, HIV is not most of the clients big issue. And the more and more I work with HIV the more I realize the issues surrounding HIV now are practically as minuscule as the virus itself ... you are dealing with all the issues surrounding sexual, physical, mental abuse.

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I think a lot of times the things they are discussing with us are things they have never dealt with before ... because HIV being such a, in most of these women, such a small issue really and everything else is so huge.

Therefore, the staff when working with HIV+ women must take into consideration this mediated character of their lives. With this, the staff must realize that working with women will require more time to gain trust and break into uncharted territory for the staff in terms of HIV+ women sharing aspects of their lives. Here is what some of the staff have to say about their work with HIV+ women.

I think my whole demeanor in terms of, it's sad to say, but I think when I'm working with women, whether they tell me or not I assume that there's been some kind of violence whether it's sexual, whether it's physical. So I am much more thoughtful about whether I touch an individual in terms of giving them a hug or something. So I create a distance I think and I think that is a good thing. I automatically ask about children, is there contact, because they may have children but they may not be residing with them.

[Ligaya-Tell me about the assistance you provide to women?] It's whatever the woman brings forward so for some, for some the fact that I'm male may be an advantage because they have maybe have a history of not trusting other women.

I think I have to remind myself that for a lot of these women it was maybe harder to come through the door than other people. So I try to remember that, so I think I'm a little slower in my okay well what do we need to do kind of thing, and often I think a lot of the women just come in and just need to talk.

There are some other constraints staff of the ASO and HIV+ women must overcome in order to provide services or make use of services. If the staff abstract these women's lives away from their lived social relations of class, race,

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and poverty they are then left with 'abuse' and 'addiction' issues for instance. Therefore, ASO staff can only address these particular aspects of these women's experiences (abuse and addiction) and not the broader socially mediated character of their lives. What this points to is the way in which the staff have constructed a class/professional relationship with HIV+ women, a relationship in which the ability of the HIV+ women to determine their own health, safety, welfare, and social needs become the property of the staff.

By not challenging relations of class, poverty, and race and through the individualization of these women's lives as particular 'cases' of 'abuse' or 'addiction' the needs of HIV+ women are de-contextualized from the broader social relations that need to be addressed. Through this transformation the ways in which the staff address these women's 'individual' characteristics becomes compatible with maintaining capitalist/professional relations rather than threatening them.

Further considerations that need to be addressed in order to provide services for HIV+ women are that the women wishing to utilize the services of the ASO may choose not to due to the ever present stigma attached to HIV/AIDS, as well as the stigma of HIV being a gay disease. Homosexualization of AIDS also creates panic which reduces people's ability to gain useful and productive information to aid their situation. Along with this fear HIV+ women may begin to live a double life in order to cover up their HIV status in the public realm, while dealing with the disease in private. This will cause HIV+ women to

live in isolation. This double life is also filled with pain and anxiety due to threats

of disclosure or being "discovered" as HIV+ (Mykhalovskiy and Smith, 1994: 17).

The stigma of HIV/AIDS and homophobia are very prevalent in northern

Ontario. These fears only serve to reduce the number of women who come

forward to get assistance, information or help. The staff of the ASO recognize

that HIV/AIDS stigma still impact on whether or not a woman will get information

when they state:

> [Ligaya-Maybe you could tell me about some of the problems
> women face in accessing the services here but also social services
> more generally]. A lot has to do with the stigma [of HIV/AIDS] I
> think that that's still very prevalent and because if a woman is living
> with HIV she must either be, or this is how society perceives it, she
> must be a prostitute or an IV drug user and she may not be.

> If the women themselves were maybe homophobic to begin with,
> coming to an agency that might be regarded as gay related
> somehow ... that is going to impact [on whether they go to the
> agency or not]. I have one woman who we've been seeing for like
> nine years, so we are talking long term here. And she still has a
> problem with the fact that there are gay men that work here you
> know.

> The aboriginal women are very reluctant to come forward. They
> get other people to do it for them [utilize services]. I believe it has a
> lot to do with the stigma and the discrimination they have endured.

The fear of the stigma of HIV and homophobia are quite prevalent in what HIV+

women are saying. Overcoming these fears is one way of making use of the

services of the ASO. Therefore, there would need to be more education around

heterosexism and homophobia, as well as campaigns to try and reduce the fear

of AIDS/HIV stigma within the community

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In the next section of the thesis I have put together some of the findings coming out of this research as well as some of the recommendations I will make to the ASO as a result of this research. The ethnographic look at the HIV+ women and the staff of the ASO help to illustrate how the findings and recommendations were developed. The staff and the HIV+ women themselves identified a need for women's specific programs and also suggest there are specific needs of aboriginal women. The HIV+ women themselves realize that they are the best experts about their lives. The staff of the ASO may not always fully realize that HIV+ women are the best experts on their lives especially when they problematize HIV+ women as `good' versus `bad' clients, or participate in pathologizing them as 'addicts' or as sufferers of 'abuse.' This individualization of 'clients' can make the social relations of class, poverty, and race disappear. It is important to learn from the voices and experiences of HIV+ women themselves. Since this is the case, it may be helpful to look at ways of reorganizing the structure and policies of the ASO in order to begin to address constraints such as the professionalized character of the ASO; the homosexualization of AIDS; funding and the stigma of HIV for instance through the use of a more collectivist model of organization.

