RESOURCES FOR HIV+ WOMEN IN BOSTON

by

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FORWARD

When I began this project I had a vague notion about compiling a guide to all of the resources in Boston available for HIV+ women and from that compilation discerning what needs are not being met and why. My advisor, Caroline Whitbeck, was supportive, but suggested I narrow my scope a little. It was good advice, but I never took it to heart. I spent hours on the phone trying to unravel the myriad of resources for HIV+ women and have still not uncovered all of them. (It may be misleading to say that there are a myriad of resources. In reality there are only a few services specifically for these women, but they have such a broad range of needs that the services they utilize range from Women AIDS Risk Network to Welfare.)

In my quest for resources I met up with the Boston AIDS Consortium. Beverly Smith, Julie Marston and Jennifer Walters were working on a resource guide, similar to what I was envisioning. They even wanted to talk to providers and HIV+ women about the specific needs of women with AIDS, as I did. Instead of focusing my vision with their help, I chose to expand it, thinking I would not want to simply duplicate their efforts. So, thinking that the factual information about resources was well on its way to being compiled, I offered to work with them while doing my thesis. In reality, we spent (and continue to spend) much time on the compilation, because, as I noted above, the needs and resources are not straightforward.

In order to get a first hand account of needs and the barriers to receiving services, I began to interview providers and HIV+ women. Transcripts of these interviews are at the back of this document. I am deeply grateful to the women who took the time to talk to me. It is an invaluable part of this thesis. The women spoke to me in confidence and I have respected that by omitting names throughout the thesis. There are also parts of the interviews that have not been printed in this document at the interviewees' requests.

I am hoping that the information about barriers to getting resources can help providers in serving this special population. I also hope that the resource guide data can help both HIV+ women and providers in the never-ending struggle to track down needed services. One common problem that I saw was a lack of awareness of what resources are available and how to access them. While many resources are just not accessible, we do need to find an effective way to use what we already have.
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ABSTRACT

The resources in Boston that are designed to meet the needs of women infected with HIV illustrate how their needs are or are not being met and the barriers to meeting them. Although AIDS services, health services, and new agencies to address the needs of HIV+ women have increased their efforts, more needs to be done.

There are some apparent barriers to serving this population: the complexity of the lives of most women affected by HIV, a lack of sensitivity toward the circumstances of their lives, a lack of information about the effect of HIV on women, and the need for women to be able to advocate for themselves. Each of these broad issues plays itself out in specific ways when we look at the services of particular agencies that address HIV+ women.

Some agencies can be considered models for effective service to the complex population. We can see in programs like the Dimock Community Health Center, Entre Amigas, and the Women AIDS Risk Network a commitment to serving women. In designing their programs they have taken into account the many complexities of the female population they serve, ranging from drug use problems to lack of transportation.

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INTRODUCTION

Resources for HIV+ women and women with AIDS in Boston have been growing in three distinct areas: AIDS specific services are modifying their efforts to address women's needs; organizations that already serve women in various capacities are adding AIDS to their list of concerns; and specific resources are being developed for women with HIV. Efforts in these areas are recent, though, and there is still a serious lack of effective services.

To understand this vacuum we must look at all of the issues that intersect in the lives of the women who need these resources. For them, HIV cannot be addressed separately from their status in society, which is often exactly what led to their HIV positivity. Issues such as sexism, racism, poverty, drug use, a history of medical abuse, family relations, and the state of our health system interact to make HIV specific resources unavailable to HIV+ women. At the same time the health systems which are meant to address the issues that affect women have not been able to address the issue of HIV adequately.

There are many areas of need for HIV+ women. These women range from those who do not even know they are infected and those who are asymptomatic to women with full blown AIDS. Their needs cover a wide range from testing and medical care to counseling and transportation. Some of their needs are specific to HIV while others involve the circumstances of their lives. In many cases they cannot utilize the HIV specific resources unless their other concerns are addressed.

In Boston adult women make up 123 of the 1255 reported cases of AIDS. This is approximately 10% of the cases, which is similar to the
national figure in 1987 of 8.6%. In New York City at that time, 25.7% of the cases were among women.¹ Most experts believe that the trend in NYC is the trend the nation will take in the future.

Of the women with AIDS in Boston, 56 are thought to have contracted the virus through IV drug use, 56 through heterosexual contact, 5 through blood transfusions and 6 through undetermined modes of transmission. Ninety-four of them are Black, 19 White, and 10 Latino (phone conversation with worker in the AIDS Statistics Office of the Department of Public Health, April 3).

The figures given reflect only the women diagnosed with AIDS. In a recent study at Boston City Hospital it was found that 2% of the 3040 women who delivered babies there were infected with HIV, as compared to a national rate of .2%.² At Project Trust, a program for IV drug users (IVDUs) and their partners, 8% of their women clients are seropositive. Of 212 women tested in methadone treatment clinics, 32% were found infected (phone conversation with worker in the AIDS Statistics Office of the Department of Public Health, April 25). These studies only begin to give a picture of the number of women in Boston infected with HIV.

The services that have recently attempted to fill the needs of HIV+ women are taking a look at the many requirements they must fulfill to be successful. Now is a time of redesigning, researching and


expansion. In order to see what the needs are, how they are being addressed and where the difficulty in addressing the needs lies we must look at the programs that now exist.

OUTREACH

For many people who are infected HIV is an unknown threat. They often are not aware that they are at risk or else they have chosen not to find out their status. Outreach programs exist to raise the awareness of women about their own risk, in order to encourage prevention and to begin helping those who are infected.

Women AIDS Risk Network (WARN) is known for its outreach to women, especially prostitutes, the homeless and substance users. In addition to outreach, the network provides testing and counseling. They were originally funded to deal with women, but realized that to do this effectively they had to address their male partners, too. As the Program Director at Harvard AIDS Institute points out, "It's all circular because the women are having babies by these men or are getting infected to a large degree, but not totally, by men" (pg 51). In outreach it is important to take into consideration the trend that one provider noted; she is not just seeing women infected through IV drug use, but also crack addicted women who are at serious risk due to the high level of sexual activity that often accompanies crack use. The level of sexual activity is due to the trading of sex for drugs and money.

In an effort to reach homeless women, a high risk and complex population, the WARN staff has entered hotels that house the homeless, such as the Milner Hotel, a temporary home for men and women. An interviewee recounts, "I remember Kattie Portis saying that the first
time she and her staff went to the Milner, they were scared; and they are streetwise folks. It's hard to get services into these places - of any kind" (pg 52). The homeless shelters themselves, such as Rosie's Place, often have outreach workers, but their resources, according to one interviewee, are limited:

Rosie's Place is a private place and deals with individual women. They have three outreach workers that deal with people who have any kind of problem. Their dining hall holds 140 people. So you're not going to get a lot of help on AIDS specific questions.... (pg 53)

Outreach is not limited to information about AIDS and risk; it includes access to resources. Some women may know that AIDS is a risk, but may not know where to get further information and help. Likewise, while there may be providers for women with HIV concerns, these women may not know about these providers. One HIV+ woman who works at a substance abuse hospital says that there are no resource pamphlets available at her workplace. She points out that these are the types of sites at which the information must be available, due to both the high rate of AIDS and the fact that some of these hospitals have HIV testing. She emphasizes, if the resources are out there they must be made known to the community (pg 111).

Some providers are aware of the need of resource guides. The women's educator at AIDS Action Committee is thinking about a chart for health centers that would map out what resources women might need regarding HIV, with the names and numbers of the organizations listed. The idea of an easy-to-read chart is that it would not be intimidating. Women with low literacy levels would be able to
understand it. Also, when sitting in a community health center waiting room women may not want to pick up an AIDS pamphlet because of the stigma. If the information were on the wall and easily visible, women would be more likely to read it.

TESTING AND IMMEDIATE HELP

There are many places now where anonymous or confidential HIV antibody testing is available. The issue of confidentiality is very important. While it is convenient for women to find testing in their own communities, where the surroundings are familiar, it is also important that testing be available to them in other locations, where they do not have to fear being recognized.

Some programs focus on testing for particular populations, such as Project Trust. They have an outreach program in the drug using community and offer HIV antibody testing. The advantages of these programs are that they can offer counseling that is sensitive to that population's concerns. One of the concerns that is raised is that a positive test might lead to further use of drugs.

Women, Inc., a residential drug treatment center for women, has a counseling program to address that concern. It is designed for women who are thinking about being tested. The program provides support, education about testing, and drug treatment. A woman who is using drugs or has quit recently must look at her reasons for getting tested. Many providers see women who find out they are positive and continue their drug habit, perhaps because the news is too overwhelming for them or they feel that they have nothing more to live for. Women, Inc. tries to provide a program where this will not occur.
Another large issue that concerns providers involves access to further resources if one is found to be HIV+. The situations of the Latino community and women affected by the disease are similar. One provider in the Latino community feels that the recent push for testing puts the community in a crisis. She says that there are not enough HIV related services that meet the needs of people from certain communities; including a lack of support groups, counseling, and bilingual providers. This crisis has led agencies to collaborate with each other in an attempt to fill the gap, but the scarcity of services in the face of testing is still a concern, she explains (pg 129).

One program that is addressing some very important needs of newly determined HIV+ people is the Behavioral Research Project (BRP). This program was originally designed by the state. It is a three week program for newly determined HIV+ people, designed to introduce participants to information about HIV and to the health care system. Currently, it is being modified for communities of color and there are future plans to adapt it for women. The modified program is being tested at sites such as the Dimock Community Health Center and the Martha Eliot Health Center. An administrator at the Department of Health and Hospitals (DHH) explains the rationale behind the modifications:

Part of the concern is that most of the people that have used the model that is currently developed have been gay, white men. What we're hoping for, and there's been good feedback from Dimock and Martha Eliot, is that in looking at the state's effort to cultivate this program in other populations they're changing the model enough so that we're hoping that this will be something that people of color also seek out. (pg 78)
One change providers must make is to become more aggressive about recruiting participants into programs for the newly diagnosed people. One provider at Dimock says that many people of color find out about their HIV status in an inappropriate way and need to take time to deal with the information. One scenario she describes is when a woman goes to the emergency room and complications arise that lead to testing for HIV. The results can be devastating: "... Along with finding out whatever the crisis was, you are also informed at that point in time that you are HIV+." Often the testing is not accompanied by counseling or referrals to HIV services. Situations like this can lead these women to not seek services immediately, and instead look for support two or three months later. The BRP should seek out the participants by going to ATS sites and hospitals where testing is being done. This would catch the women before they fall through the cracks for a few months (pg 98).

Another change that seems necessary for the BRP is lengthening the duration of the program. One DHH employee points out why a longer time is needed:

Three weeks will probably just not work. That's something that very compliant patients have used and patients who have been educated to ask a lot of questions and have a high sense of self-importance. They also tend to be patients who, if you give them information they tend to take the information and use it.... What we are talking about with some other parts of the population are people who don't know how to use a resource guide, don't feel comfortable necessarily finding a number and a name and calling that number. That will require a little bit more time and sort of a sense of trust to develop there before that will be a useful process from one step to the next. (pg 79)
MENTAL HEALTH

Could you imagine if you got this news, are you going to get on the phone and call all sorts of people. Of course not, you are devastated. Why somebody hasn't figured that out is beyond me. If you are going to have testing, you need to have support groups right there immediately available.... (Interview with HIV+ woman, pg 118)

While the BRP is beginning to address this problem, there is also a need for immediately accessible and ongoing emotional support and counseling. As we know from experience, HIV brings on issues of guilt, fear and discrimination particular to the nature and history of the disease. One service that addresses this is the Andrews Unit at Massachusetts General Hospital. It is a clinic providing comprehensive services for people with HIV concerns including competent counseling in regards to HIV concerns, psychotherapy and neuro-psychiatric evaluations for people affected by the virus. It also has support groups for women with AIDS. According to the administrative assistant at the Andrews Unit, the program does not have a support group for HIV+, asymptomatic women because it has not encountered any.

The AIDS coordinator at Dimock explained the important role support groups can play for women:

They are women really struggling to survive. They are women that have been battered around not only by people that are close to them in relationships, they have been battered around by institutions. They are people that are scared, that want to do the best thing, but may not know how or know the mechanisms to do that. They're women with lots of issues, HIV just being one; “Where do I get work, how do I take care of myself, who's going to take care of my children, do I live or do I die, do I want to?” That's really where they come from. They are people full of hope.
People that believe the best will come. They are strong people that sometimes aren't really in touch with how strong they really are. And they need a safe, understanding place to be able to work out those issues. A lot of times all you have to do is provide that place and provide it on a consistent basis, and let them do the work, most of the time that's the way it is. (pg 100)

Entre Amigas is a model support group program designed for Latina women and their children who are affected by AIDS, not just infected. There are separate support groups for women and for children. They are held in a neutral site in the community, so there is no stigma, as there might be in an AIDS-related building. Also, they provide services such as meals and transportation which improves their success. A provider in the Latino community pointed out that when offering services such as support groups, it must be kept in mind that each woman has different needs, including child care and transportation, that must be addressed before the women will be able to attend the groups. She concludes, "(T)here are a host of things you have to take into consideration in order to make the support group a viable one" (pg 132).

Both AIDS Action Committee (AAC) and Multi-cultural AIDS Coalition (MAC) have pastoral concerns units. For women who wish to have counseling that is religiously sensitive they can contact these groups for referrals. Groups like Interfaith AIDS Ministry are trying to make it easier for women who wish to seek this help within their own communities, including their own religious communities. Interfaith encourages congregations to volunteer to address the needs of HIV+ people. But they also try to educate the religious communities about AIDS and how to be more supportive for members that might be
affected by HIV. It is the responsibility of the churches, an Interfaith worker feels, to show their compassion for HIV-related issues so that their congregation members can feel comfortable going to the church for support. She thinks that so far many churches have not come out and told their members that it is safe to disclose their connections to AIDS.

In the past Interfaith has tried to enter churches in the Black community. She says that these churches are very important because they are the foundation of parts of the Black community. “They provide a lot of support and empowerment in the community,” she continues: “They cannot be discounted. The problem is getting them to talk about AIDS. It’s been a real battle. We’ve had minimal success” (pg 76). She says that some of the churches may be organizing themselves, but she is not sure what effect their efforts have had.

MEDICAL SERVICES

Q: What do you see as the main barriers to getting the resources or what resources don’t you think there are?
A: Well the underlying barrier has to do with where people get health care or if they get health care. Women and children tend to be poor and tend to get their health care in community health centers or not get it at all, or get it in emergency rooms in hospitals. (pg 49)

Although AIDS is a relatively new disease and is often treated as a unique phenomenon, it is a disease we are going to have to incorporate into our everyday health care, as we have colds and cancer. Some health providers have done this more effectively than others. Boston City Hospital (BCH) and the Dimock Community Health Center have been
among the first to incorporate comprehensive care for AIDS into their already existing programs.

Along with the inpatient care provided at BCH there is the Immuno-deficiency Clinic. It's an outpatient clinic with a range of providers including primary care physicians, infectious disease consultants, nutritionists, psychiatrists, and sub-specialists. This means that clients can get all of their needs taken care of at the clinic instead of being referred to another service. This is important, as an administrator in DHH explains: "We find that many of the patients at BCH get lost if referred to other clinics, so we have tried to pull together as comprehensive of a clinic as we can, recognizing that patients are also very sick" (pg 81).

As of about a year ago the clinic's patients were 27% female, a number which appears superficially high since less than 10% of AIDS cases in Boston are women. This is probably due to the fact that a much higher percentage of HIV+ women than men are poor and/or of color, and that they only have access to care at a limited number of places since they are often uninsured or on Medicaid. According to a Dimock provider, often the reality is that people of color are sent to either BCH or Dimock, because these institutions are known for their care of uninsured or Medicaid covered patients (pg 102).