IV Conclusions

1. The Professionalized character of the ASO can prevent women from fully accessing services.

The women interviewed suggested that the social relations of professionalism are quite apparent although they are also taken for granted, because they have become so fetishized and so much a part of the common sense everyday workings of the agency. This creates a power/knowledge relationship. For instance, one HIV positive woman interviewed, compared the ASO to another agency which offers services to her. Although she does not use the term "professional" as a means of describing the nature of the ASO, aspects of what she describes are what have been socially constructed as meaning "professional" or what it is to be professional, such as the term 'mandate.' When asked to describe the distinction between the two agencies she states,

> There is no agenda. There is no mandate. They are not there as a function for anything they are there as support. Like the ASO has a mandate to blah blah blah. Well the [drop-in centre] doesn't. They are just there for HIV positive people. More than anywhere they go out on a limb for you.

What is often associated with being professional is the mandate of the organization which clearly outlines the objective of the organization. The mandate is often created by a Board of Directors or staff constrained by the guidelines of the ruling relations of the state including, for instance, rules around incorporation and what is required of the agency in terms of bylaws, a constitution, and a hierarchy of governance within the agency. The other AIDS

related agency that she describes seems to be less grounded in professionalized forms of organizing but rather more grassroots oriented in that it is for HIV+ people. This HIV+ woman seems to gain the support she needs from an agency other than the ASO. She has constructed a relationship that defines the role of the ASO as less of a support mechanism but more of an agency with a mandate it has to fulfill. Further, the mandate of the ASO is also in keeping with what provincial and federal funders would constitute as an AIDS related agency; for instance, what groups and projects are suitable to be funded through federal programs or provincial programs such as the Ontario HIV Treatment Network for example.

There is a clear distinction between staff and women who access the services of the ASO, whereby the staff are viewed as the experts on HIV/AIDS and not the women who accesses the services of the ASO. For instance women who access services of the ASO complained that they are often left out of the loop in terms of being notified of conferences, "[name of ASO] doesn't tell me until it is too late to apply." This could also be occurring because the method of communication between the women accessing the services and the ASO is through a quarterly newsletter put out by the ASO. When women have a lack of formal education (many have not finished even grade school or highschool, and a few women would be described by the staff of the ASO as 'illiterate') or are unemployed, their ability or even availability to read a newsletter is limited. Further, if these women are living or working on the streets the chances of them

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even receiving information is next to impossible.

The professionalized distance is maintained when staff come from professional backgrounds such as health care or social work. Along with this the background of the staff is far removed from the reality of most of these women's lives in that the lives of the staff are more socially privileged because they have access to information and resources which are not always accessible or readily available to the women who utilize the ASO. The staff are educated, in that they are familiar with the resources they have available to them and how to use them or access them, and they are white in character (although they recently hired an Aboriginal woman). 'Privilege' is used here not as some inherent or essential characteristic but to point towards the social practices that grant some people more access to information, wealth and resources than to other groups of people in this society. This notion of privilege is also developed through the professionalized relations that staff of the ASO develop and maintain.

The HIV+ women have a particular relational construction between themselves and the staff of the ASO. The social relation between the two are based around constructions of power in which HIV+ women need certain supports and services and the ASO staff are the gatekeepers of the supports and services. These women rely on the staff in terms of receiving information because of their limited ability to read or write, and because of the staff's ability to access information networks not readily available to HIV+ women. HIV+ women also rely on the ASO and its staff to assist them in manoeuvering through

the social system since the staff of the ASO are familiar with how the system operates and the type of language used and information required. The ASO also provides an accessible, free place, where, if organized, HIV+ women could meet to share ideas, concerns, needs and issues. The HIV+ women rely on the staff to provide them with all of the appropriate information, although with some skepticism, since some of the women have already suggested that they have not been informed of conferences which would have been useful for them or they have not received information. Yet, both staff and HIV+ women who utilize the services of the ASO have expressed their concern for the lack of time staff have to truly do the kind of work they would like to be doing since they are overwhelmed with other commitments. As some women interviewed suggested:

> They [the ASO] have more important things to do. They are busier. [Name of a staff person from another agency] she has more important things to do but she is rarely too busy for a client. You can call her and say can you do on a certain time of day and she will find the time. So she is not as busy as the [ASO].

> If I go and he [the counselor] is busy I have to come back the next day.

The social process of the relationship of women to a northern Ontario ASO is one which reveals that the relationship is built around relations of class and gender. Class is not simply a theoretical concept which is often operationalized in economic ways, but is a relation which is discoverable through the everyday world of HIV+ women's experiences, one which reveals that the relationship is built around relations of class and gender. In other words, class

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must be looked at in a social way, a reflexive way in which making sense of the

social relations of class is mutually determined. Class is a social relation

produced by people, it is a social accomplishment (Smith, 1999; Smith, 1987).

Class relations are constituted in many different social locations in this society

and not only in a narrowly defined 'economic' realm.

Part of what is going on in the relations between the staff of the ASO and

the HIV+ women, is the construction of aspects of a class relation in which the

HIV+ women are marginalized as not being 'middle-class' and not being

'respectable.' Gender and class cannot be understood by abstracting them from

the context in which they socially come into being. They are embedded in

everyday interactions and experiences including in the everyday social

organization of the relationship of HIV+ women to the ASO.

A problem or point of disjuncture occurs when we treat women in

universal ways, by abstracting away from class, race, sexuality, poverty, injection

drug use and literacy. This creates a false universal which suggests that all

women will have equal and complete access to an ASO, and have all their needs

and wants fulfilled in the same, equal fashion by the ASO. This is highlighted as

one staff from her standpoint, defines some HIV positive women in the following

manner:

> what I am finding more and more is the majority of the female
> clients are not highly educated. Very few of them finished high
> school. Some of them didn't finish grade school. What I'm finding
> is again frustrating, I suppose it frustrates me, as someone who's
> got a keen interest in education is that none of these young women

reached their potential.

Therefore we already see that the women accessing the services of the ASO do so on an unequal level from the staff of the ASO because of their level of education which is also one feature of a class position. Again, we can see the way in which HIV+ women have been defined in ways which problematize the HIV+ women themselves, and not the social implications of why a woman may not have been able to continue to go to school. What is suggested is a middle class standard which then situates some of the HIV+ women interviewed outside of that standard. Class relations are further complicated by the life experiences or activities of the HIV+ women using the services of the ASO. For instance some women described themselves as:

> I myself am a woman who has not had a charmed life, and it would
> make me feel much more comfortable if we had a woman available
> who had some life experience with marginalised peoples, because
> I identify as a marginalised person.

> Most of the women who come [to the ASO] are all like me we are
> all ex-users, or in the process of quitting, or we are not quitting.
> But it all revolves around drugs and we have all taken drugs.
> Pretty well.

> I am really shy. I have a hard time asking for anything or you know
> like, so it's just basically overcoming my own self.

Thus, all women's lives are not universal in character, but diverse in their make up and therefore the needs of these women will be different. These descriptions locate common social barriers that HIV+ women confront in different ways, depending on their social locations and the mediated character of their lives.

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There is no unitary HIV+ woman's experience. Instead, HIV+ women's experiences are shaped by their different social locations and the social relations that shape their lives, only some of which are directly related to HIV. These descriptions also indicate the ways in which gender, race and power imbalances in terms of abuse have an impact on these women's lives and that class relations are not uniform, abstract or universal in character, but a reflection of the social location of each woman and her everyday experiences.

Due to the social class of HIV+ women and their social activities, or practices (for example injection drug use) the medical establishment does not view them as credible. For instance, as one positive woman, who is also a cocaine user, suggested when talking to me about her HIV treatment and cocaine habit said, (I am paraphrasing since this was a conversation in an informal context) I told the nurse that the coke was affecting the treatment I was taking and that I should not be on this prescribed drug anymore. In fact the combination of the two prescribed and 'illegal' drugs, could be lethal in that someone could eventually overdose with the combination. The nurse said she would not tell the doctor. A week later three more women had to be removed from the drug due to similar complications and the threat of overdosing. The positive woman knew best about her body and the reactions she was having due to her cocaine habit and HIV treatment yet she was not viewed as the "expert." When an HIV+ woman becomes labeled an 'addict' it cuts out all her credibility. Again, this is an example of the power/knowledge relations occurring between

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HIV+ women and the staff of AIDS related agencies.

Credibility of the HIV+ women is further complicated when the ASO does not advocate on your behalf when explaining the reactions to treatment you are receiving. Credibility is again questioned because we often socially construct the medical establishment as being knowledgeable and all knowing. Finally, credibility is undermined when it is an 'addict' who is still using, trying to state her experience in terms of the drug reactions she is facing. Just because she is an active 'addict' whatever she is saying is questioned and could not possibly be of use to other HIV+ women.

The way to address all these diverse needs is not necessarily in a professional manner but in a way which suggests that the HIV+ woman who accesses services is the best expert about her life and experiences. Often these positive women know quite a bit of information about their HIV status and the disease itself, at times even more than the staff since their health is important to their everyday lives and survival.

2. Positive women's lives are socially mediated through several relations of their lives and not just their HIV status. This must be considered when providing services for HIV+ women.

When funders and state agencies do not clearly identify the needs of women in their programs or funding proposals women become invisible or removed from the central aspects of the work of the ASO. This neglect of women's needs becomes systemic in character. For instance, because ASO staff have not been directed by funding bodies or state agencies to create

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women's specific programs, programming becomes more general in character directed at a generic PHA who is often coded as male. Further, this occurs in a social context where HIV+ women's needs are grounded in the broader social constructions of what it is to be a woman, gender attributions of women, as well as institutional relations such as religion, and cultural discourses of femininity. Finally, the systemic ruling relations which socially marginalize HIV+ women occur when research and policy development around HIV/AIDS has been gender biased.

What I have stressed throughout this thesis is that the mediated character of women's lives must be understood through a 'personal is political' framework, one that recognizes these women as the best experts about their own lives. We can best learn from them how their needs have not been met or are being met in some areas. What I also recognize is that social relations or processes have a historical and social character to them, but what often occurs is that ideological and institutional relations become so ingrained in people's everyday lives that they appear to be 'normal' or 'natural' in character. This has occurred in the lives of women living with HIV/AIDS.

All HIV+ women or women using the services of the ASO are seen as a universal category, all having the same needs in relation to HIV. HIV positive women were and are omitted from drug trials due to systemic social relations which define women in terms of our reproductive capacities versus our willingness and ability to make our own decisions about our bodies and lives. It

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is the control over women's bodies and the desire to ensure our reproductive capabilities which help to inform research and policy around HIV/AIDS. There has been an abundance of research conducted on men and HIV; women want equal amounts of research conducted on us, by us, and for us.

Like that of women, men's lives are also mediated in character but a problem occurs for HIV+ women because most of the programs and education around HIV/AIDS have been designed for men's bodies and needs. As one staff members remarks about the lives of positive women,

> Their needs are different, their physical needs are different, their medical needs are different. I see women especially who have children with them as actually really complex. The system was designed for men and the intake system was designed for men, the medical system has been designed for men. So, I think that you know, well everything you know, from seeing what's happened from drug trials and things were designed for men, women have been left out of the loop on a lot of things.