The administrator at DHH states that there has never been a good way to integrate asymptomatic, HIV infected people into the health care system at BCH; the large number of symptomatic patients they see keeps them from opening the clinic to asymptomatic clients (pg 79). Also, because of the large numbers of HIV+ people going to BCII, they
make an effort to refer them to community health centers if they are at a less critical stage of illness. The administrator continues:

We would like to educate patients to want to be seen at neighborhood health centers, and educate them to believe that there are good providers at the neighborhood health centers and that confidentiality won't be a problem. (pg 81)

It is necessary that HIV+ patients be seen at health centers due to the large numbers of patients. But women's fear of certain providers is also real and has a basis in experience. Many places are not ready to respond to AIDS compassionately or effectively. One HIV+ woman who works in the health profession tells of her experiences:

I work in a private hospital, I know how doctors and nurses feel about this disease. And 70% of them don't want to come close to people like me. I've heard what they say, because they don't know that I'm HIV+. They don't want to have anything to do with it, so it would be a big injustice to send a woman out to a clinic when they don't have anyone there that knows what they are doing. (pg 107)

Sending women to such places would endanger their health. There needs to be a way to identify resources that can respond to AIDS now and to educate others to respond in the near future.

Dimock is one community health center that is well prepared to address the needs of HIV+ women. They provide a wide range of medical services, support groups, HIV testing, gynecological services that are sensitive to the issues of HIV and pregnancy, and many other applicable services.

One of the reasons BCH and Dimock are so effective is that they have not only comprehensive HIV-related services, but also resources
for all of the other issues an HIV+ woman might be concerned with. They both have drug treatment available; they have child services and methods to secure payment for the services; they are located in areas accessible to the women; and they are generally sensitive to the situations the women are in. One provider at Dimock explains what it means to be comprehensive:

When I say comprehensive, coming from a community where we have always had to go from the grassroots approach, what I mean is you begin to truly truly network and you look at the kinds of services in the community already being provided and you incorporate what else you need in order to address this virus, so it's not always a separate entity. (pg 101)

Women present some different medical issues than men. Some of their symptoms differ from men's symptoms. This can lead to misdiagnosis of women who have HIV-related illnesses. This also brings up problems in caring for the women medically. One HIV+ woman relates her thoughts on the virus and women's symptoms:

See, gyn is one of the areas where some of our serious problems come up. I'd suggest talking to some gynecologists who work with this, I don't know where you'd find one, and see what they recommend. My recommendation is to get a pap smear every 6 months. If you have the papaloma virus you are at much higher risk for cancer if you are HIV. So I get tested every six months. Since lymphoma is a big issue for HIV people, how does it effect you gynecologically? Does it put you at high risk for other kinds of cancer? Nobody seems to be able to tell me. They don't know. They don't have a database large enough to draw any assumptions. Doctors are taking care of women who are HIV+ and don't know anything about the disease. (pg 116)
Right now there is an NIH study looking at HIV+ women and HIV- women at high risk for infection. It is designed to look at the natural course of the infection in women. This includes answering questions such as: how quickly do women develop symptoms, how does drug use affect this, and how do drug treatments affect women. Besides answering some important questions, this study is a way for women to get medical care that they might not otherwise receive for themselves and their infants.

Women also need special services in regard to pregnancy. Some of their needs are not different from HIV- women. For example, Planned Parenthood provides contraceptive and abortion services to them just as to other women. But there is also special counseling available at places like Dimock. One prenatal care provider says that now that HIV+ women are entering the prenatal population their special needs are being recognized. This includes, she continues, a woman’s fertility decision, pediatric care, and appropriate counseling (pg 120).

The issue of appropriate counseling involves sensitivity and knowledge both about HIV and the communities from which women come. The prenatal caregiver from Dimock says that prenatal counseling includes information about the chances of having an HIV+ child. She believes that people are recommending that HIV+ women delay pregnancy until more is known about treatment, but that Dimock does not advise the woman either to continue the pregnancy or to terminate it (pg 124). As both of the HIV+ women interviewed pointed out, it is a personal decision that only the woman can make.
HOME HEALTH CARE

Since AIDS is now seen as a chronic disease there is a growing need for care in the home. There is a need for both medical care and assistance with daily living. An Interfaith worker tells of organizations such as the Visiting Nurse Association (VNA) that provide medical care at home:

They go in and do whatever needs to be done. They may go in and change dressings, or check on an IV drip, or give medication, administer shots, change linens in some cases - whatever the recommended procedures, or whatever they are told to do by whatever the doctor assigns. (pg 69)

With more people with AIDS (PWAs) staying at home for chronic care there is a need for a rest for the caregivers in the family. The Children's AIDS Program (CAP) at BCH provides respite care for children from 0-5 years. This serves parents and foster parents of HIV+ children in times when they need a break, are too sick to care for the child, or are unable to attend to a sick child on a daily basis.

There is very limited availability of respite care for adults. At Lemuel Shattuck Hospital there is a medical respite shelter where people can stay for two to three weeks. It is for anybody who is too sick to enter the shelter system, but not sick enough to need hospitalization. They generally have some people with AIDS at any given time.

An Interfaith worker feels that respite care is not being adequately addressed. She explains that while the Buddy system works for some, it does not address the client when that client is a whole
family. She concludes that there needs "to be another model in place for respite care" (pg 68).

Interfaith is a program that is filling in some of the gaps for women who need care at home. One worker there says, "(W)hen they are at home without salaries and all of those other things, a lot of basics slip through the cracks. People who are isolated from their families and friends and are cut off from everything that would normally give them support – this is where we fill in" (pg 65). Over the last year and a half the program has been seeing a lot more women and single mothers. The requests have also shifted towards basic food supplies. Caregivers working inside of the home make requests for supplies including food, linens, cleaning supplies, toiletry articles, funeral expense coverage, and transportation to medical appointments.

**DRUG TREATMENT**

Women, Inc. is one of the programs well known for its care of HIV+ substance users. A director at the Harvard AIDS Institute describes the program:

It's a multidimensional program where they have drug treatment for women coming out of prison. They have a program to unite them with their children where they have their first visitation. Also, a drug treatment program, a daycare center and sometimes the children actually live there as they are united to help the women stabilize their lives in order to move back into the community. (pg 48)

The program itself is comprehensive for women coming out of prison. They have built upon an effective program and made it receptive to HIV+ women. An Aid to Incarcerated Mothers (AIM)
worker emphasizes the importance of accommodating the special needs of HIV+ women in the following terms:

At Women, Inc. we are very supportive to women that are positive. We support them with not keeping their status a secret, but sharing that information with their peers so that they can be supported with the HIV, what it means to them, how they feel as a woman with it, and we just give a lot of support. In treatment a lot of times rules are just that - rules, and they are not bent and there have been changes made around policy and treatment issues and how women are dealt with in treatment with this virus simply because of different needs that they have.... Just general allowances around a woman being able to lay down during the day or sit or keep appointments.... (pg 57)

There are various drug treatment programs – self-help, detoxification centers, halfway houses, and outpatient clinics – that have integrated HIV issues into their services. Since AIDS is increasing in the drug using community and among the partners of drug users it is necessary that all treatment programs be sensitive to HIV issues. One HIV+ woman said that she would advise women to not disclose their status in some treatment programs due to insensitivity in the environment. Hopefully, as services increasingly address HIV, women will be able to disclose their status and get support.

One provider feels that the need for drug treatment cannot be stressed enough, especially since there is evidence that continued use of drugs can quicken the rate at which one becomes sick. She continues:

When you are looking at HIV positivity you cannot separate it from drug addiction, which is extremely difficult to treat.... It is the drug addiction that leads to HIV positivity. So, it is the resources that are available in helping women deal with their addiction that we need to be pushing for, we need to be talking about. (pg 123)
SHELTER

As was mentioned earlier, homeless women are a complex and high risk population. Rosie's Place is a temporary shelter for women that is addressing the unique needs of the women. Rosie's houses them and offers support in the form of referrals and aid in taking advantage of existing resources. One employee at Rosie's says that many of the HIV+ women there are actively using drugs and lack health care and insurance. As we have seen, these circumstances just add to the difficulties posed by being homeless. Rosie's collaborates with AIDS service agencies in order to effectively fill their clients' needs.

While Rosie's is reacting constructively, many shelters are not addressing HIV at all and many homeless women are not even in shelters. The circumstances of life without a home often lead women to drug use and alienation from the resources that could help them. Often the physical conditions, such as poor diet and inadequate clothing and shelter, lead to poor health. This is particularly threatening for women who are HIV+ and very susceptible to sickness.

HOUSING

Advocates for women who find themselves homeless will often search for subsidized and affordable housing. Affordable housing in Boston is always an issue, but for HIV+ women it can become more complicated. Now, in a time of financial crisis, waiting for available housing takes even longer. According to a housing advocate at AIDS Action, one man waiting for subsidized housing was told he would have to wait 6 to 7 months. Later he got a letter saying that the wait would be 2 to 3 years. That is too long for somebody who is sick, he stressed;
by then he might be too sick or dead. There is some subsidized housing for the elderly that is underused in which PWAs can be placed in emergencies. But the housing available to some PWAs is limited for women. They often have children or a partner, making them unwanted in housing for the elderly and necessitating larger apartments, which are more difficult to find.

DRUG STUDIES

There are few AIDS-related drugs that have been approved by the government. The ones that are approved are often expensive. It is common to enter drug studies in order to have access to the drugs. There are so many protocols for various AIDS-related drugs that it is hard to keep track of them all. One method to connect the volunteers with the studies is a hotline, the National Clinical Trial Hotline. A woman can just call and tell where she lives and what her disease status is and they will provide her with information about her options. They can give her a contact in the Boston area, tell her about the criteria for the studies, what drugs they are testing, the side effects of the drugs, and other practical information.

Another method is through referral. For example, one's doctor might recommend studies to enter. According to an HIV+ woman: "These guys all know each other and they are connected. They talk to each other a lot" (pg 143). Nevertheless, this method is only effective if one has a doctor and the doctor is "connected."

There are also requirements to enter a study. Many women are unable to meet the criteria. One provider has noticed this:
I don't see that the protocols being done in the teaching hospitals are addressing the issues of women and children necessarily. I know lots of people who are on protocols, various drug protocols, but as far as I know, the majority have been set up for gay men with the disease or maybe middle class people. I don't know what drug protocols do to the female physiological make-up, what do they do to a body that's been abused by drugs, what do they do to prenatal care, what do they do to lactating women, those kinds of issues. (pg 170)

Officially, studies have never been closed to women or people of color. They have been restrictive structurally due to the sites chosen for testing. In the past year tests have become more accessible; for example, testing protocols now exist at Boston City Hospital and child care is being provided at some sites in order to encourage women and people of color to participate (phone conversation with a participating physician investigator in Beth Israel AIDS Clinical Trial Unit).

The Community Research Initiative (CRI) was started to address the barriers that women and people of color experience in accessing drug trials. The clinical trials that the CRI sponsors are designed to be community based, drawing people in through neighborhood health centers and individual doctors' offices. In trying to increase access to studies, it became clear that the participants needed education about the studies and their options in order to become volunteers in good faith. To address education CRI has begun support groups at health centers that deal with all HIV-related issues, with the goal of educating the participants to the point of being able to make an informed decision about the option of drug trials (phone conversation on 4-5-90 with the administrator at CRI).
MONEY

The expense of being chronically ill can be overwhelming. Most women who are HIV+ do not have private insurance; many rely on Medicaid. Others have no insurance at all. On top of the medical costs there is loss of income due to the illness, and added costs, such as increased need for child care.

Medicaid is welfare medical insurance that covers people with very low income and few assets. Massachusetts has a good Medicaid program, with no deductible and no copayments. It also fully covers AZT for people with a low T-cell count (under 500). This means that people with AIDS and many asymptomatic HIV+ people are eligible. It also covers aerosolized pentamidine treatment for people with a T-cell count of under 200.

There is also the Social Security system for those who are unable to work due to disability. One program's payments depend on how much the recipient has paid through payroll deductions. Many women are not eligible for this because they have not worked at all or have worked very little. The other program is based on assets – one must have less than $2000 in assets to be eligible. If eligible for this, one automatically receives Medicaid and is eligible for Food Stamps.

Welfare, including Food Stamps, Aid to Families with Dependent Children (AFDC), and General Relief, is another source of income. General Relief is often relied upon during the 5-month waiting period to be eligible for Social Security disability benefits. Also, disabled people with no other benefits and undocumented aliens are eligible for this program. It supplies less than $200 for two weeks for an individual to live on, however.
As in most systems, there are cracks for women to fall through. One provider explains:

...a woman, once diagnosed, is eligible to get SSI (Social Security Income) if she is sick and can't work. However, a woman who is pregnant is not eligible for AFDC because she doesn't have a child. She may not be capable of working, she may only be positive and not diagnosed with AIDS; you have to be symptomatic to have AIDS. Where is that going to place that woman? (pg 54)

For those who have no insurance, some care centers will provide services anyway; one provider describes the process as follows: "You get plugged into a program that will then cover your expenses until you are able to get disability or Medicaid, or whatever one might need in order to do long term medical services" (pg 103). These programs will often help the client sign up for the financial aid, which is very important, since many do not know their way around the bureaucracy. Nevertheless, this route can only be useful if the woman is able to find a program to "get plugged into."

CHILDREN

The Boston Pediatric AIDS Project (BPAP) is a comprehensive program based at Dimock Health Center made up of multiple community service organizations, AIDS service organizations, and governmental agencies. The project is designed to identify HIV+ women and their children, and to provide services to them. Each of the groups involved provides a service to the women and children.

There are three programs in the Boston area designed to offer child care for HIV+ children. Care for the children of an HIV+ woman is
very important, since she is likely to be sick or at least fatigued. There is also an issue of providing for the care of the children after the death of the mother. If these needs cannot be met within the family, often the Department of Social Services (DSS) will get involved. This creates a conflict, as one provider points out:

There are tremendous problems for women who do have children and need care for their children. There are a lot of feelings - ranging from fear to hostility - particularly in the poor and minority communities towards public agencies like DSS who are charged with making sure that the children are taken care of. They have responsibilities to be sure the children are adequately cared for. On the other hand, sometimes the agencies aren't run as well as they could be, or individual workers have whatever opinions they have so they may jump in and remove the children from the home too soon. So there are a lot of serious issues about how you know when children in those situations are at risk. (pg 47)

Women not only fear seeking help for their children, but also for themselves. An Interfaith worker says, "One has to deal with a fear and reluctance on the part of certain women to seek care. They don't want to know, or they suspect they know they're HIV+, and will not seek support because they are afraid that their children will get taken away from them maybe" (pg 70).

AIDS SERVICES

There are organizations that have begun specifically to respond to AIDS. The AIDS Action Committee (AAC) was begun by gay men when AIDS was primarily associated with the gay community. Since then the Latino Health Network was started to address AIDS in the Latino community. Recently the Multi-cultural AIDS Coalition was formed to
provide for people of color in a racially, culturally, and linguistically sensitive way.

AAC provides a wide range of services for its clients. They coordinate many education, policy, legal and lobbying efforts. In terms of direct services, they provide a range of support groups, including ones specifically for women. They also offer Buddy services – individuals who basically play the role of a friend, providing informal support. A large service they offer is advocacy. Advocates link the client with the various resources they need: housing, medical services, legal aid, money, etc. Some of the interviewees had the perception that there were relatively few women clients at AIDS Action. One employee at AAC recognizes a few factors that could contribute to this: it was begun by gay men and has been largely perceived as a gay male organization, the organization has not made a full commitment to serving women which would require implementing services such as child care, and they generally serve people with AIDS or ARC while many women never get diagnosed as such (pg 90).

One HIV+ woman found that when she became eligible for AAC services it opened many doors for her. She suddenly had links to many resources that she could not reach before. This included services such as acupuncture treatment and drug treatments. Since AAC is so large and has so many networks it is able to track down a service to fulfill almost any need. This has been helpful for those who have access to their services.

One provider at Dimock hopes that the Multi-cultural AIDS Coalition (MAC) will be able to provide the networking services for communities of color. While they may be limited in their ability to
provide direct services, they can make it easier for people to reach the resources they need. MAC sees its role as one to encourage networking, collaboration, and advocacy on issues of HIV for people of color. They provide services that are racially and culturally sensitive, and linguistically appropriate. Since they are relatively new they are still in the process of assessing exactly what resources they will provide.