The women interviewed were living in poverty, and most were living with substance use or addiction issues, and all had children. It is often these other aspects of their lives which come before anything to do with HIV, or AIDS and these aspects of their lives also inform how they live with HIV/AIDS. Some of the staff interviewed described the mediated character of the women's lives by stating:

> If they are looking at issues of child-bearing or if they are pregnant and concerned about that we talk about treatment, that's probably one of the first things we do. So they can make informed decisions. And if they are an addict, I'm looking at whether they want to slow down or whether they want to stop all together, we will talk about harm reduction or the [treatment] program or whatever.

I think I have to remind myself that for a lot of these women it was maybe harder to come through the door than other people. So, I try and remember that, so I think I'm a little slower in my okay well what do you need to do kind of thing, and often times I think a lot of women just come in and just need to talk.

I think my whole demeanor in terms of, it's sad but I think when I'm working with women, whether they tell me or not, I assume that there's been some kind of violence, whether it's sexual, whether it's physical ... because they may have children but they are not residing with them, like you are working on the streets, like you know there is a whole bunch of questions that I ask women that I wouldn't necessarily think about asking a man.

Women are caregivers and so the fact that they have to ask for something is often difficult because often they would be asking for their family or for their children or whatever the case may be. But now they are actually having to ask for themselves.

Another staff person is making her next appointment with an HIV+ woman and she states,

I'm coming in the next four weeks what would you like to talk about. And a lot of times it has nothing to do with HIV or Hepatitis or it has something to do with how to do a good manicure to keeping a site clean [individual jail cell] to knowing what certain diseases are.

All of these distinctions in the lives of women impact upon their health, their ability to keep their immune system up and healthy, and their ability to access services. Thus, the mediated character of women's lives has to inform all aspects of programming and activities within the ASO. Further, we also must consider the gender division of labour in that these women are performing several social relations such as mother, wife, caregiver, and providing support services. Therefore, in order to make the ASO more accessible to HIV+ women

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these aspects of their lives will have to be considered.

3. The Social Stigma of HIV/AIDS.

Women living in northern Ontario are limited in their access of the services of an ASO due to the social stigma of HIV/AIDS. The stigma threatens access for women in two ways: firstly, because the stigma is related to the fear of the disease; secondly, the stigma of HIV/AIDS becomes a threat to women because of the homosexualization of AIDS. What is meant by this is that some women, because of the homosexualization of ASOs, AIDS, and AIDS education, feel that their needs are not met or that they cannot approach the ASO for support or services. Initially, AIDS was identified as GRID or Gay Related Immune Deficiency Syndrome. As a result of this name people thought you could only contract the disease if you were gay or practiced what was identified as "gay sexual activity" or anal intercourse often associated with gay sex even though many heterosexuals engage in it. This stigma of AIDS being a gay disease has not gone away but is still quite prevalent today (Stoller, 1998). This type of thinking that AIDS is a gay disease or that the work that gets constructed around HIV/AIDS is queer in nature is still quite prevalent. It is not so much whether or not the work is actually queer in character, but it is the fear or phobia associated with this that prevents people from utilizing the serves of the ASO.

It is these two forms of stigma associated with HIV/AIDS which often prevent women from accessing support groups or seeking information. Often they do not want others to find out because this may threaten their ability to

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parent or may cause difficulties in accessing drugs, or may impact upon their

family, lovers, and/or partners. As one staff person suggests,

> A lot of it has to do with the stigma. I think that's still very prevalent
> and because if a woman is living with HIV she must either be, and
> this is how society perceives it, a prostitute or an IV drug user or
> she may not be. But that stigma has prevented a lot of women
> from accessing services. Or, if the women themselves may be
> homophobic to begin with is coming to an agency that might be
> regarded as being gay related somehow you know how this is
> going to impact. I have one woman that we have been seeing for
> nine years and she still has a problem with the fact that there are
> gay men that work here.

The HIV+ women themselves are aware of the stigma when they

state,

> I've met a lot of native women and its really hard for them they say
> because there's you know either it's gay or it's for men, you know
> they don't fit in anywhere.

> I see a lot of people just try to ignore it and pretend they don't have
> it, they don't talk about it.

> I know a lot of people who are HIV positive. They stick to
> themselves, they don't come out about it. So I wish they would.
> 'Cause I know a lot of people that have it and I just wish they could
> use all that is available to them. [Ligaya: Do you think there is any
> way that these people will ever access the services of the ASO?]
> No-because of the stigma.

Thus, often times the social constructions of the disease seem more

problematic than the medical construction of the disease (Adam and Sears,

1996: 2). The problematic becomes one which raises the question, "How does

this affect the other aspects of my life such as children and family?" Due to the

social attributions of what it is to be a woman such as caregiver or nurturer, a

woman rarely enters into the ASO without considering these other important aspects of her life. This is quite different from the ways in which AIDS organizing and education has occurred for men in that when dealing with men there was a focus upon the men as individuals or how HIV/AIDS has an impact upon their partner. Therefore, the mediated character of an HIV+ woman's life often means that aspects of her life take precedence over others. For instance the care and health of her children may be more important to her than even her own health or needs.

4. Moving Beyond "Good" versus "Bad" Clients.

The investigation of this finding or the desire to even investigate this distinction was based on the comments made by one of the staff members in a public context in which the staff person referred to some clients as, "a client from hell." This was contrasted with the 'good' clients that used to exist according to the staff person. The notion of 'good' client was also shaped by the anti-injection drug use approach the agency has taken up. Initially the 'good' clients were white, gay, middle-class men, who were not usually injection drug users. These men came into the agency to get whatever they required and left. The 'client from hell' or 'bad' client is usually an individual who is defined as 'deviant' in character because of the activities they engage in such as drug use or sex work.

When I first heard the statement 'client from hell' I knew that the statement was a disempowering one which served to undermine the life experience of the woman the staff member referred to. What a comment like this further did was

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exemplify the manner in which the mediated character of each of these women's lives is quite prevalent, and that the ASO was probably not considering that in the type of assistance they provided.

What the comment also exemplified to me, was that the possible behaviors the client was expressing were a reflection of her life experiences whether that be a lack of trust; because she was abused in some fashion; anger and frustration because of her life situation where there is a lack of money or available affordable housing; or that her children have been taken away, or that there is an impending threat of that. Therefore rather than trying to understand the woman, her experiences just become undermined by being referred to as a "client from hell." Using this negative terminology as a means of identifying clients also suggests a means of morally regulating peoples lives, through the construction of the injection drug user as problematic or 'deviant.'

The Shortcomings of the Research

In summing up this thesis I must first acknowledge the contributions of all the HIV positive women who took part in this research. Their willingness to share their lives and experiences with me have provided the insight and theoretical framework for this body of research. It is only through them that I have been able to begin to understand what the social process of a relationship between positive women living in northern Ontario to an ASO is like.

A relationship is considered to be some sort of connection between two people. This thesis was an evaluation of the notion of relationship as a social

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process. What I bring out in this thesis is the human element involved in the development of the relationship between HIV+ women and a northern Ontario ASO. In other words, I try to maintain the agency of the HIV+ women and the staff of the ASO.

I explored the relationship of HIV+ women to the ASO by starting from the standpoints of HIV+ women. Starting from the standpoint of HIV+ women suggests that I am interested in how these HIV+ women socially organize and accomplish their relationship with the ASO.

What was revealed in learning from the standpoint of HIV+ women was that their relationship to a northern Ontario ASO is shaped by the mediated character of their lives. For instance, the HIV+ women interviewed are dealing with several social locations, such as poverty, abuse, drug 'addiction', class, gender, race, sexuality and family, along with the homosexualization of AIDS and HIV stigma. Therefore, when an HIV+ woman is accessing the services of the ASO all the mediated aspects of her life must be taken into consideration. Most of all, the HIV+ women interviewed just wanted someone to listen to them and hear all the other aspects about their lives. Therefore, the relationship between HIV+ women and the ASO was not just about HIV, but something much broader and more socially dynamic. The relationship was one which was ever changing depending on the social location of the HIV+ women at the particular time they are utilizing the services of the ASO.

Conducting research is a learning process, therefore, not only did I learn

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about the relationship of HIV+ women to the ASO from the women themselves, but I also realized shortcomings to my research. I have discussed how class relations and social inequalities exist for the HIV+ women yet I could not get funding to pay each HIV positive participant for their time. This may have been one of the factors which meant that only six HIV+ women could be interviewed or were willing to be interviewed. I suggest in my recommendations, the mediated character of these women's lives suggest that payment for their time is essential in order to reduce the stress for these women in terms of the constraints other aspects of their mediated lives may construct. Payment for their time may have interested more women to become participants.

The other shortcoming was that those women I interviewed within the ASO, when interviewed, seemed hesitant to respond fully whereas women that I had the opportunity to interview elsewhere seemed to be more forthcoming. The interview setting at the ASO was possibly stifling or threatening to the HIV+ women interviewed in that it was not their territory, they had little power within that agency so they were not going to possibly jeopardize their access to services by critically speaking against the ASO or its services. Outside of the ASO the women seemed less inhibited or threatened. They felt they could speak more freely and criticize or speak out about the services or the ASO. There was probably more of a feeling of anonymity in that no one at the ASO knew they were being interviewed whereas within the agency people knew that interviews were being conducted in a particular room.

Another contributing factor was that most of these women have lost trust in other women or people in their lives. We did not have a level of trust or rapport established, thus this may have been another reason for what seemed at times limited responses or responses which seemed to only highlight the positives of the ASO, while also having a clear unwillingness to highlight any faults with the ASO. I could maybe say there were not faults with the ASO, but when examining interviews with women interviewed at other venues they clearly had some problems with the limitations of the ASO.

Further study in this area of research is needed. It would be useful to develop an analysis of textual materials, proposals, funding documents, the intake forms, pamphlets which promote the activities or programs of the ASO, flyers that they use to publicize events for PHAs, and ASO newsletters. These textual documents can provide a historical and social character to the work and relationship of the ASO to HIV+ women. Unfortunately, my thesis does not undertake any form of textual analysis, although I tried on several occasions to receive information which pertained to women's programming or the previous women's project, on all occasions I was told by staff of the ASO that no textual materials existed.

What is abundantly clear is that there is a need for women's specific activities to start taking place at the particular ASO I studied for this research. Next I will be discussing the recommendations I have developed as a result of what the women interviewed suggested were needed within the ASO.

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Recommendations For Change

The organization of the ASO has to be transformed, particularly in terms of the professionalized/bureaucratized nature which presently exists. A major way of transforming the ASO is to place the power of the ASO in the hands of the people who access its services, the 'service users.' Freeman (1973) suggests that leaderless, structureless organizations, which have existed in the women's movement, are one type of alternative which redefines the professionalized nature of organizations. A collective would be a way of transforming the professionalized character of the ASO in favor of one which places the activities of the ASO in the hands of the people who use the services most, people living with HIV/AIDS. A collective would mean that HIV+ women would be active agents in the work that the ASO does.