The Latino Health Network was also founded recently, in 1987, by Latino professionals in order to address AIDS in the community. The network works in collaboration with other agencies in order to act as a clearinghouse for Latino specific resources. A coordinator of AIDS services in the Latino community feels that there are not enough services that are culturally sensitive and linguistically appropriate, so it is necessary for the community to take advantage of all of their resources by working together.

ADVOCACY

One key to creating access to resources for women is providing them with advocacy and case management. While many services are theoretically available, in practice they can be very hard to locate. Women are often in a position where they do not know of the resources or are intimidated from getting them. One provider states, "They need to have a voice to demand the services they need. That may be the hardest thing to do" (pg 76).

One provider at Dimock sees women who need one person that they can trust and get help from. They have many needs, and many barriers to fulfilling them. One advocate can link them to all of the services they need, because they know better the way around the
myriad of services and agencies that one must contact. In compiling the information for this thesis I can see how hard it would be for an individual in difficult circumstances to track down all of the services she might need. Another role the advocate can play is to empower the woman so that in the future she can act as her own advocate. As a woman gains familiarity with and confidence in the service system, she will be more likely to reach out for herself. One advocate from Aid to Incarcerated Mothers tells of her role as an advocate:

Advocacy is, for me, helping to empower the woman to learn to do things for herself. I don't like to do everything for a client. There are times when the woman just can't do it.... We help the woman to look at the reality of the situations and we help them to determine what is best for them and then we help them to see how that is going to be set up and what you need to do to obtain those things. We will make calls to the different agencies, we will help to locate the resources and we offer referrals. We will also walk a woman through that if she is incapable of doing it, which is the case sometimes. (pg 59)

CONCLUSION

By looking at some of the resources available for HIV+ women it becomes evident what their needs are and how they are or are not getting met. While agencies are trying to approach this population from different aspects, few have fully encompassed the range of issues at hand. The programs that have been effective in addressing this population are not capable of accommodating all of the clients who need their services. There are four themes that became clear in the interviews that specifically affect HIV+ women and their access to resources.
First, there is no way to address HIV in a vacuum. The women needing HIV services usually have many other needs that must be met in order for the HIV resources to be effective. For prevention methods to be effective, women's partners must be addressed. For health care agencies or support groups to be accessible, they need to provide child care and transportation. For some women to deal with their status their drug addiction must be treated.

Second, before women will willingly enter into services they must feel that they are being treated sensitively. This may mean cultural and linguistic understanding. Workers in agencies such as DSS must be able to distinguish a situation that is different from their own from a situation that is actually dangerous. Services must hire full staffs to address the needs of each community, not just a token member of that community.

Third, there is a scarcity of information about how HIV affects women physically. Since drug studies have focused on homogeneous populations, little has been discovered about the course of the disease in women and the effect of treatments on them. This has left women with inadequate medical care and a lot of unanswered questions. It has led to misdiagnoses, resulting in a lack of treatment and unnecessarily early deaths.

Fourth, above all, it is important to strengthen women's ability to obtain care. This includes their ability to insist on prevention, like the use of condoms. Women's health should be recognized as a priority by caregivers and by women. There is a need for economic and emotional support and alternatives that will allow women to insist on proper treatment. The health profession needs to be more aware of women's
concerns and the means for addressing them. Women must be in a position in society from which they can advocate for themselves. They should not continue to be a secondary population for which services must be adjusted, but a population for which services are designed.
Appendix A: Resource Guide

INTRODUCTION

As an appendix to my thesis this resource guide is oriented towards providers for HIV+ women. It is the basis of a resource guide that is now being designed for HIV+ women in Boston with publication by the Boston AIDS Consortium this summer. It is important to compile the resources available so that women can take advantage of the few that exist.

I have given a brief description of agencies when necessary. I have noted the services that are either HIV- or woman-specific. Also, most agencies have a sliding scale, free services or accept Medicaid and other insurances.

This guide is not complete. No doubt, there are agencies that should be listed here, but are not. No doubt, there are specific services that should be noted, but are not. However, I have followed up on every lead given to me, and I hope that what I have found is useful.

AIDS Action Line 536-7733
toll free in Massachusetts: 1-800-235-2331
Mon-Fri 9am-9pm; Sat 10am-4pm; Sun 10am-4pm

Latino AIDS Hotline 262-7248
Inquilinos Boricuas en Accion/Latino Health Network
Mon-Fri 12am-10pm

Public Health Service AIDS Hotline 1-800-342-AIDS
24 hours, seven days a week

TESTING

Massachusetts Alternative Testing Sites (ATS) 522-4090
Mon-Fri 8am-6pm. Collect calls accepted. Anonymous.
MENTAL HEALTH

COUNSELING

Brighton-Allston Mental Health Clinic
77B Warren Street Brighton MA 02135
787-1901

Cambridge Guidance Center
5 Sacramento Street Cambridge MA 02138
354-2275

Cambridgeport Problem Center
One West Street Cambridge MA 02139
661-1010

Chelsea Community Counseling Center
301 Broadway Street Chelsea MA 02150
889-3300
HIV antibody test counseling
Counseling for families of PWAs

MGH Andrews Unit
Wang Ambulatory Care MGH Fruit Street Boston MA 02114
726-6772
Specifically for HIV related concerns: comprehensive mental health care and support groups

Solomon Carter Fuller Mental Health Hospital
85 East Newton Street Boston MA 02118
266-8800
A public mental health hospital with both inpatient and outpatient treatment: provides AIDS education to clients

SUPPORT GROUPS

Project Trust, Boston City Hospital
818 Harrison Avenue Boston MA 02118
354-4495
HIV+/PWA support groups
Anonymous HIV antibody testing and counseling
Outreach for drug users and their partners

Women AIDS Risk Network (WARN)
244 Townsend Street Dorchester MA 02121
424-9276
HIV+/PWA support groups
Counseling for families of PWAs
Confidential HIV antibody testing and counseling
Entre Amigas at Martha Eliot Health Center 522-5302
33 Bickford Street Jamaica Plain MA 02130
Support group for HIV+ Latino women over 18 years that lasts
8 weeks and includes education and case management
Corresponding support group for their children 6-13 years
Provides transportation and dinner
Individual counseling available
(May not be funded past June, 1990)

PASTORAL COUNSELING

AIDS Action Committee Pastoral Concerns Unit 437-6200
Multi-cultural AIDS Pastoral Concerns Unit 536-0390

MEDICAL SERVICES

PRIMARY CARE

ABCD, Inc. 357-6000
178 Tremont Street Boston MA 02111
Designated anti-poverty agency in Boston
Family planning counseling
Some sites have ATS

Boston City Hospital Immuno-deficiency Clinic 534-4290
AAC 5 at 818 Harrison Ave Boston MA 02118
Comprehensive care for symptomatic HIV+ people
Support group for women clients

Bowdoin Street Health Center 825-9800
200 Bowdoin Street Dorchester MA 02122
Confidential HIV antibody testing and counseling

Brookside Community Health Center 522-4700
3297 Washington Street Jamaica Plain MA 02130
Counseling for families of PWAs
Confidential HIV antibody testing and counseling
MGH Chelsea Health Center
100 Bellingham Street Chelsea MA 02150
Counseling for family of PWAs
Confidential HIV antibody testing and counseling
WIC (Women, Infant, Children nutrition program)

Codman Square Health Center
6 Norfolk Street Dorchester MA 02124
Confidential HIV antibody testing and counseling
WIC
Family planning

Columbia Point Health Center
350 Mount Vernon Road Dorchester MA 02125
Counseling for families of PWAs
Counseling for HIV antibody testing
Day care

Dimock Community Health Center
55 Dimock Street Roxbury MA 02119
PWA/HIV+ support groups
HIV antibody testing and counseling
Women’s health

Fenway Community Health Center
93 Massachusetts Ave Boston MA 02115
Anonymous HIV antibody testing and counseling
Specialists in HIV care
Living Well series (workshops for HIV concerns)
Boston Women AIDS Information Project

Joseph Smith Community Health Center
51 Stadium Way Allston MA 02134
Confidential HIV antibody testing and counseling

Martha Eliot Health Center at Children's Hospital
33 Bickford Street Jamaica Plain MA 02130
WIC
Counseling for families of PWAs
Confidential HIV antibody testing and counseling
Roxbury Comprehensive Community Health Center 442-7400
435 Warren Street Roxbury MA 02119
Counseling for HIV antibody testing

South End Community Health Center 266-6336
400 Shawmut Avenue Boston MA 02118
WIC
Counseling for families of PWAs
Confidential HIV antibody testing and counseling

Southern Jamaica Plain Health Center 522-5900
687 Centre Street Jamaica Plain MA 02130
WIC
HIV support groups
Counseling for families of PWAs
Confidential HIV antibody testing and counseling

Whittier Street Health Center 427-1000
20 Whittier Street Roxbury MA 02120
WIC
Counseling for families of PWAs

WOMEN’S HEALTH

Mom’s Project at Boston City Hospital 534-4558
818 Harrison Ave Boston MA 02118
Outreach and services for pregnant women at high risk
Drop-in site at corner of Columbus and Mass Ave

Planned Parenthood 738-1370
Counseling hotline: (617)731-2521
1031 Beacon Street Brookline MA 02146
Abortion, counseling, contraceptives, family planning
TEMPORARY SHELTERS

Lemuel Shattuck Shelter
170 Morton Street Jamaica Plain MA
Medical care respite associated with the shelter

Rosie's Place
889 Harrison Ave Boston MA 02118
Shelter, support, referrals

My Sister's Place
62 Berkeley Street Boston MA 02116
Daytime advocacy for homeless women and their children
Training for women getting off welfare

ALCOHOL AND DRUG TREATMENT SERVICES

SELF-HELP

Alcoholics Anonymous
286 Summer Street Boston MA 02210

Narcotics Anonymous
639 Granite Street Braintree MA 02184

Al-Anon
375 Broadway Rm 310 Chelsea MA 02150

Cocaine Hotline
1-800-COCaine

DETOXIFICATION CENTERS

CASPAR Detoxification Center
245 Beacon Street Somerville MA 02143

Dimock C.H.C. Substance Abuse Treatment Center
55 Dimock Street Roxbury MA 02119
Anonymous HIV antibody testing and counseling
Ranges from inpatient to outpatient treatment
FIRST, Inc. 445-6009
34 Intervale Street Dorchester MA 02121
All-women and coed residential treatment programs
AIDS education center

Women's Alcoholism Program of CASPAR 661-1316
6 Camelia Ave Cambridge MA 02139
Ranges from emergency care and inpatient to outpatient
Child care
Services for friends and family

RESIDENTIAL/HALFWAY HOUSES

New Day 628-8188
242 Highland Ave Somerville MA 02143
Residential treatment for pregnant, drug free women and their
newborns

Womanplace 661-6020
11 Russell Street Cambridge MA 02140 TDD: 661-5855
Residential drug-free treatment for women
Services for families
Services for deaf women

Women, Inc. 442-6166
244 Townsend Street Dorchester MA 02121
HIV+/PWA support groups
Day care
Services for pregnant substance users
Ranges from inpatient to outpatient treatment

OUTPATIENT

Alianza Hispana, Inc 427-7175
409 Dudley Street Roxbury MA 02119
Outpatient alcoholism treatment
Day care
HIV+ support groups
Services for families of clients

Somerville Portuguese-American League (SPAL) 628-6065
92 Union Square Somerville MA 02143 1-800-232-7725
Opening an ATS in June/July, 1990
AIDS DRUGS STUDIES

AIDS Clinical Trials 1-800-TRIALSA
Information about local clinical trials

Community Research Initiative (CRI) 424-1524
Sponsors clinical trials
Support groups at some health centers including education
about clinical trial system

LEGAL SERVICES

GENERAL LEGAL SERVICES

Legal Services Center 522-3003
3529 Washington Street Jamaica Plain MA 02130

SERVICES FOR INCARCERATED WOMEN

Social Justice for Women 482-0747
108 Lincoln Street Boston MA 02111
Administers the Women and AIDS Project that brings AIDS
education and counseling inside prisons
Administers the Neil J Houston House, a residential program
for pregnant women in the criminal justice system

DISCRIMINATION

AIDS Law Project 426-1350
P.O. Box 218 Boston MA 02112

Massachusetts Office of Handicapped Affairs 727-7440
TDD:1-800-322-2020
One Ashburton Place Rm 1305 Boston MA 02108
FINANCIAL AID

Department of Public Welfare
General Client Services 1-800-841-2900
General Relief and Medicaid 1-800-322-1443
WIC (Women, Infant, Children) 1-800-WIC-1007
Fuel Assistance 357-6012

AIDS SERVICE ORGANIZATIONS

AIDS Action Committee 437-6200
131 Clarendon Street Boston MA 02116
Wide range of services and referrals
Serves symptomatic HIV+ people
No charge for services

The Boston Living Center 236-1012
140 Clarendon 7th Flr Boston MA 02116
Drop-in/Self help center for HIV+ people
Various workshops and recreational activities

Interfaith AIDS Ministry 969-8511
Mobilizes congregations to volunteer to fill needs of HIV+
people

Haitian AIDS Project (HAP) 436-2848
12 Bicknell Street Dorchester MA 02124
Provides case management and education

Multi-cultural AIDS Coalition 536-0390
566 Columbus Ave Boston MA 02118
The MAC mandate is to encourage statewide networking,
collaboration and advocacy on issues of HIV infection and
AIDS on behalf of all people of color. The MAC provides
education and prevention assistance that is racially and
culturally sensitive, and linguistically appropriate.
Latino Health Network 262-9362
32 Rutland Street Boston MA 02118
Support groups for PWAs
Information line (262-7248) – provides referrals

EMERGENCY PHONE NUMBERS

Mass. Alcoholism and Drug Rehab. Info. and Referral Service 445-1500
toll free in Massachusetts: 1-800-327-5050

Hunger Hotline 523-7010

Boston Area Rape Crisis Center 492-RAPE

Battered Women's Hotline 661-7203

General emergency services 911

CHILDREN

Boston Pediatric AIDS Project (BPAP) 442-6758
55 Dimock Street Roxbury MA 02115
Comprehensive care for HIV+ children and their parents

Children's AIDS Program, Boston City Hospital 534-5903
818 Harrison Avenue Boston MA 02118
Daycare and residential child care for HIV+ children 0-5 yrs

Judge Baker Children's Center 232-8390
295 Longwood Avenue Boston MA 02115
Child guidance center: counseling for children and families

Project Star 783-7300
77B Warren Street Brighton MA 02135
Outreach for women and children at risk for or infected with HIV
Provides education, counseling, advocacy, and daycare
Project WIN
77B Warren Street Brighton MA 02135
Comprehensive care program for children 0-6 years with IV drug using parents in recovery
Identifying children at risk for HIV infection

MISCELLANEOUS

Casa Myrna Vasquez, Inc
P.O. Box 18019 Boston MA 02118
Battered women's shelter

Aid to Incarcerated Mothers (AIM)
95 Berkeley Street Suite 410 Boston MA 02116
Services to women incarcerated at Framingham MCI
aimed at keeping the family together

Waterman's JS and Sons Funeral Service
495 Commonwealth Ave Boston MA

783-7300
262-9581
695-1588
536-4110
Appendix B

February 20, 1990

Interview with a program director at Harvard AIDS Institute and a former manager at the Department of Public Welfare and Department of Social Services.

[begin interview]

(looking at DPH service guide) The places I see listed that I know personally, that I've talked with people at are Brookside Community Health Center – there are several community health centers who are very interested in the whole AIDS area. Brookside is one of them, Dimock is another. The Martha Eliot Health Center which is over next to the Bromley Heath housing project. Those are community health centers. The Martha Eliot is affiliated with Children's Hospital so their focus is more on women and children – families. Of those, the people from Dimock are very involved. So those are three places that are a must if you want to try to get information or try to visit. As well as the community organizations – Women, Inc. and Project WARN are both run out of the same place and they do a lot of street outreach. Project WARN is one of the three projects throughout the country that is funded by the federal government to do education and prevention particularly with women who are substance abusers or who are at high risk for one reason or another. That's a really excellent program. So that's another one you should contact. And if you can make contact with them I think you would be able to make contact with people who have already tested positive. To get the perspective of somebody with the disease, I think you might be able to reach them through one of those organizations. First, Inc. was, I thought, more focused around men, but they do outreach on the street and go into the shooting galleries and stuff. I don't know about the women in terms of it. Now Casa Myrna Vasquez I know from previous work in social services. I think that is a battered women's shelter – a group that deals with Hispanic women and so that might be another one. So, those are ones looking through here that I know of. It doesn't seem that these are all, though.

k- This is not a very complete guide. I've been getting most of my information by calling programs, sending them surveys and getting references from them. Programs for women with AIDS are kind of limited.