As Morgen (1994) states,

Instead of basing personnel decisions (hiring, remuneration, advancement, and job separation) solely or primarily on criteria such as specialized training or certification, previous job/career experience, seniority or meritorious job performance as evaluated by a superior, collectivist workplaces often replace or supplement these criteria with others, that are more personal or political (p.666).

We can begin to question professionalized relations when we remove the formal hierarchical process and begin to recognize the emotionality of an organizational experience. Professionalism and bureaucratization become fetishized in the daily activities of the ASO especially since community based

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AIDS organizations have now come to be referred to as ASOs. Initially community based AIDS organizations were grassroots in nature, but as state agencies wanted to develop 'partnerships' with these organizations - for instance the Ontario Advisory Committee of AIDS - as a means of getting community groups to take responsibility for public health and other regulatory strategies community based grassroots organizing has become more professionalized in character (Kinsman, 1996: 398).

On the other hand, a collectivist model fosters social relations which are more personal and democratic, and fosters a sense of empowerment since all members of the collective become active participants within the everyday world of the collective. Therefore, rather than the professional leaving their emotions at home, a collectivist model values staff expressing their needs and concerns and the expression of the needs and concerns of the HIV+ women who utilize the services of the ASO. Women who access the services of the ASO are members of the ASO by the fact that they use their services. They should therefore be a part of the everyday decision making because they are members, or participants who utilize the services of the ASO. Due to their membership, HIV+ women should be part of the monthly staff meetings, and the overall workings of the agency more generally, in order to contribute to the overall workings of the ASO. By contributing in this fashion, women will feel more empowered and realize their voices and contributions are worth something. Further, they will value the work and services that exist or that may begin to exist

for them. By being a part of the overall workings of the AIDS organization, women may feel more empowered to take part in women's support groups or support groups that fit their needs. Collectives, along with feminism, challenge bureaucratic structure in organizations and at the same time they question the "merits" of professionalism as a criteria for authority and leadership within the organization.

Another means of transforming the social processes of professionalism is to begin with the experiences of the women who access the services, and draw upon their standpoints. In order for the staff to be of benefit to the women accessing services there is a need to understand how these women make sense of the social character and social organization of the ASO. Maintaining an indexical and reflexive character to the way in which staff and HIV+ women who access services interact and share information and resources not only serves to empower the HIV+ women, but removes the professional distance and lack of emotionality which often takes place in a professional relationship. A process of mutual determination where the standpoint of the HIV+ women accessing services is maintained, prevents the conversion of these women into objects. This maintains the indexical/reflexive character of the social worlds of the participants. Thus, in order to achieve this task, a needs assessment, or a means of gaining an understanding, of the women accessing the services of the ASO is required immediately. This needs assessment should be directed by and for HIV+ women and should encompass their words, worlds and experiences.

More specifically, the needs assessment should look at particular concerns already identified by the HIV+ women such as family, children, substance use, poverty, aboriginal issues, advocacy work regarding treatments, medical care, social services and marginalized women. A needs assessment should be organized through participatory research defined by the HIV+ women themselves.

Although HIV+ women are producers of their social world, they may often be constrained by the ruling relations of professionalism, for instance, feeling they lack the experience or expertise to contribute to the everyday work of the ASO. If knowledge is produced by people and power is also produced by people, maintaining the agency of the 'service users' can assist in eliminating the professionalism, and power imbalances. Given the social character of bureaucracy and professionalism all knowledge is social in character and produced by people. The use of the standpoint approach as identified by Dorothy Smith (1987) does not address the female seeking services of the ASO in a universalized fashion, but rather seeks to explicate the females experiences, needs and wants from their vantage point, far removed from any theoretical or professional view point.

The services HIV+ women seek are often located outside the ruling relations for example, state agencies, the funders, the staff, the medical and public health establishments. Therefore, in order to meet the needs of women accessing services the ASO and it's staff should not begin in the worlds outside

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of the HIV+ women's everyday lives, but instead, begin with those they are there to serve, as well as those most directly affected by HIV/AIDS. Therefore, when offering any sort of programming to women the ASO must consider having money available for these women. Women may even have to be compensated to attend support groups since their everyday worlds are mediated through other aspects of their lives such as family, child care, poverty, housing and food. To do this work in a more proactive fashion, the ASO needs to take up anti-poverty and childcare issues, by creating alliances with groups such as anti-poverty coalitions, or through viewing these issues as a central part of the advocacy work the ASO takes up since these issues are important to the lives of HIV+ women.

Currently, the government does not fund HIV+ women to attend support groups on an ongoing basis but will fund aspects of their mediated lives such as child care or transportation concerns, as long as these needs have been clearly outlined in funding proposals submitted by the ASO to government funding bodies such as the OHTN (Ontario HIV Treatment Network), or the AIDS Bureau. A place for women to leave their children within the agency may be required. A play room with child activities, which could also be HIV/AIDS relevant as a means of educating and breaking down barriers, would also have to be considered. In order to have women feel like an active part of these programs they should have an active role in their creation and maintenance.

In order to help break down the barrier of the stigma of HIV/AIDS it may be useful to have activities which are centred around family or children rather

than HIV/AIDS per se. Of course, HIV/AIDS programming and education could then be brought into these activities when women are present and feel comfortable. This may also mean that such programs would have to be offered outside of the ASO and in places these women frequent such as the drop in centre. These programs may have to be given names which seem less threatening and more centred around the everyday activities of these women.