45
Another place you might call is the Multi-cultural AIDS Coalition (MAC).

k- I've talked to Rochelle Rollins.

Have you gotten the data on proportion of women of color?

k- Not the exact figures, but it's really high.

So by the time you finish you hope to have a sense of what's available and what's needed?

k- Yes.

Needs assessment, as you may or may not know, in health services is a hard thing to do.

k- Yes.

There are a lot of issues. I don't have a particular list of resources. Those are the places I would go to. I would have confidence in what they told you in knowing what's out there. Are you focused on any area like education or treatment?

k- No, I'm trying to get a sense of medical, legal, mental health, dealing with children, pregnancy....

There is a really interesting program I heard about a couple of weeks ago at a conference. It's run out of Martha Eliot Community Health Center. It's not terribly far from here – near the Bromley Heath housing project, on the other side of Mission Hill. I forgot the name of it. It's a program which involves a consultant from the Solomon Carter Fuller Mental Health Center called Victor de la Cansela. They do groups for Latino women affected by AIDS, not necessarily infected by AIDS. The way that it is structured is that there is a group for the women and a group for their children. So it is a very interesting program. It's supposed to be an education group in that they do a lot broader issues than treatment. They try to teach them prevention as well as how to deal with issues with their children and so on. They actually hold the sessions in a Puerto Rican political action center – in a totally neutral site. There is a lot done to preserve confidentiality and all. (She was referring to Entre Amigas.)

k- I was interested in your involvement with Project WARN.
I am working with them and the Multi-cultural AIDS Coalition on planning a conference basically about caring for the caregivers. So I'm working with Kattie Portis, who is the head of Project WARN, and Nat Askia who is the head of First, Inc., and Wayne Wright and his staff at Multi-cultural AIDS Coalition. So I've gotten to know a lot of them over the course of time. That's going to focus on renewal for those working out in the trenches. The problem of AIDS is not the most important problem in those communities. There are lots of aspects to it that tie into basic problems around poverty, racism, substance abuse... all of these other problems that affect the daily lives of people in a way that makes it hard for people to focus on AIDS specifically. It's different than dealing with it in the middle class where there are other kinds of support.

k- A lot of the women who are infected are also caregivers. What do you see out there for them?

In terms of programs? That's one of the problems. Five or 6 years ago I used to work for social services - DSS. There are tremendous problems for women who do have children and need care for their children. There are a lot of feelings - ranging from fear to hostility - particularly in the poor and minority communities towards public agencies like DSS who are charged with making sure that the children are taken care of. It's a very fine line. We talked about this in one of the discussion groups at a recent conference I went to - that people who work in these programs, particularly for women, have very complex problems to deal with because as health professionals, or whatever they are, they have responsibilities to be sure the children are adequately cared for. Sometimes the agencies aren't run as well as they could be, or individual workers have whatever opinions they have, so they may jump in and remove the children from the home too soon. So there are a lot of serious issues about how you know when to involve an outside agency and how you know when children in those situations are at risk. I think people who talked from that one program, for parents and kids, basically spent a lot of time trying to figure out how to deal with those situations, and they talked about it with their clients to make sure that people were aware of and talked through what the issues were. But they tend to try to support the people as much as possible.

Another group you might talk to - they have a good handle on women's issues - is the AIM project, which is Aid to Incarcerated Mothers. That project started years ago at Framingham. Basically all women who are in jail before or after trial go out there. It's extremely
overcrowded. 85% of the women have used drugs intravenously. 85%, not the same 85%, have children. It's an extraordinarily high risk population and there's constant turnover. There are some there long term, but women tend to move in and out of prison quicker, and many are there for pretrial. So there's lots of women who are at risk and lots of women who have AIDS, not to speak of the HIV infected. There are lots of problems with having other people know, particularly in the prison - it makes you more vulnerable. Many have problems connecting with their children at all because they are in prison, and so AIM attempts to facilitate bringing children in and out and talking to them and counseling and helping the children maintain contact even though their mothers are in prison and even though they may be sick or dying. That's definitely a program that services a very high risk population and quite a number of women who have AIDS or are HIV infected. I think we tend to not think of that population, but it's a very important population in terms of AIDS.

[interview interrupted]

WARN is connected to Women, Inc., which is actually a halfway house or something - I'm not familiar with the drug treatment world that well. It's a multidimensional program where they have drug treatment for women coming out of prison. They have a program to unite them with their children where they have their first visitation. Also, a drug treatment program, a daycare center and sometimes the children actually live there as they are reunited to help the women stabilize their lives in order to move back into the community. That's the Women, Inc. side.

We are in the process of writing a case study on a program in New Jersey. It will be written in 2-3 weeks. I can send you a copy. NJ has the highest percentage of children and, I believe, women in the country in terms of AIDS prevalence. When it started out there was a children's hospital AIDS program in NJ. They started dealing with kids, but since it was a children's hospital they couldn't provide care for the mothers and often the children were getting care the mothers couldn't get because other hospitals wouldn't provide for them. The numbers were growing and the children's hospital couldn't take care of all of the kids, so the state tried to use the children's hospital model, and now they have expanded to 4 different sites in different hospitals. The program model, as it always is when you are dealing with mothers and children, has to involve not only the regular access to primary care and all of the other issues anyone with AIDS gets into, but also the child
welfare system. You are dealing with families where the mothers, the caretakers, are dying.

k- What do you see as the main barriers to getting the resources or what resources don't you think are there?

Well the underlying barrier has to do with where people get health care or if they get health care. Women and children tend to be poor and tend to get their health care in community health centers or not get it at all, or get it in emergency rooms in hospitals. So certainly the underlying question is just plain ordinary access to health care of any kind, as in who will accept your Medicaid card and which doctors will provide care, because a lot of them won't. There aren't any private doctors in Roxbury, or at least not very many.

I think getting in touch with programs where they have sensitivity around child welfare issues is a very difficult problem because many of these women are also substance abusers and difficult to handle. If people are not trained it is very easy to have communication problems with someone who is sick and using cocaine, who from a child welfare professional's perspective is not taking care of their child, but who actually really cares about their child. Aside from not having access to medical treatment, the impact of not having enough drug treatment programs is also a piece of the puzzle that's real hard to address. Those are underlying problems that AIDS tends to exacerbate. So where do people get care? There's the AIDS clinic at Boston City Hospital. It's certainly a good program and they handle a lot of substance abuse cases. The Brigham and Women's Hospital has gotten into this lately because something like 25% of the babies born there test positive for drugs.

k- I was interested in the conferences you organize.

A foundation funded the 3 doctors I work with. These are national invitational conferences, so people come from all over the country to look at strategic questions around how we're going to take care of all of the people who are infected: what kind of financial resources, what kind of program models, what kinds of staffing, how issues around health care are organized, all kinds of things. We had one conference on alternatives to hospital care, since the disease is a chronic disease. The first set of cases is all related to either home care programs or residential programs and the next will be on primary care, where we will get into the program models for women and children, but those won't be finished for another month. This other conference I'm working
on with Multi-cultural AIDS Coalition is something we started talking with Cambridge College months ago. We wanted to see what we could do that would be helpful to people working on AIDS in community of color. There are some really amazing people working in less than ideal circumstances with a huge commitment. Its very different looking at it from their perspective.

k- Do you have sessions specifically covering women?

No. Well the national conferences have those case studies, but for the one with Multi-cultural AIDS Coalition we are really trying to step back and look at it from the empowerment perspective. It's more personal empowerment: how do people take care of themselves, how do people keep going given their commitment and given how difficult things are in the community.

k- Is the conference for caregivers that are working within organizations?

Those will be target populations, but we'll also invite a much broader list – social workers, etc.

k- But institutional caregivers?

Well, it's open to anybody. We talked about this and decided that caregivers included anybody affected by AIDS. There's a lot of interest from the people we have talked to so far because so much of the other stuff that has been done hasn't been done in a very culturally sensitive way. The issues are very different. And there's not just one culture, there are lots of different cultures that have lots of different issues. That makes it even harder to think about program models that work in a variety of cultures, much less minority communities and the gay/lesbian cultures.

k- What do you think these people really need as caregivers?

Well, we had a focus group. They talked about the first part of the conference as being a process of letting go; really confronting issues like: do you overprotect your clients, do you practice safer sex yourself, raising issues that make it more emotionally draining to deal with it. Then the second part will be on the renewal parts of it, like looking at the cultural issues around death and dying and how do you get support for the grieving process that is culturally specific. Letting go of the
things that are difficult and getting the things you need so you can go on and do your job.

k- This conference addresses this now, but what about 6 months from now?

I think that the Multi-cultural AIDS Coalition sees this as a first step to bringing people together, and then obviously if you can get some mutual support networks going then perhaps the next step can be to be more organized in the sense of advocacy for programs. We will probably have one session which will look at it from the political advocacy perspective — like where do we go from here, because certainly advocating for more services is going to be key. Women and children are critical, but you can't deal with them without dealing with their man and with their family and community network. You have to get into the systems. The men are the ones least likely to get care in those communities because at least the women and children are eligible for Medicaid. Many times the men are not eligible for any kind of health care so they don't get anything. They don't go to the community health centers because they don't have money and because they don't have any access to the state or federal funded programs. It's all circular because the women are having babies by these men or are getting infected to a large degree, but not totally, by men. In fact, WARN has recognized that specifically. They were funded federally to look at women's issues, but after a time into the program they said, "We have to deal with men, too." That's basically what happens in these communities, which is different than what happens in the gay community. You have to deal with everyone, which makes it more complex.

k- Do you feel like there's anything now addressing the needs of the caregivers?

Not really. I think there has been a great need for education of health care providers. There hasn't been enough of that, but the education efforts have focused on the specifics of how do you recognize the symptoms and how do you recognize who is HIV+ and how do you recognize if somebody is high risk. And who do you recommend for counseling, testing, and which kinds of treatment and services. Mostly education has focused around those issues, and it's only now that these other issues are being addressed.

[interview interrupted]
At Rosie's Place they are working on a residential model. Julie Brandler just said what I was trying to say to you – their greatest need is for women who are using drugs and on methadone, but have no place for treatment. So that would definitely be a place, as far as shelters, to get in touch with. But, what I was saying earlier is that you can't treat this as just a women's or just a children's problem.

k- Caroline Whitbeck mentioned that you knew a lot about the issues of homeless women.

Well, I used to work at the welfare department where I worked on programs for homeless families – shelter programs, hotels and motels. Many of these programs are now being cut back due to the budget crisis. Homelessness for women and children is a major problem in this country as well as this state. Specific to AIDS – all of those populations are at high risk for AIDS. It's true that a large proportion of the families that are homeless are temporarily homeless. They are poor but they are ultimately employable. They are in a serious crisis in their life – as opposed to the other part of the population, which is composed of multiproblem families. They are the same families with substance abuse, mental illness, and other problems. Those are the families that often can't make it in a shelter and end up in a hotel. Often the hotels aren't supervised. It allows, if not promotes, high risk behavior, whether it's sexual or drugs. They are high risk in almost every aspect of their lives.

k- And once HIV+ what are the main factors keeping them from resources?

A lot of the problem now is a drain caused by the cuts due to the budget crisis. There are cuts in the social workers who could do outreach into the shelters. The shelter staff, I'm sure, do education on health and needs and stuff. But the core social work staff is being cut down so all of those linkages are weakened. The actual transience and multiproblem nature of the women and children that end up in places like the Milner Hotel. I remember Kattie Portis saying that the first time she and her staff went to the Milner, they were scared; and they are streetwise folks. It's hard to get services into these places – of any kind. The Milner is the only hotel that will take homeless in Boston, not for lack of trying to get other places to do so. There are some really excellent shelters, but the funding for them is precarious. The real answer is to provide permanent housing, but all of the certificates and
stuff to get people into housing is being cut dramatically. It's pathetic. It's not like people couldn't figure out how to run a program. Rosie's Place is a private place and deals with individual women. They have 3 outreach workers that deal with people who have any kind of problem. Their dining hall holds 140 people. So you're not going to get a lot of help on AIDS specific questions if there are 3 outreach workers to do all kinds of education and help. Also, the individual shelters have another problem which is that they can't stay there all day. All of those populations are the same vulnerable populations. That's why it's hard.

[end interview]
Appendix C

March 7, 1990

Interview with an advocate for HIV+ women.

[k- Could you please start by telling me a little about the work you do with HIV+ women?]

I am contracted from Boston Pediatric AIDS Project. What I do is identify women who are either HIV+ or at risk for infection with the virus. I am not presently in Framingham, however at Charlotte House and in Lancaster pre-release I will be working to identify women who are on their way back into society, offer them and set up services and referrals to different agencies that can provide some of the needs for them. My project works directly with housing, with respite care, with pre- and post-test counseling. We have an alternative testing site, which is completely confidential. We are also, with the name Pediatric AIDS Project, working to identify babies born to infected mothers and to provide services to these families. We believe in dealing with the whole family unit, even the members that are not infected with the virus, but living with someone who has the virus. We offer a lot of therapy and a lot of counseling. We have a full time psychologist on staff. The project is a collective interest that consists of all of these projects (BPAP pamphlet). That's basically what I do. I do a lot of case work. Right now I am in the middle of a crisis, so as soon as you leave I will be on the phone doing some case work.

The typical client that I see is poor, usually of color, HIV+ or at risk, not so much the IV drug user as most people think. I am finding more and more that the crack addicted woman is more at risk than the IV drug user because of the multiple sexual partners. Currently I am working with a few women that are pregnant and HIV+. It's really difficult, and I'm sure you have heard this a thousand times, housing is a very big issue for these women. Two of the women I am working with are living with their families, and all of these women are seeking housing. As it stands right now, I don't want to say this factually, but I have heard that on March 31 the Department of Public Welfare is going to be shutting down General Relief. No more people will be added to General Relief. This for me is very important; a woman, once diagnosed, is eligible to get SSI if she is sick and can't work. However a woman who is pregnant is not eligible for AFDC because she doesn't have a
child. She may not be capable of working, she may only be positive and not diagnosed with AIDS; you have to be symptomatic to have AIDS. Where is that going to place that woman? So that's one of the things I am looking into right now.

We do a lot of advocacy work. Here at AIM my role is an advocate. That is basically how I get involved with these women, advocating for them if they have child custody issues, or any issues that arise during their imprisonment, whether they are in pre-release or on their way out, in halfway houses. If they need treatment I also work half time at Women, Inc. I'm on a split contract where I work half time at Women, Inc. and half time here at AIM. There the needs are a bit different. There I do more education because the women are already basically dealing with their addiction and we hope that when they leave they won't use again. They have their own treatment plans, if they are HIV+ then their status is dealt with while they are in treatment. They get different kinds of support in that. By and large I have a number of roles.

k- You were saying how women who are pregnant but not yet sick fall through the cracks. I'm interested in pulling out some of those areas where they are not getting their needs met and why.

They're not getting their needs met at the Department of Public Welfare. They are just not being met. For example there's a woman presently at Boston City Hospital. The woman is pregnant. She's not known to be positive, but she is an at risk person. In other words she had multiple sexual partners. Her intake shows she's at risk, she has not been tested. This woman tried to get housing from Boston Public Welfare. She was told that she could not get housing until she had the baby, which meant that while that woman was pregnant she was living from here to there in different shelters, sleeping in cars, that sort of thing. Now the woman during her pregnancy had stopped using drugs. She was on the methadone clinic. She used drugs again during this ordeal and then her baby was born. Now the Department of Social Services will step in with a 51a because the baby was born with a positive toxic screen. Which means this woman will still not get an apartment because now they won't give her an apartment because she won't have custody of the child. This particular issue does not only apply to women that are positive. It applies to women in general and people in general. For the HIV infected person it is more serious simply because of the nature of their disease; they can't afford being in situations that are unhealthy to them; where there are a lot of germs, where there is not controlled heat, where there's possibilities that they
will be more susceptible to opportunistic infections, because the infections are what actually kills them, not the HIV virus itself. My project has been on the phone for over a week with this case where a woman is 4 and a half months pregnant, she's HIV+ with symptoms, she has a broken tailbone, she lives outside of Boston, and this woman is on the methadone clinic at Boston City Hospital. She has no transportation. She's living with her mother. She has nowhere to live. She has a broken tailbone. She spent 8 days at Boston City Hospital. She has no SSI. She's getting general relief right now. And we've just been trying to get her transportation.

k- Have you tried Interfaith?

Interfaith? No, that's one we haven't tried. This is just to give you a general idea who we have tried to talk to: Brockton Welfare, Boston Welfare, Habit Management in Cambridge. My concern and my issue and what I'm trying to do is have her prescription, the methadone she has to have on a daily basis, transferred to her city hospital, and I don't understand why there's so much red tape around being able to do that. There are extenuating circumstances because this woman right now is involved in a legal issue with Framingham Prison where she got her broken tailbone. I believe there is a lot of reluctance to even deal with her because she has a lawyer who is actively working with her. So a lot of doctors don't want to do anything that will open up a can of worms for them. The cases are just getting to be more and more involved.

Housing and finances are major issues. And it's not getting any better because of the condition our state is in. Just where our state is in terms of organizations or agencies that can advocate for funds now that funds are being cut. At Women, Inc. our funds are being cut. At one point women could do certain activities because they had general relief. A lot of things are being cut back. The whole treatment model will have to change because that agency depended on that. It was self supporting. The women basically supported it along with some outside contributions.

k- Could you tell me a little about Women, Inc. and the WARN Project?

Women, Inc. is not WARN. WARN is housed at Women, Inc., it is a separate entity. The best thing to do is call and talk to one of them. I do know that WARN is Women AIDS Risk Network. They do a lot of outreach to prostitutes, women on the streets, homeless women. They offer pre- and post-test counseling, they offer support groups, they have individual counseling. They do a lot of street outreach. I don't do
a lot of street outreach. My outreach is mostly within the agencies. When there are outreach days that come about, maybe 5 to 6 times a year, I participate in those because of the 2 agencies I work with.

k- What does Women, Inc. do with HIV+ women?

We have HIV+ women in the program. We have a special support group for the women. There's also a group that has just begun that helps women that are thinking about being tested; they get support, they learn about testing, what testing means, what a positive or negative result means. They get treatment also because it is always important for a woman that's dealing with substance abuse to understand why at that particular point she wants to be tested. Is it because they want to be tested simply because they want to take precautions, or is it because they may be thinking about, "Well if I'm positive I'm just going to go back out there because I don't have anything left to live for." So it's very important for women in treatment to understand why she wants to be tested. That's basically what we do. At Women, Inc. we are very supportive to women that are positive. We support them with not keeping their status a secret, but sharing that information with their peers so that they can be supported with the HIV, what it means to them, how they feel as a woman with it, and we just give a lot of support. In treatment a lot of times rules are just that — rules, and they are not bent and there have been a lot of changes made around policy and treatment issues and how women are dealt with in treatment with this virus simply because of different needs that they have. So the adjustments have been made. For example at Women, Inc. it's not a therapeutic community, but I guess I could call it a tough love community and sometimes a woman may be in the kitchen and need to get up at 6 in the morning, an hour and a half or two hours before everyone else. If the woman is positive then that may be adjusted for her. She may go into a different part of the kitchen, or she may just have a different job function. If she's on what's called a learning experience and she has a physical chore she needs to do for that particular infraction then they may change it and give her something written. It's hard to put it into detail because it depends on the woman and her issues and how her treatment is set up for her. I'm not the one that makes those decisions. Just general allowances around a woman being able to lay down during the day or sit or keep appointments, just going out to a lot of appointments. It's just compromises and it's real individual because it depends on the person. Everyone that is positive doesn't need to be treated differently, but some do. So those allowances have to be made. It's tough to deal with.
Right now at Women, Inc. I'm getting ready to go into the daycare to educate the parents and daycare staff. A lot of parents have concerns about if there's an HIV+ kid here, how safe is my kid. Unfortunately, many people, regardless of how much they hear how this virus is caught and how you can protect yourself against it, people still think that if you hug them or if we use the same toilet, they are going to catch it. And that's what they think about these kids....

I get a lot of frustration, especially asking people for money for different issues that women might have. There are a lot of problems HIV+ women have. I'm sure you must have heard this already. There are a lot of homeless women and the problem is that if these women don't have children then they will probably stay homeless. Even as a person with a job, the housing situation is such that without having another income in my household I might be homeless, it's just like that. There's no real affordable housing. There are no real homes, that you can pick up the phone and call right now and find places for these women to go. If they aren't able to get into the shelter by a particular time today then they are subject to be anywhere. Rosie's Place only has capacity for so many. If you're thinking about having this virus and being subjected to those surroundings it's very unhealthy and that's what's happening with these women. I may be more sensitive than I need to be, but I don't think so. If I'm positive and I'm being subjected to that on a daily basis, why not drink, why not use drugs? What else do I have to do? I'm living with a disease that's deadly, I have nowhere to live, I have children that I can't get home because part of why they aren't home is that I have no home to bring them to. That is one of the DSS requirements.

I have a sister that's living with me right now. She does not have custody of her daughter. In trying to seek custody of her daughter for the past nine months she's been dealing with DSS and public welfare trying to help her get housing. Imagine for an HIV infected person that doesn't have a sister, that doesn't have somebody else in their corner to support them. There are not enough treatment facilities, especially for women. There aren't enough for anyone, but especially for women. I had numbers on bed space that I can't remember – it's about 30% of the bed space that is for women and the other 70 for men. And for women with children it's even less. I just found out that there are a couple more agencies that take children, one is CASPAR, Women, Inc. and New Day, and I'm not sure about the criteria for New Day. I know one of the places will take a pregnant woman and a newborn, I don't know how many will take the other kids. Women, Inc. might be the only one that will take the other kids. You may have 2 kids that are in foster care or
whatever. But you can bring the other 2 kids in. That's a big issue in
treatment for mothers.

k- What exactly is the job of an advocate. To get somebody through the
system?

Basically. Here as an advocate what I do if women have DSS issues we
have a lawyer that's on staff so I may contact the lawyer and help
present the case and then get information from them as far as feedback
on what routes I need to take to help this client. Advocacy is, for me,
helping to empower the woman to learn to do those things for herself. I
don't like to do everything for a client. There are times when the
woman just can't do it. This woman I'm working with, she's pretty good
as far as reaching out for herself, but there just comes a time when
someone who can give more information than just their name is helpful.
As an advocate we work with child custody issues. We help the woman
to look at the reality of situations and we help them to determine what
is best for them and then we help them to see how that is going to be
set up and what they need to do to obtain those things. We will make
calls to the different agencies, we will help to locate the resources and
we offer referrals. We will also walk a woman through that if she is
incapable of doing it, which is the case sometimes.

k- What happens to a woman that cannot get an advocate. Obviously
there are not enough advocates for all of the women.

They're lost. I have women I've set up appointments with to see and
for whatever reason, especially with homeless women, homeless women
get lost a lot, they just get lost. Some of these women if you don't catch
them on the run you may never be able to help them. Especially the
woman that's using drugs. Normally you might not see her until the sun
goes down. And during the day she could be anywhere. And if she
hasn't been able to find someone that she feels she can trust then she's
probably just out there on her own and surviving, not really living, just
surviving. These are the survival tools that women gain from being in
the streets, just knowing how to get from today to tomorrow.

k- How can you reach these women?

Street outreach is the only way they can be reached. What we are
doing here is to reach women who have already been released from
prison, which is something that wasn't in place before, we're trying to
put that into place for women that have left and let them know that we
now have the services available here, that we do have an AIDS person on board and to let them know that services are being offered and try to at least get some of these women. Because AIM within the prison is respected by the women. They trust it and they trust us. We are hoping that some of these women that are just out there now learn that there is some place that they can go; that they can begin to get serviced. The problem with that is that a lot of the agencies are real sticky about doing something outside of that particular city. The monies that I have to work with are not AIM's monies, they are Boston Pediatric AIDS Project's monies. Not that it can't be done but it takes a lot more to do it.

k- In another interview somebody said that women from various communities, Black or Hispanic..., have a difficult time entering AIDS programs that are already set up, but mostly dealing with gay white men. Are there enough programs that do service these women?

There are a lot of programs. What I see the problem to be is that the programs do not have the capacity to fulfill those needs like an AIDS Action Committee (AAC). AAC, when it was formed, you have to realize who it was formed by. It was not formed by the poor, lower class people. We had these white gay males; doctors, lawyers, who formed this organization. It was built up with power and it's maintained by power. They have a lot of money, they have a lot of resources. Part of the problem I see with AAC, it's not that it's unreachable for the women of color, but you have to have ARC or AIDS to be serviced at AAC. They have just recently hired a person to work within the communities of color, so maybe things will change there. I believe part of the problem may have been that a woman of color had a hard time to go in and face all of these white gay males, and vice versa. There's just not enough money in the smaller agencies that are just getting started working with AIDS, and that's something you have to realize. It's something I have to look at, most of these agencies have just begun to come into existence in the last three years. That's a short life time for an agency. Regardless of how hard we are working to network and to build that system so that between agencies we can make one phone call and get the information we need to help a client and make that easier, it's just getting started. There is an agency that's come into existence for just that purpose, which is Multi-cultural AIDS Coalition, and I have hopes that with this agency some of these problems can begin to subside, but money is the big problem. There's just not enough money.

There's plenty of money for education, but education is no good if you cannot take care of the families basic needs. For example, if a
mother, even if she has a home, needs her rent money, or a mother
doesn't have food in her refrigerator, or a mother doesn't have milk for
her baby, then her using a condom or not using a condom is secondary.
That's going to be neither here nor there, her priority is going to be the
rent or taking care of her baby. Those are some of the things that my
project sees and is trying to work on, like trying to help the mother deal
with her immediate needs so that if she needs to go to a doctors
appointment and she doesn't have a babysitter we will pay someone to
babysit, so she cannot say, "Well I could not go because I didn't have a
babysitter." If she gets to the hospital and the doctor says her T-cell
count is very low and her symptoms require her to stay in the hospital,
and suggests she check in immediately, she will have to concern herself
with the fact that she has her kids with her and what is she going to do.
And have to put her life on the line because she has her children with
her. We provide emergency babysitting. All the woman would have to
do is know someone she trusts to take the child and we would pay that
person. So that's some of the stuff we do. We try to deal with the
immediate needs of the mother or the child, which always effects the
mother, to allow them to get the proper medical care.

k- Do the women generally have insurance or are many without?

Maybe Medicaid if any. If they have Medicaid that's good, if they don't,
they don't have anything. You find very few with private insurance.

k- Does Medicaid cover everything?

Medicaid has gotten a lot better. At some point there was a question
about AZT, whether Medicaid would pay for the AZT. The information
that I've recently received is that they will pay for the AZT, but the T-
cell count has to be at a certain place, which doesn't go along with some
doctors theories that the earlier usage of AZT helps to prolong the
progression of the virus. There's an agency for people who don't have
money where they can get AZT free.

k- Are a lot of the women also caregivers for others who are HIV+?

I'm sure that a lot are. I'm not presently working with a lot that are.
It's been my experience through some of the case management
meetings that I participated in that that's a big issue, especially within
the IV drug using community. Even if the woman is not an IV drug
user and that is not her method of transmission they ultimately end up
being together, which is really hard because a lot of places, if it comes

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time for them to be placed somewhere, these people are separated. If the woman is the caregiver and the mate becomes sick and she is also not well she will, as we have grown up to do, put her health and what she needs on hold to take care of this other person. There's a lot of that, just within the community as a whole. And I don't know that there's anything that can be done about that, because it takes a relearning and instituting a new value system into a woman, which doesn't happen overnight. I'm just learning how to do it myself. I would imagine for the woman who has the HIV infected baby this is even more of an issue.

k- Could you talk a little about specific needs and problems of women who are incarcerated or newly getting out?

For women who are incarcerated specific needs are to be able to be diagnosed early. They are not doing that because of the lack of confidentiality within the prison system. They need their confidentiality rights protected around this virus. They need to be treated in a humane way. For women incarcerated at Framingham, especially women in the awaiting trial unit or in the hospital unit there are 5, 6, 7, maybe 8 women confined in one room together. That puts the woman who is HIV+ at risk for infection. The women who are coming out of Framingham or are in pre-release centers need to have an option as to where they receive their medical care. As it stands now anyone that is incarcerated has to be seen at Lemuel Shattuck Hospital. Not to take anything away from the hospital, but a woman needs her right to choice. Women that are pregnant that think they are positive or know that they are positive need to be able to get through that system fast enough if they want to have an abortion that they will be able to do that and not, like the woman I'm working with, be kept, and waited and held until it is too late physically to do that. Women need to be able to get AZT earlier on, rather than waiting until their T-cell count is below 200. They need more support. The guards need more education, there needs to be more sensitivity as to the virus. They basically and overall need to be treated like human beings. They are not being treated like human beings. They do have some existing support, the problem with the existing support is that it's identified as the AIDS office. Women whose risk or status may not be known are keeping silent because of the repercussions that come from being identified as a person with AIDS. That's real basic. It's not asking for anything that a woman doesn't deserve. Another issue is that they have a rule about shackles when one is going from one destination to another. For a woman that's sick and being transported to a hospital there need to be some changes in some procedures and the way that
they happen. Women are transported in a closed up nonventilated van from one point to another. From the van, when they get to Shattuck Hospital, they are placed in 3x6, 4x8, something like that, a very small room. They are enclosed in there with a big glass door there, no air or anything coming in. The men are in a big open cage where there is at least ventilation, if nothing else. Also, I've been told that they keep one hand shackled. So still you remain partially shackled the whole time. That's cruel and unusual to me. When a person is in a locked place completely confined with guards outside sitting there watching them and they are at the hospital... some of the methods they have of doing things can afford to be changed. I believe that women too should be treated individually and not just as "they are a criminal" and leave it cut and dried like that. The majority of women in Framingham are in for prostitution, they are not in for any harm on anyone or violent crimes. They are not even in for long periods. That's the majority. There is the small portion of your average criminals. But most of the women are there for nonviolent, crimes to self.

[end interview]
Appendix D

March 9, 1990

Interview with a Protestant minister who organizes volunteers to provide direct services for people who are HIV+.

[begin interview]

k- Could you talk a little about Interfaith and how it services HIV+ women?

We have 2 areas. One is education and outreach to members of the religious community. One, because it's an untapped resource for volunteers and help; and 2, because it's also a community that has tended to ignore it, or is viewed as ignoring it. And that's not quite accurate. The education we do is anything from AIDS 101 to the types of needs that need to be met and the kind of resources the religious community may be able to offer. The second area has to do with the needs. We work primarily through home health care agencies, the Boston Visiting Nurse Association, Deaconess Home Care, Cambridge Visiting Nurse Association, the Lynn Visiting Nurse Association, and various other places like that. We are also working in Lowell. We receive requests from the caregivers who are in the home to see if that person, most of them are fairly indigent clients, is having certain needs met. It's often food, emergency food supplies, linens, cleaning supplies, toiletry articles, sometimes medication that's not covered, such as vitamins, that sort of thing, funeral expenses that are not met by medicaid, filling in the gaps. Sometimes respite care, transportation to doctors appointments. We get requests from the VNA (Visiting Nurse Association) who go to our volunteer coordinators who then put a request out through a network of churches and synagogues. These places will meet certain requests. We also work with certain residential programs, such as the CAP's program (Children's AIDS Program), their daycare, as well as Project Star.