Since most service agencies funded by the government "assess" their 'clients' through what is called an intake form, this process of "assessing" HIV+ women who utilize the services of the ASO has to be transformed to account for the mediated character of HIV+ women's lives. Along with this, the intake forms and the intake process should be specific to women. Therefore, there may be a need to have an outside evaluator assess the current way in which this process occurs in order that an improved process can be implemented; one which is more in keeping with women's needs and the manner, often mediated through other aspects of their lives, in which they seek services. What is meant here is that women seldom seek services for their own needs but rather the needs of others in their lives such as family or children, and these aspects of an HIV+ woman's life must be taken into consideration in the development or revision of an intake form and process.

Finally, there is a need for a women's specific program and support group at the ASO. The staff and some of the positive women interviewed have suggested this would be of importance to the ASO at this time.

Hope for the future

What is hopeful about this research is that the relationship discussed in this paper is social in character thus, it is created and changed by people. Further it has a historical and social character to it. Therefore, what is always hopeful about the relationship of women to a northern Ontario ASO is that it can be transformed, or changed by these same women. This can only happen though if these same women feel that their voices are important to the organization, and that the organization is hearing them via aspects of programming which will cater more to their specific needs.

What is also hopeful is that more than 500 women attended the first Annual Women and AIDS Conference in Toronto in late May 2000 hosted by the Canadian AIDS Society. This may be a stepping stone for the government to actually realize the need for not only more funding for HIV/AIDS and ASOs, but the need for funding for women's programs which may also include children. This type of funding increase would certainly assist an ASO like the one described throughout this thesis in starting to develop programs most of the staff and the HIV+ women suggested were needed for women. In order for these types of transformations to take place, the ASO and the HIV+ women will have to begin to actively challenge issues around funding and regulatory constraints.

Along with this, since the start of this research back in November 1998, there have been some staffing changes which may make the ASO more accessible to women. Some of the women wanted staff who were of Aboriginal

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descent, while others wanted one woman counselor. Both of these needs have now been met.

What is also hopeful is that when provided the opportunity and a safe space in which to do it, the women interviewed were creating a version of the social world from their own standpoint, speaking from their own experience. Developing a sociology for women from their standpoint serves to challenge ways in which women have been silenced. This is always hopeful when looking towards the future. Finally, what is always hopeful to realize is that our world is social in character, created by people, therefore, we always have the ability to transform it. In meeting with and learning from the HIV+ women interviewed I also gained and shared knowledge with them. Some of the women I have talked to after completing my thesis research are starting to actively transform the ways in which they are involved with or socially organize their relationship with the ASO.

Endnotes

1. Mediated character is a social way of theorizing developed by Himani Bannerji (1995). In trying to maintain the agency of women Bannerji (1995) suggested that class, race and gender are interlinked with each other and through each other. Women can not be constructed in a universal fashion, but rather through the mediated, or multilayered, character of their lives.

2. Gary Kinsman (2000) during a lecture in his Sociology of AIDS course taught at Laurentian University, discussed the concept of the homosexualization of AIDS as part of his larger discussion on the construction of the social and historical organization of the AIDS crisis. The AIDS crisis was initially constructed as a 'gay' disease. What is now defined as AIDS was named G.R.I.D., or Gay Related Immune Deficiency. By constructing AIDS as a gay disease the systemic discrimination of homophobia was emphasized, at the same time as AIDS was homosexualized.

3. Eric Mykhalovskiy and George Smith in a March 1994 report titled, "Hooking Up to Social Services: A Report on the Barriers People Living With HIV/AIDS Face Accessing Social Services," discuss the ways in which stigma of HIV/AIDS create barriers for PHAs trying to access social services. Mykhalovskiy and Smith (1994) suggest that, "stigma of HIV/AIDS is actually established and reproduced in the language of risk groups, HIV transmission and so on" on the other hand, "PHAs through conversations tell us how stigma is socially organized" (p.20). One aspect of the social organization of the stigma of HIV/AIDS occurs in the work that epidemiologists and public health officials engaged in. They labeled the syndrome as a "gay disease" and attributed the syndrome to "promiscuous" sex. My research tries to understand stigma by emphasizing the social character of stigma. My research highlights the ways in which the social relations of stigma shape the relationship that occurs between HIV+ women and the ASO.

4. Patricia Morgan (1981) suggests that the professionalized and bureaucratic relations of people working in a battered women's shelter become fetishized. The professionalized and bureaucratic relationships become fetishized because they are no longer obvious to those participating in their social relations. We come to accept these social relations as taken for granted rather than realizing their social character. We begin to fetishize the professionalized and bureaucratized relations so much so that we give them supernatural powers and treat them as "things."

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Appendix I

Interview Schedule For Female Service Users of ASO

1. When did you start using the services of the ASO?
2. How did you come to find out about the services offered by the ASO?
3. Why do you use the ASO?
4. Are there certain needs you approach the ASO about, and other needs you use another agency for?
5. What do you believe is missing from the ASO that may cause you not use the ASO?
6. Do you believe the ASO to be women friendly?
7. How could the ASO make itself more accessible to your needs?
8. What barriers exist for you in terms of accessing the programs available?
9. Which programs are the most helpful and why?
10. Which programs do you feel are not helpful? And why?
11. Which programs need improvement? And why?
12. For the programs which you have identified as requiring improvement, how do you think they can be improved?
13. What other types of programs do you think should be developed?
14. Has there ever been a women's project or program geared specifically towards women?
15. Do you see any use in the development of a women's specific program?
16. Do you have any other comments, concerns or questions?
17. Would you like to add anything that I have not asked about?

Thank you for your time.

Appendix IA

Interview Schedule for Staff and Volunteers of ASO

1. How did you determine the needs of women in the community?
2. What types of programs were developed to meet the specific needs of women in the community?
3. How do you ensure that the programs are accessible to the women who wish to utilize them?
4. What types of promotional activities are done to make women aware of the services available to them?
5. Has there ever been a women's project?
6. If so, how was it funded?
7. What happened to the project?
8. Why was the program continued?
9. Was funding ever applied for again for the same or similar programs?
10. Would this ASO be interested in developing another women's project?
11. What do you believe to be the barriers to women who wish to access the ASO or its programs?
12. What seem to be the needs of women accessing the ASO or its programs?
13. Have these needs changed over the years?
14. What is the level of involvement of women in the ASO?
15. In what way are women involved?
16. What are the goals and objectives of the ASO in terms of access to women?
17. Are there any documents which I could read which refer to the existence of a women's project or the involvement of women at the ASO?
18. Should you feel there are other women who may be interested in becoming involved in this research could you please give them my number to set up an interview.
19. Are there any questions, concerns, or comments you would like to make?

Thank you for your time.

Appendix II

Consent and Release Form

Outreach and Access: An evaluation of the relationship of women to a Northern Ontario ASO

Researcher: Ligaya Byrch

I, Ligaya Byrch, am a student in the Masters of Arts in the Applied Social Research Program, housed in the Sociology Department, at Laurentian University. I am exploring the relationship of women to a local Aids Service Organization (ASO). The aim of this research is to reveal women's understanding of their relationship to the ASO which may include benefits, positive experiences, limitations, constraints, or barriers. At the end of the research the thesis will be given to the ASO for their records.

Further, I commit myself to maintaining the confidentiality of all participants in this study through the use of pseudonyms, and the removal of all identifying information. I know that the participant has the right to withdraw from this research at any point. If I have been informed of the participant's desire to be removed from the study the audio cassette recorder will be shut off and the tape destroyed. I also know that I will be the only person listening to the cassettes and transcribing the cassettes. The only other person who may listen to the transcripts in an advisory capacity would be my supervisor, Dr. Gary Kinsman. Once transcribed the tape will be erased.

I hereby commit myself to following the procedures outlined above in doing this research.

_____   _____

Date   Investigator's Signature

I understand that Ms. Byrch is a student in the Masters of Arts in Applied Social Research at Laurentian University. I am aware that she is interested in exploring the relationship of women to a local AIDS Service Organization (ASO). I know that she believes this research will reveal women's everyday experiences which may include benefits, positive experiences, limitations, constraints, or barriers in terms of the relationship between women and the ASO. I have been informed that although this research is being conducted with the approval of the ASO, this research is entirely independent of the ASO. Finally, Ms. Byrch has informed me that a copy of her thesis will be given to the ASO for their records.

I have been told that the potential benefits of conducting this type of research are

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the creation of awareness, education, outreach and access for women with HIV/AIDS and for the women's community at large, as well as to provide possible ways of improving programs.

I understand that discussing my experiences and relationship with HIV/AIDS may cause some anxiety. If such anxiety arises the interview can be stopped at any point and the tape recorder turned off. I further understand that my participation/non-participation in this study will not hinder or affect my access to any services I currently use or plan to use in the future. I realize that the interview will take approximately one hour of my time, and will involve answering questions. I understand that an audiotape will be used during the interview.

I know that my participation is strictly voluntary. I know I have the right to refuse any questions with which I feel uncomfortable, and that I can withdraw from this study at any time. The researcher will be the only person who will have access to the audiotapes, with the exception of her thesis supervisor, who may be asked to review a section in an advisory capacity only. After the research is over, the audiotapes will be erased to ensure confidentiality.

If I have any questions about the study or about being a participant, I know I can call Ms. Byrch and her supervisor, Dr. Gary Kinsman. I may reach them at Laurentian University at (705) 675-1151, extension 4221.

I agree to participate in this study, and I have received a copy of this consent form. I have been assured that my name and my identity will not be revealed at any time. I understand that a pseudonym will be used in place of my name, and that all personal identifying information will be removed, and that the name of and location of the AIDS Service Organization, or any women's organization in the community will not be revealed at any time.

_____   _____
Date   Participant's Signature

Appendix III

Referral Script

The following script will only be used should a participant feel they have experienced stress and anxiety as a result of the interview and needs support or counseling services. Once a crisis has occurred the interview will immediately stop, and the cassette recorder will be shut off. Since the researcher is not in a position to undertake any form of crisis intervention a referral will be made to an AIDS Support Services program in the city.

Should a crisis occur Ligaya Byrch will say:
"Are you alright? May I give you a copy of the AIDS Support Services Program's phone number and address. You may use the telephone here to call if you like right now. Please contact them to discuss what you are feeling."

The confidentiality of the participants could be jeopardized by providing the actual name, address and phone number of the organization in this appendix. The referral sheet each participant can take with them will have the following information on it. The information shown here acts as a template for the actual information which will be provided to the participant. Printed copies will be made available during each interview.

AIDS Support Services
Coordinator's name
Street address
Unit #
City, Ontario
XXX XXX

(000) 000-0000 phone
(000) 000-0000 fax
(800) 000-0000 toll free