We have found that the kinds of requests over the last year and a half have been shifting. Or the kinds of women. We have been getting a lot more women, single mothers, with children, anywhere from 1 to 4 in a house, some infected and some not. And the types of requests have changed, the food orders have increased a great deal – milk, basic food supplies. And I think that reflects the change in which way the epidemic has moved, significantly. I work in various capacities with Project Star. I serve on the trans-agency board to make
recommendations for services and how services can be met. I've worked, at least as an observer, with the Boston Pediatric AIDS Project. And with CAP, supplying furniture or whatever else they need down there. So that's what we have been about. We are made up of a cross-section: we have a board of directors that is representative of Christian, Protestant, and Catholic faiths. It is interracial. It has ordained and nonordained folks working on it. Some have been involved in AIDS work in their own ministry, others just feel that they need to be there. That's what we are up to.

k- All of your requests come through the VNA?

Yes, we are very small. It was a way to set up a network for delivery of care. A lot of people who have AIDS have some sort of home health care. They don't spend all of their time in a hospital because of the way the disease works, obviously. More and more of them are receiving care at home. The VNA particularly supplies a lot of that care, but there are others.

Some of their other needs, like their major health care are supplied in the hospital. But when they are at home without salaries and all of these other things, a lot of the basics slip through the cracks. People who are isolated from their families and friends and are cut off from everything that would normally give them support – this is where we fill in. That was the need we saw initially. Katrina Finley who started the agency as a chaplain as Mass General discovered this and set up a network. The best way to get into the home or figure out what people need is through a home health aid who is in there, or the nurse. We went to the Boston VNA, to their AIDS coordinator, and discussed this and she and Katrina and several other members of congregations got together and said this is what we see and can we set up a network. We need to have referrals simply because it's easier. We are not in the home so we don't know. Because we work with all volunteers in providing the services, in order to give them a certain amount of distance and privacy, we have coordinators in place, whose numbers are given to the nurses. We don't give the numbers to clients simply because we need to protect the volunteers to some extent. The need is so great and it's just a courtesy to them that we try to keep things.... It's not a hard and fast rule, but we find it works better if there is one person calling and making the assessment about what is needed and who knows what we can provide. It's been my experience that a lot of people, particularly the women who are coming now, have so many other issues involved besides AIDS and HIV, that we have to be very clear about what we can and can't do as far as services. So the nurse
knows what we can and can't provide, so that makes it easier. It's just a method and it works, it works very successfully.

At one time it looked like we were financially having a lot of trouble. The VNA made a strong pitch for us to stay in business because there's very little paperwork – there's no paperwork, actually on the part of the nurses. There's no red tape, it's just a phone call. We have had a fairly successful rate of supplying requests, within 24 hours in most cases, like with food and that sort of thing. It's a little harder with furniture. That kind of thing takes a little longer. But on basic emergency supplies we've been pretty good. We're small, we're not AAC, we can't do everything they can, we don't try to. But we fill a niche.

k- Could you tell me about the range of needs and the circumstances you see?

Well, I went over the requests for last year to get a sense of what's coming in. As far as I can tell, the women we have worked with, either within their families or on their own, have all been HIV+, two have died, and the situation has been: for instance, a woman in Brighton, a family, who was referred to us through St. Elizabeth's, a social worker there, had had difficulty getting an apartment. Got settled into an apartment. She had two children, one who was school age, 10 yrs old, and the other was a toddler, who was 2. Two different fathers. The first one was not around at all. The youngest child's father was around, had a history of drug abuse, and had been in and out of jail. She had no support, her family was in Puerto Rico. Both of her partners were Puerto Rican. So that was the cultural base. The problem was that she was very very ill at that point and had antagonized the system to some extent. She had been playing the system in order to get what she could when she could. So the welfare agencies did not look kindly on her to some extent. They were reluctant to give her money. She had used money that was supposed to be used for food, for instance, in order to go bail out her partner when he was arrested. So the issue there, after finally getting her in an apartment, was to get the older child so she could go to school. A very bright child, who would thrive in a regular school setting, and had not had that for 10 years. And then the issue of where to place them when she died. There were no grandparents around, or at least none that were acknowledged. The only other person around was the father of the younger child. So the question of custody was an issue. We went in and provided food, which was everything; fresh vegetables, cans, cereal, milk, all that sort of thing, to get her started in the apartment. As well as linens, towels, cleaning supplies, that sort of
thing, to get the apartment set up. She had managed to get some furniture. And also books for the children, toys, because there was none of that. And then, until there was a home health aid in place, we provided babysitting so that the 10 year old, who was a parentified child at that point, who took care of her younger sibling and wouldn't go to school, she would not go to school unless we had someone in there who could watch the younger one, so she was free to go to school. So we were able to get child care coverage for a week until the home health aid was in place and could help with that sort of thing. What that says is that while there are services that were eventually put in place they are slow sometimes. I'm not sure if DSS was involved, but it was clear that unless something happened the child was going to miss school and was in danger of then being moved out once her mother died. And where to go, whether to go to Puerto Rico. Then there was the whole issue of the hurricane that had gone through. We weren't sure whether the family down there had lost everything or were even still alive, what their situation was. So that was kind of hard, working with a social worker. There was an advocate in from AAC who had worked with substance abusers, who said pretty much, "Don't rely on the man to be around," even though he wanted to be around.

Another issue was a woman in Dorchester with 4 children, two of whom, I believe, were positive, one of whom was also ill. She herself was ill. Her husband, or the man who was father to some of the children anyway, had left leaving her $25 and just disappeared. She had no other resources. That was simply finding toys, and food, and some clothes for the mother. That was filled by a church in Jamaica Plain.

We have had an issue with a woman in Revere with a history of alcohol abuse, 2 children, one who is not positive, one who has to be retested because it is not clear whether the child has HIV. She has had 1 husband who has disappeared. She is living with someone else. She has 4 kids, actually, 2 who have been taken by DSS and placed in foster care, 2 are home. The father of one of them is there. She is under restraint from even seeing the other children at this point, because of her history of alcohol abuse. She is HIV+, her partner is not HIV+ at the moment, and there's an issue of getting different services for the different kids. I think what happens is that in the cases we have seen where there are one or more children in the family there's usually two fathers involved. It's not always the same biological father.

There's also, given the history of problems in the family, there seems to be a number of different service agencies involved. And I think it gets really confusing as to where the lines of care are. Who is responsible for what. Whose turf is it. Whose supposed to provide
services. It seems to me that the services are all very fragmented. They get done, it just seems to me that there needs to be some sort of case management set up. It's very hard to figure out who's doing what. That's where I think people fall through the cracks. A woman may be under Women, Inc., and getting some sort of service that way, but may have DSS involved, may have other agencies involved.

k- So it seems to you that if they had a case manager all of the resources are out there for them?

I'm not quite sure that that's true. But I think that it would at least make it easier for them to get what is available. I don't know, I've been working in this for 3 years, I understand to some extent what is available. My question is, how do you access the system? That's what seems very confusing. Some of the clients that I have seen that come under Project Star, for instance, they provide pediatrics and have very strict guidelines for what they do. One of the issues that keeps coming up at Board Meetings is limiting how much the social worker on the early intervention team is responsible for in the house. You walk in and see a family that is decimated with problems, you want to go in and do it all. The problem is that you can't or your other clients won't get serviced. What I think needs to be done, and I've heard repeated, is that there has to be a way of managing the case so that the services are clear as to what is available and how you access them and helping the client feel that they have the power to access the system. A sense of empowerment that they can do this. You don't have to pass this off to all social workers. I think that there are a lot of services being provided, I just don't think that there is a system in place for getting it done efficiently.

I think that respite care is an issue not being taken care of. That's one area I would say is not being addressed. The AAC Buddy system doesn't work in a situation like that, I think. I have not looked at it in the last year, but I don't see.... The issue here is that there is a family, whether it's a mother and father, or whatever, but a parent and children involved. What needs care is the whole family, the unit is the client in that case, and I don't think that the Buddy system addresses that. I don't know if it can or that it should, but it seems that there's got to be another model in place for respite care. We've talked about that with the VNA, training of the volunteers to go in and give a break to the parents who are probably very ill themselves. Because often there are extended family, grandparents, aunts, other people involved, but they may or may not be capable of handling the situation. Especially if they have kids at different age levels, some who may be

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sick and some who may not be sick. So I think that there needs to be a
volunteer system in place, or some kind of system in place that will give
respite care; go into the home and help keep it running. That I don’t see
coming around, that's something that needs to be plugged in I think.

And also, making sure that when there are 2 or more siblings,
where one is sick, there may be healthy children whose needs are not
getting met because the focus is on the sick child. God knows they have
enough problems generally as it is dealing with that, and trying to
provide the child with as normal a childhood as possible. That may
mean being able to take them to the movies or take them to the park to
play, to get away from the sick child, to make them feel that they are
just as important and part of that family system as well. I think that is
important, and those needs are not being met.

k- How does the VNA work and how do they get into these cases?

I think that they have referrals. I understand that a doctor or whoever
is providing the primary care will make a referral to the VNA and they
will pick it up. I'm not sure how they are paid. They get most of their
reimbursement through insurance, third parties. But the primary
caregiver will make the referral, will say, "This person needs a home
health aid, this is why they need them...." Some places like Staffbuilders
have nurses that can give IV treatments. It depends, they all have
areas of expertise and what they can and cannot do. That's how they
get involved. It's like anyone else who needs home health care, the
primary caregiver will give these home health agencies a call and set it
up. Or the discharging teams at hospitals will get involved, it depends.

k- What exactly is their role?

That depends on the case and how often they need a visit. The VNA in
Boston has 3 or 4 satellite offices. They go in and do whatever needs to
be done. They may go in and change dressings, or check on an IV drip,
or give medication, administer shots, change linens in some cases -
whatever the recommended procedures, or whatever they are told to do
by whatever the doctor assigns. There is a part time pediatric nurse
now who goes around talking about care for infants with HIV or
prenatal care. It depends on the level of expertise. They have RNs and
LPN's and home health aids. How often they go in depends on the
severity of the case. Once a week at least, sometimes more. It depends
on the case load and how many nurses they have. Sometimes they have
to go in under escort depending on the area. They go in at night. There
is a nurse association that provides an escort.
k- Are most people able to get access to VNA's?

If they are found, if they are identified. One of the issues that has come up in the BPAP is the fear that there are a lot of children, particularly, and mothers who are not identified as needing HIV services. One has to do with a fear and a reluctance on the part of certain women to seek care. They don't want to know, or they suspect they know they're HIV+ and will not seek support because they are afraid that their children will get taken away from them maybe.

k- Does that happen?

Not if the mother is able to provide or they have a system of care, unless she is abusing them. The children won't. The children may get referred into the CAP's program to give her a break, but they are not removed as a punitive measure in that respect, I've never heard that happen. I don't know of that, unless there are other problems, like drug abuse involved, and the mother doesn't have it together to take care of the kids.

Placing HIV kids is a whole other issue. You may want to talk to Sarah Sneed about that one. She works through the DSS in the children's AIDS network. She is in charge of placing foster care. I'd have to get her number from the office. She's quite involved particularly with trying to place foster and adoptive families for HIV+ children, or children who have lost parents to HIV.

There's a problem of identification. There's a problem of once people are identified if they will keep appointments, or if they will go get into the system of care. I know that there are nurses that have gone to do their visits and have not been let in. In one case there was a woman who was drinking who wasn't supposed to be drinking, and wouldn't let the nurse in. But the nurse went every time she was supposed to go and just couldn't get in.

There's a mistrust of the teaching hospitals particularly from people in different communities; Dorchester, Roxbury, Mattapan. Women are particularly reluctant to go into places like MGH or Deaconess or Beth Israel, or any of those places. They want to stay with their community health centers because they know them, they want to stay with one person, they don't want to be passed around even though HIV requires lots of different special kinds of care and different agencies become involved. They want one person that they know and that they can relate to and trust, and that's hard. So I don't know that the needs are being met. It takes an aggressive kind of activist position
on the part of the caregivers to go into the house, into home sites and say, "We will give you these services," and to build that bridge. Make the trust, establish the trust.

I don't see that the protocols being done in the teaching hospitals are addressing the issues of women and children necessarily. I know lots of people who are on protocols, various drug protocols, but as far as I know, the majority have been set up for gay men with the disease or maybe middle class people. I don't know what drug protocols do to the female physiological make-up, what do they do to a body that's been abused by drugs, what do they do to prenatal care, what do they do to lactating women, those kinds of issues. What do they do if you are taking riboviron, is it going to do this or that to your cycle. So I don't see protocols answering those questions, I certainly don't see it in Boston, I haven't heard it. There are people on the Community Research Initiative who have not seen it happen.

There's an AZT protocol for children going on at BCH, but there's no active recruitment of women to these things. So I don't know what the availability of the medication for some of these women is. I suspect they are not getting what they need.

k- You mentioned that you take food and other emergency supplies to clients. Is this a one time thing or are there people that get ongoing service?

Yes. If we get a request from a nurse, and the nurses are pretty good about knowing where they can go for things, we have repeat orders. There is a man, a Haitian family, in Mattapan, and there's a church in Brookline that brings food on a weekly basis that is culturally specific. They learn what people want to eat and take it to them every week. But we don't do it only one time, we often get re-requests, for things like diapers, all sorts of things.

k- You said that there was a woman who was HIV+ and her partner wasn't. Do you see them getting education about safer sex and all?

That's not our role. That's usually the VNA's role. And yes there is some of that going on. There are recommendations to get into alcohol counseling, to find out what are the local groups, and there are lots of them around. I was really surprised to find that there are a lot of small local groups around that will do substance abuse counseling, alcohol dependence, that sort of thing. The education that I've seen done, an awful lot of it is done by the home care workers, sometimes the social
workers. I don’t know that, I’ve just heard it from the cases that come up.

k- So it seems that the VNAs try to address the whole range, they almost become the case managers.

Sometimes it is, unless DSS is involved or somebody else. If there’s a social worker involved they usually manage the case. I don’t know if you have talked to the VNA. Talk to Beverly Wancho, who’s the AIDS coordinator for Boston VNA. She’s in the East Cambridge office. Her assistant is Janet English. They would be able to tell you more specifically about what the nurses do. Dr. Modesto who is in charge of the BPAP at the Dimock.

One of the hardest things that we have is that we are mostly suburban. We have some inner city churches.

k- You mentioned making plans for when the parent dies. Can you talk about that?

I’m not sure how they get that set up. We had one case where a mother and an aunt died within a day of each other. And there was a father with, I think, 3 kids. The aunt might have had a child as well. He was in a pretty stable situation, not great financially, but pretty stable. In that situation the kids had a family to go to. I think there was some extended family around, too. What we provided in that situation was funeral expenses. Medicaid only covers up to, I think $1100 for funerals. Waterman’s is a good place to go, they have done an awful lot of AIDS funerals. We had to raise money because they didn’t have any Medicaid, and it was 2 funerals back to back. $2000 at least. I think that it’s not clear how people work out their funerals. We have provided expenses, we have never had to provide any kind of pastoral stuff for that, they have usually been able to find someone from their faith tradition to do the funeral. That’s not been a problem we have run into.

But what happens to the kids when there is no family around to take them, is an issue that’s becoming more and more a problem. How you place them and keep sibling groups together, and that sort of thing. That involves planning with the parents. If they are going to die then who addresses that? I assume the social worker does that. But I’m not sure there’s anyway to deal with that in any organized way. You might want to talk to Sarah Sneed about that. What to do with the kids. That’s a big issue, and helping parents cope with that issue.
k- Does Interfaith provide pastoral support, religious counseling?

Well, what we've done is, if it's requested then we can do it, those of us who have some training might do that. We work a lot with the ecumenical task force and their healing services. We've participated in those. We're not formally set up for that. The Pastoral Concerns Committee at AAC, that's what they do. But we've certainly had some. The nurses generally don't ask for that. I think there is a need for it, but it has not come through us. We are going to set up some support groups. We try to stay non-denominational. If it's requested we will certainly go and do that. One of the ways to gain credibility particularly in the fundraising community where we have to go for money, is to remain as a religious as possible. It's not that we wouldn't provide pastoral services, we would, but we focused our attention on services that people would not feel uncomfortable funding. Even then we have to bend over backwards to say that we don't proselytize, we don't try to convert people. The people that I've been involved with personally through my own chaplaincy work, I have provided a great deal of pastoral support for those people, mothers in particular. And pastoral support can mean providing food. It doesn't have to be "God" stuff.

But being religiously sensitive, aware that people do have spiritual needs. I had a woman who I worked with directly who was terrified about telling her church that she had AIDS. And it was my being a representative of an institution as being an accepting part of it. It's not all Jerry Falwell and folks like that. There are an awful lot of congregations that are sensitive and will provide pastoral support.

k- Do you think that a lot of people are not getting what they need because they are afraid to go to their churches?

I think so. I think part of the responsibility of the churches in the different communities is to make it safe for them to come. People with AIDS, in my experience, have an awful lot of things to be afraid of. Disclosing risks losing all support that they have. And churches have not really come out and told them it is safe to be there. When I go talk to churches I tell them that one of the biggest things that they can do is to make yourself safe and extend yourself to these people in you own spiritual life. Because they are not going to come to you as much as they would like to. Or someone in the congregation might not have AIDS, but have a mother or father or sibling, who will not tell you, because you have not made it a safe space to talk about that. So that's their responsibility.
I know women in prison, I've had calls from chaplains at Framingham, to come out and do prayer groups. That's another whole issue. Some of the issues out there, that's another whole can of worms.

k- You said you work with Project Star. Could you tell me a little about that?

Project Star is sort of the next phase of development of several projects of early development that's been done for children in multiproblem families in particular. Project Star - Star because it's a 5 agency board, which includes South Shore Mental Health as their fiscal agent, and Alianza Hispana, ABCD Headstart, AIM and Women, Inc., I'm not quite sure because things got shifted around in starting it. What they do is they have an early intervention team, actually they start with an outreach team, they are street workers, who are affiliated with the other agencies. They find potential clients for the programs. Project Star is limited to birth to 5 years of age, for children who have or are at risk for HIV. They may not be infected but may have HIV in the household. It's within the Boston area. The outreach worker goes in and makes a referral to the early intervention team. The early intervention team then picks it up and does an assessment to see if there is eligibility for the program. Then if they are eligible they are placed into a program that includes both home visits by the social worker, child development specialists, and nurse, plus a family and daycare program at Dimock. At Dimock they have the actual daycare and they also have the family center that includes classes for parents and assessment of development and that sort of thing - special needs for the child. Part of the program is to reach those children that are lost and won't get the kind of care that they need, and early intervention to thrive and succeed and provide them for mainstreaming into the public school system or where ever they go.

The model is a trans-agency model, with a trans-agency board. At any time on the board there are 20 different agencies involved. We hear cases presented by the early intervention team. And then recommendations are made. There are enough of us around to tell you where you can find a particular service, who to call. That's where there is trouble with case management, who's in charge of the case, because often DSS is involved as well. But it's a way of putting it on the table and seeing what these people need. The problem is it has had a hard time getting off the ground. Project Star officially began in September, though Project Win was before that, which was just home sites. I think once they get going they will get a lot of referrals. Center based services are something that haven't been done so much before. To
provide ongoing center based services in the city will be something different as far as I can tell.

Another thing that defeats the client is turf issues, that's hard. Who's stepping on whose turf.

k- Do you find that agencies feel that something is their area and they don't want other groups....

I don't think it's that cut-throat. It's a matter of negotiating who is doing what. You don't want to reinvent the wheel. The lines of communication have to be clear. Who's going to manage the case has to be decided. Also, finding where the clients have some say in it.

k- Is that a problem you see?

I don't know. I suspect that that is sometimes a problem. Maybe there's a model of what you do in certain circumstances and that is applied across the board no matter what the situation is. There are benefits to that but sometimes the client might be trying to tell you, "I don't need that, I need this." I don't know that that is always heard. "We know what's best for you." That's an issue that comes up in Project Star, for instance - to hear what the client is telling you and know whether it is accurate. Obviously a client may not make a correct assessment about what they do need. But, that doesn't mean to say that a client shouldn't have participation. One of the things that Star does is try to get the parents involved in making assessment of the child.

As far as women and children go, the move has been to consolidate care and services that are given so that the mom is not on one track and the child on another. Because the way it had been set up it seemed to me was that if you were a mother you could only access this way - this is how you went to get your services, and if you were a child you went this way. It's a family unit. The family should go the same route. Hopefully I think that's the direction it's moving in. There shouldn't be 2 or 3 different bureaucracies you need to go to.

I think education is very important. First to reduce the risk for women. I think there have been a lot of things tried. There are a lot of wonderful people doing outreach and health education. I don't know that it's making much of a dent. My friends in the black and Hispanic communities have expressed a lot of frustration on the part of the churches to make it a safe place for these kind of educational and support services to be done.

I know about the religious communities and the issues there. That's a very difficult and complex situation.
The Multi-cultural AIDS Coalition has a pastoral concerns unit. When we first went into churches in Roxbury we heard, "I hope you can get in there. The churches don't want to talk to health educators, but if you come across as someone who is religious, maybe they will listen to you." The Black churches in certain parts of the community are the foundation. They provide one of the few stable institutions within the community. They are extremely important. They provide a lot of the support and empowerment in the community. They cannot be discounted. The problem is getting them to talk about AIDS. It's been a real battle. We've had minimal success. But then we haven't given it the push. Maybe other places have, or they are working within themselves. I don't know how successful they have been. That might bear investigation. They are much closer, I see it from the agencies point of view. I don't see it as the street outreach workers do, or the people who live in the community do. I'm removed from it to some extent. But what I know is either my own personal experience or because I've worked directly with the caregivers who have said, "These are the problems we are up against."

k- Thank you very much for your time. Is there anything else you would like to add?

No. There is so much to say. As far as women and children, there's always more that needs to be done. There has to be some way to give that population a voice. They don't have a voice. They don't have the resources to mobilize like the gay white male population. They have resources and got their act together. There is no voice for that.

I went to a national convention in Washington DC in September called the AIDS National Interfaith Network. It was a coming together of all these little agencies like ours from across the country, about what they were doing. The thing that I came away from there with was, first that the epidemic clearly was shifting. A lot of the people who had started a lot of the programs and done a lot of the initial work and the pioneer work were gay men. It was wonderful, but the question was how to provide the same services and get the same resources and mobilize the people who are now looking at the disease. I was talking to a woman who is working in the South Bronx, and she said these people don't have a voice. That's really it. They need to have a voice to demand the services they need. That may be the hardest thing to do.

[end interview]
Appendix E

March 12, 1990

Interview with the Administrative Director of Public Health AIDS Activities for the Department of Health and Hospitals.

[begin interview]

k- First you could give me a way to identify you in my thesis.

I'm the Administrative Director of Public Health AIDS Activities for the Department of Health and Hospitals.

k- If I use that everyone will know who it is.

That's fine. You understand that the Department of Health and Hospitals is subdivided into several different areas. One is the Health Department, that's the division I work for, the division of Public Health. One is for Boston City Hospital, the other division is Mattapan Chronic Disease Hospital and Long Island long term care hospital. I work very closely with the clinical services, both pediatric and adult.

k- Do you really provide services directly?

Let me describe what our department does. We oversee prevention/education activities, community programs and the Children's AIDS Program and the Special Parent-Child Center. In doing that we also offer about a million dollars worth of proposal money that goes out to, the last 2 years it's gone out to 14 different agencies to provide prevention/education services. We do direct trainings for providers, we also offer train-the-trainer workshops, so that we train people who go out and do trainings. I supervise Deanna Forist who runs the CAP program and the Special Parent-Child Center. We are also moving into the planning stages of offering what are going to be adapted forms of the Behavioral Resource Program, which is the state program. The state has developed a three week module for newly HIV+ individuals. It is a mechanism by which we can offer education, support and linkage to health care or to some kind of a group so that people have someplace to go once they have been diagnosed. Often these folks have never used the health care system before, and need some orientation to the health care system and to the HIV disease. What we are also in the process of doing, and why I say adapted, is that
we are moving beyond the current Behavioral Resource Program model. The state has been working with the Martha Eliot and Dimock Health Centers to adapt that model for communities of color and the Latino community. In addition, we are looking at it in a couple of other ways and through discussions with providers we hope to see how the model may work for some populations but it might not be working for other populations. We're hoping to consolidate some of those changes and offer a 4 to 5 week series sometime in the spring. We're hoping to start it in the women's center at Boston City Hospital.

k- I've heard of the state's support group. What population gets channeled into that?

The state run Department of Public Health (DPH) program has a well publicized main number to call. It is very similar to how referrals are made to an Alternative Testing Site. Part of the concern is that most of the people that have used the model that is currently developed have been gay, white men. What we're hoping for, and there's been good feedback from Dimock and Martha Eliot, is that in looking at the state's effort to cultivate this program in other populations they're changing the model enough so that we're hoping that this will be something that people of color also seek out. And also as long as service providers know about this model they can also refer patients.

k- Is that true now?

At this point, I don't know whether or not that's true. The model that we are working with is that we are expecting that Department of Health and Hospitals clients will use these services that we are planning. For example, if it's a four or five week group and a closed group. We can open it up only every six weeks. We've found that that works well at Dimock and Martha Eliot, so that we are encouraged by what we've seen there. We're really in the beginning stages of this and we're hoping that we can come up with a consolidation of all the things that we have learned and the state has learned.

    This model has been discussed and worked on for over three years. And what we're also trying to do is recognize the barriers for why people of color and IV drug users wouldn't want to use this group, because we do know from places like Project Trust that there can be a long lag period between the time that someone is tested positive and the time that they can enter into a medical primary care system if they even have access to primary care. At Boston City Hospital there can be up to a three month wait. We're hoping that this program becomes a
mechanism of education and support and a place where people can look comfortably at their behavior ultimately to change their behavior and begin that process early. There are a lot of needs. We know from talking to the clinic providers at Boston City Hospital that patients do need orientation and that medical providers, both physicians and nurses in the clinics, spend a lot of time answering questions, orienting patients about basic information. And also the way the Boston City Hospital clinic is set up at this point in time, historically there has not been a good way to integrate HIV+ asymptomatic patients into the health care system at Boston City Hospital. Because of the large number of people we are seeing we are seeing symptomatic patients primarily. We have opened, as of January 1990, a diagnostic evaluation unit (DEU), which is a triage center and a place to streamline all entry of HIV+ patients into the whole health care system at DH&H. As that has developed we are hoping to add the educational piece to the DEU, as it is called.

k- You said you were looking specifically at the barriers to people of color and IVDUs using this model. What do you see?

I have to say that it is too early to make a clear assessment of that. One of the things that we know is that a three week model is not long enough, most likely. It will have to be longer. There is a longer orientation period so that people can feel that they trust the group and open up and use the group. Three weeks will probably just not work. That's something that very compliant patients have used and patients who have been educated to ask a lot of questions and have a high sense of self-importance. They also tend to be patients who if you give them information they tend to take the information and use it. For example, if I gave you a resource guide you'd know how to use it. What we are talking about with some other parts of the population are people who don't know how to use a resource guide, don't feel comfortable necessarily finding a number and a name and calling that number. That will require a little bit more time and sort of a sense of trust to develop there before that will be a useful process from one step to the next.

One of the things that will be very challenging will be that with the drug-using populations, oftentimes keeping appointments is very difficult, which is why we have established walk-in services as much as possible. In situations like this that would be very difficult. We will probably also have to devise a daycare program, hopefully come up with some meals so that people won't have to miss a meal or somehow this can be accommodated into their busy schedules. Also, we would like to accommodate women with children that can't necessarily bring them to daycare. It's unclear about the site – when and where. Perhaps
while patients are here at the center, have daytime sessions so that if the patients are here for appointments, this can be an integral part of their visit.

k- Could you talk a little bit about the services of the adult AIDS clinic at Boston City Hospital?

The adult clinic, officially called the Immuno-deficiency Clinic, sees somewhere between 300 and 325 clients. The average number of visits per month is about 1.2 visits per month. Patient breakdowns are: roughly 52% have a history of IV drug use, 20% homosexual contact, 4% homosexual contact and IV drug use, 15% heterosexual contact, and unknown is maybe mothers known to be HIV+ and have an infant, mothers presumed to be HIV+ but their test results haven’t come back yet, or they are symptomatic and refuse to be tested, that kind of thing. Ethnicity and race might be interesting to you: Black is 35%, Black/Haitian is 14%, Hispanic is 13%, White 38%. Male is about 73%, 27% female, which is very high. 52% have CDC defined AIDS. 48% are symptomatic HIV+ or ARC. These numbers are about a year old. We anticipate them to be roughly the same with some minor variations. The AIDS clinic runs five sessions a week. It’s quadrupled since it’s beginning in July of 1986. There is an ACTG site there - AIDS Clinical Trial Group. It’s one of 20 NIH sponsored sites for the completion of research protocols. Those research protocols are determined by the site, the population that’s being seen, in conjunction with NIH and Harvard. At any given time there are probably between ten and fifteen research protocols going on in the clinic.

k- You said that there are five sessions....

A session is three hours, 3-4 hours five days a week. Patients are scheduled during that entire time. Plus there are many therapeutic sessions, which means that clients are in for intravenous therapeutics of many sorts. There are more and more therapeutic drugs being seen over time and if patients need to have that done in the clinic as opposed to in the home; sometimes patients don’t have a home, sometimes you can’t get care providers to go in the home because it’s in a dangerous area, and sometimes they just need to be monitored. Like an outpatient treatment center, is what it is really.

k- It's mostly for medication or....
It's an outpatient clinic in which patients are seen by a multidisciplinary team including primary care physicians, family practitioners, sub-specialists like psychiatrists, dermatologists, infectious disease consultants, neuro-psychological assessments, nutritionists, social services, and a mental health team. There are other sub-specialties available to come to the clinic to provide services for patients there. We find that many of the patients at BCH get lost if referred to other clinics, so we have tried to pull together as comprehensive of a clinic as we can, recognizing that patients are also very sick. Although patients are ambulatory and able to get there, patients tend to be on the sicker end of the spectrum.

k- With all of these options, do you go through them every time a patient comes in, or do the people there....

Before every session the clinic team gathers and discusses every patient. The staff discusses the patient's status, needs, problems, successes, etc. Initial assessments are done from a medical perspective.... Actually let me tell you about how a patient walks through. At this point in time the diagnostic evaluation unit is the place where all new patients come in, unless they are heavily symptomatic in which case they would be directly seen in the clinic. The diagnostic evaluation unit actually takes place in the primary care unit of the hospital which is two floors below the Immuno-deficiency Clinic. A nurse intake is done. That's an extended physical, a medical history is taken, some preliminary blood samples are taken, and a TB test is done. The patient comes back the following Monday, gets the laboratory results, and at that point in time the patient is triaged by the nurse provider and physician together. A social service intake is also done. It is determined at that point in time whether or not that patient needs to be seen in the clinic because they are a more complicated or symptomatic patient, whether or not they can be seen at another health center, or at the Primary Care Clinic at BCH. Often times one of the problems we have with clients is that they would prefer to be seen at Boston City Hospital. We would like to educate patients to want to be seen at neighborhood health centers, and educate them to believe that there are good providers at the neighborhood health centers and that confidentiality won't be a problem. The other possibility is a primary care clinic. If the patient is not symptomatic and does not need frequent medical assessment, then they can be seen in primary care.

k- Where do the patients come from generally, around Boston or....
Predominantly from the Boston area. We don't deny patients entry because they don't give us a Boston address. Patients come from all over the place. This general area: Mattapan, Roxbury, Dorchester, South End.... Patients come referred to the clinic. One of the things that we've noticed with the AIDS Clinical Trial Group and before that in doing some of the trials including DDI is that we were getting much broader referrals from all over the place. Because we are the AIDS Clinical Trial Group. So that adds to the types of referrals we're getting. We are getting people from out of state, for example, to be part of that. A lot of patients who come to the clinic have not traditionally had access to health care. This is not a population of people who notice a spot and come in right away. We're often talking about people who have advanced disease. Because there's a very high rate of patients who have a history of IV drug use we also see a number of patients who are also being followed elsewhere in the institution, including drug treatment centers here. So there is a body of patients that is dosed with methadone daily and then comes up to the clinic for care.

k- There is drug treatment right in the hospital?

Actually it's not sited at the hospital. Frontage Road is a narcotic addiction clinic which is not far from here. It is a service run by the Department of Health and Hospitals in this division within the Addiction Services Department. There's also a referral to many different aftercare programs, therapeutic communities, detox centers, not run by Department of Health and Hospitals, but with very close referral ties to all of them.

k- The other two projects at Boston City Hospital are Trust and MOMS...

There are lots of projects. Those are two specific AIDS-related projects. Project Trust is a drop-in anonymous testing site for IV drug users and their partners. They've seen well over 800 people at this point in time and one of the very positive things that we found early was that there was a very high compliance rate of clients coming back for their test results. About 80% of patients initially tested came back for their test results. One of the things that that did was encourage us to believe, as we had had experienced earlier on, that people who had a history of drug use were interested in maintaining their health and actively pursuing something to give them control over their health. From Project Trust, not only do we do anonymous counseling and testing, but we also do outreach including street outreach. The history of that is that city councilor Thomas Menino requested that the Department of
Health and Hospitals start a street outreach program to combat AIDS. He did this about three years ago. The department hired four street outreach workers. These outreach workers do street outreach within a two mile radius of Boston City Hospital, including Villa Victoria, Orchard Park, and a number of other housing developments. They also go to Roxbury District Court and visit people who are in holding, who are there for some drug related charge, to talk about treatment options, the importance of using bleach and condoms, and the importance of how terrible AIDS can be, how terrible AIDS is, how important it is not to get it.

k- What exactly do street outreach workers do?

The Multi-cultural AIDS Coalition is doing a great job of pulling people together to ask those very questions: what do street outreachers need, and can we evaluate what outreach workers are doing. There have been a number of evaluation tools that have been used. Based on our understanding of what street outreach is and what Project Trust does, people go out in groups of 2 or more and basically canvas people, randomly and openly, and talk to as many people as they can about AIDS. For example, they might come up to you and ask, "Do you know anything about AIDS?" and elicit responses and get people to engage in a conversation about AIDS and how important it is to know what it is. "Do you use drugs? And if you do use do you use clean works? If not why not? Have you ever heard of bleach? Here's a bottle of bleach. Have you ever used it before? Do you know how to use it? Let me show you how to use it. Would you use any pamphlets?"

One of the strategies is to talk to a lot of shopkeepers and shop owners in this particular area, one to two mile radius of Boston City Hospital. We've canvassed people to see if they will keep bleach on the counter to give to people for free. In effect, to make the shopkeeper, not responsible, but aware of how important clean works and safe sex information was to the people that they serve. Presumably many of these people we talk to could be drug users, either recreational, infrequent users, or regular users. Part of the strategy to go into housing projects is to target high risk areas for drug use. There's a real interest in talking to the adolescents in the projects and knocking on doors. There's often a community center, and we get to know the people in the community center as well as in tenants organizations within a housing development, for example.

One of the things that has been very important is to look at the staff make-up of Project Trust and the outreach team. It's a multi-cultural, multilingual team. Many or most are recovering addicts
themselves, and are well known in the area. When outreach workers walk around, they are often people known to the community. And if they are not known, then the more outreach they do the more they become known through word of mouth. They become identified as somebody to talk to with questions or problems or.... A trusted member of the institution who can walk into the community, living in both worlds. That's a very critical piece of why we think Project Trust has been successful. Again, street outreach is a very big area right now. Project WARN is an AIDS education/outreach project coordinated by Kattie Portis specifically looking at intervention with women and their partners. Multi-cultural AIDS Coalition is doing street outreach. There are many agencies at this point in time that are doing street outreach. I'd refer you to Tracy at Multi-cultural AIDS Coalition who's recently been trying to put together some coordination efforts to answer some of these questions.

k- What exactly is General Relief?

The Department of Welfare offers certain benefits including General Relief, SSI – Social Security Income, SSDI – Social Security Disability Income (the last two being of Medicaid actually). There's also AFDC – Aid for Dependent Children. And there are a number of state subsidy programs, particularly for AZT and or aerosolized pentamidine, which are another form of benefit you can receive without being on any of those. I'd refer you to somebody to explain the intricacies of GR and all of the others, because they have a lot to do with income. Obviously from state to state it differs. They look at assets, a whole series of things, how long you've been disabled, what your diagnosis is, for example.

k- What is respite care?

What we are looking at with AIDS is the need, for both adults and children who are requiring intensive amounts of care often at home, to assist and support the home caregiver. What we have tried to develop are respite programs to bring the patient into our care settings so that foster parents, parents, a lover or whatever caregiver can take a break, go on vacation, do whatever they need to do. Take two weeks off. Somehow support themselves so they can come back to take care of this intensively needy person. The respite care center that we run is the Children's AIDS Program. It offers both residential and respite facilities, long term and short term respite. For example, some of the children might have a mom in the hospital for two weeks and there's nobody
else to take care of the child, who's HIV+, who does not necessarily need acute care facilities, which is all we can offer, or a bed in the nursing home, pediatric nursing home. We will offer, if we are able to, a bed for that child for two weeks. Or in one situation, the father is taking care of three other children. The father of one of the children cannot take care of him, he can only care for the child say three nights a week. So that we are able and willing to provide care for that child the other four nights a week. It's a mechanism to try to keep families together by offering what we can.

Similarly, the more you get to know about foster care programs, foster parents also need some respite. It becomes extremely difficult to ask for that very intensive and draining care without any relief. We have tried to build that in at least with the pediatric population as much as we can through the Children’s AIDS Program. We have spent a lot of time lobbying for this particular activity because we’ve been notified over and over again that this is something that foster parents and biological parents need. There’s a tremendous amount of violence in some of the families we serve. We have dealt with that over and over again in the CAP program. And when a family member dies it is often difficult to ask the primary caretaker in the family who is dealing with the funeral, the death or incident, etc., not to mention the emotional impact of that, to take care of a very needy child as well.

k- So it mostly centers around taking care of the children?

As of now for Department of Health and Hospitals it does. We don’t have the facilities, other than in acute care facilities, to do that for adults. There are two day health programs that are being developed in Boston. One is Seton Hall and the other is Lemuel Shattuck who are developing adult day care. Very similar idea - daycare respite - to offer some therapeutic measures during the day, but generally we’d like to see it as a mechanism to help primary caregivers continue keeping the patient at home, which is ultimately the best way we’d like to see patients being cared for.

k- Some people have mentioned that there is nothing like AAC to address women, being often poor and of color, but that MAC is trying to put something together. How do you see that role....

That's a very complicated question. When you say "like AAC", AAC is a huge, very complicated organization doing many different tasks. They are performing education, they're performing community based education, corporate based education. All sorts of coordination efforts
to make brochures from all over the country available. They are doing a tremendous amount of policy and legal work, legal access for patients and lobbying in the area of access to housing for the clients and many other things. They have a very large client services department, offering Buddy services, shopping services, the other things buddies do. So it's vast. Multi-cultural AIDS Coalition is going into it's second year of existence. AIDS Action has a staff of over 70 and a volunteer base of about 1300. Multi-cultural AIDS Coalition has a staff of about 6 or 7 at this point, maybe 5. They (MAC) are really in the process of defining, as best as I can understand it, exactly what their services are going to be over the next, probably short term, rather than projecting out, I don't know what their long term goals are at this point in time.

I think there's no question that people in the city of Boston are extremely glad that the Multi-cultural AIDS Coalition has formed. And there's been a long development period of Multi-cultural AIDS Coalition as well, not just the two years that it's been in existence, but it's very important to look at the amount of time and commitment and ethnicities that came together to support Multi-cultural AIDS Coalition forming. To compare one with the other at this point in time is extremely difficult to do. Clearly Multi-cultural AIDS Coalition can't offer the client services or.... It's very hard to compare them, and I'm uncomfortable comparing them. What I do want to say is that I'm very encouraged that both of those agencies and many other agencies are trying to work closely together to figure out how to incorporate Multi-cultural AIDS Coalition. To figure out what services AAC doesn't do very well, or could do a lot better, and what services other agencies could do to replicate some of the positive things we have found out about what AAC has done. In addition AIDS Action services can't accomplish what Multi-cultural AIDS Coalition can accomplish for certain populations.

k- How does it work better in these populations do you think?

One of the things I like to remind people is that although AIDS Action did come out of a history, there's a history of gay white men forming that organization, AAC are very clear to say that they perform services for all people with AIDS. And if you look at their numbers, about 30% of the clients they serve are people of color. That's something that usually gets put on the back burner as if it doesn't matter. That's not to say that it isn't extremely important for people of color to develop services for people of color – that is African-Americans, Latinos, Puerto Ricans within the Latino branch, Cubans, South Americans, American Indians, Haitians, people from Cape Verde, Portuguese people, a lot of
people who do come under the rubric of some of the reasons the Multi-cultural AIDS Coalition formed. It's still extremely important for these populations, individually and collectively, to come up with mechanisms that will better serve those populations, in close cooperation with the Department of Public Health and Department of Health and Hospitals and other major funding services like AmFAR, NIH, CDC, who have been offering funding directly to community based agencies.

What we are trying to do is facilitate the evolution of Multi-cultural AIDS Coalition coming together and deciding what it is their area is to be. Clearly at this point in time, if they are getting a call saying, "I need housing right now," what Multi-cultural AIDS Coalition has been able to do is, unfortunately, be in the position of advocating for patients who don't feel that they can get the services they need, because they can't advocate for themselves. Sometimes that has been based on racial issues, oftentimes that's been based on racial issues, or that's the way it's been presented by the client. I think we have to do two things. One is make sure that Multi-cultural AIDS Coalition can deliver the services that they choose to deliver, and at this point it is unclear to me whether that is client services. For example, it is unclear whether communities of color can participate in a buddy system and gigantic volunteer system generally the way that AIDS Action has mobilized its resources. And the gay community has come forward as the bulwark of that volunteer force. It's very unclear if we can replicate that model in communities of color, in fact I think it's very unlikely. So we are not looking at replicating the same model necessarily, but figuring out what models work. At this point in time I think there are a lot of efforts to see what does work. One of the ways the Multi-cultural AIDS Coalition would like to proceed with that as far as I understand it is to offer grant awards of their own. That's one of their areas of interest. AIDS Action also does that as one of its activities.

It's a round-about way of answering your question, but it's like comparing apples and oranges at this point in time. One of the things that is so irritating is that people tend to compare them as if they are roughly similar, or could have the potential to be roughly similar. There's no question that they have similarities in their abilities. Wayne Wright has demonstrated exceptional leadership in an exceedingly short time. There's tremendous potential and the development of Multi-cultural AIDS Coalition with a very strong board of directors, to effect funding resources, legislation efforts, statewide, nationwide, citywide policy issues. Some of the things that AIDS Action has done very successfully I see the Multi-cultural AIDS Coalition doing very quickly, and with those things they are right on track with every bit of that.
When it comes to actually providing services though, we are talking about very different organizations in their development.

k- One of the differences I see is that when you walk in the door at AAC you can get your case manager and all of your resources are right there or readily referable. And in other communities that's not so true – you need to dig around to find out where to go.

I think that's partly true. With the development of the Latino Health Network, for example, not that they provide case management, but there is a staff at Latino Health Network. The Haitian Multiservice Center has been a tremendously successful case manager for patients with AIDS and families with AIDS. A number of neighborhood health centers have provided excellent services for people with AIDS: Dimock, Martha Eliot, Codman Square to some extent. It's not as simple as one place, as you say. But it's also true that the client advocates at AIDS Action average a case load of 80-90 individuals at this time. So that while once the numbers were much smaller than that, at this point in time they are concerned that they will not be able to offer the services that they once could, or that they will have to cap the numbers. Similarly, Multi-cultural AIDS Coalition is coming to terms with whether or not they will ever provide case management or they will be able to provide that kind of service at some point. At this point, as I understand it, they are concentrating on education efforts – multilayered educational efforts. They have hired a research coordinator.

[end interview]
Appendix F

March 14, 1990

Interview with a resource developer around mental health and former worker in women's substance abuse program.

[begin interview]

I can talk generally about my experience in helping to run a women's substance abuse program, and some of the issues that come up there, but I can't give you specific client information.

k- The first thing that I am interested in is AIDS Action in general: what it's providing in general and specifically for women.

There's a client advocate clinic services department that does a lot of different client centered work. They have a lot of volunteers that serve as buddies for people, who's basically a friend and provides informal emotional support. And the advocates are staff people who play more of a case management role. They help people with information and getting hooked up with a variety of services they need. So there's someone who's a specialist in the financial end of it, there is someone who specializes in substance abuse kinds of things, there's someone who... we have two residences that are run by AIDS Action. There's also other kinds of work done in terms of housing; helping people get vouchers, helping them sign up for some of the programs that do exist for people with AIDS. There is also a support group program which is coordinated by a staff, but the support groups themselves are run by volunteers. So there are about 30 volunteers that run about 15 groups, which really go the gamut from, I think, a HIV+ group.... Most of the clients that are seen here are people with a diagnosis with AIDS or ARC, and the line has had to be drawn there, given the limited resources, and there are not a lot of services in general and certainly not here for people who are HIV+ and asymptomatic. So there are support groups, bereavement groups, and there are groups for people who are long time survivors of AIDS. There are groups for people who are addicts in addition to having AIDS. There is a women's group. My sense is that relatively few women are clients of AIDS Action, either in the support groups or here for the advocate services. There is also a large department in AIDS Action that is policy, education, and planning. That's what I'm in. That's where a lot of the community education and resource development gets done. My role is resource development
around mental health. There's a long term care developer, a housing developer, there are policy people trying to effect legislation and other kinds of policies having to do with AIDS. And then a large department of people who do the community education. There's Wanda Allen, who you met yesterday, who is the women's educator. There's a gay male educator. There's a Latino man who does resource development and education. There's a Black man who does Black education and resource development. So at this point it's fairly specific to the needs of the communities.

k- How do people get referred here?

People just decide on their own. It's not a place where you need a formal referral. Somebody can just call up. There's been some restructuring here so there's now something called an access team, so when someone calls they speak to an advocate on call. That advocate will make a determination about what kind of a question it is or what kind of concern it is: "Does this person need an advocate, or is it just a financial question, is it just a housing question, is it a crisis?" There's also the hotline here that gets thousands of calls every month for information.

k- Once a person gets hooked up here are they generally set as far as help in getting all of their needs addressed?

I think they are much more supported than people that are not hooked up to an organization such as this. But given the limits on the growth of AIDS Action as an organization and the changes in the size of the epidemic, case loads are pretty big. So that I'm sure there are people who don't get all of what they need because of that.

k- Why do you think there are so few women clients coming in here?

Well, I'm sure that has a lot to do with both the perception of this as a gay white male organization and the reality that most of the clients still fit that description. This is an organization that was started when a few friends got together because of what they saw happening to their friends and lovers. And it was gay men that started it. And for a while that was who was part of this epidemic. As the face of the epidemic has changed, AIDS Action has been trying to respond to that, and I think with more or less success depending upon who's view it is and what's being done. I think that it is definitely a factor in keeping women away and certain communities of color, although there are more people of
color coming here and there are a substantial number of substance abusers who come here. So I think that it is changing, it's certainly not all white middle-class gay men anymore, but I think it takes a while for perception to change. The other thing I think, is that as an organization it has not made a full commitment to doing what you need to do to serve women. I think there needs to be concerted outreach to do education, so that women do see this more as an issue for themselves. There needs to be more specialized services for women, more women only groups. I think if there were more daycare options that it would be more possible for women with young children to participate. And that doesn't really happen here. I guess what I am saying is that it is not only the perception, it's that the organization has not taken this on as a priority. Part of it is that if you look at the numbers women still make up a relatively small percentage in terms of actual women with AIDS, but there are a lot more women who are HIV+, there are a lot more women who have AIDS where it never gets documented as AIDS because they die first or because they have symptoms that don't fit the CDC definition, because their opportunistic infections aren't necessarily the same opportunistic infections that men are getting. And I also think that an area that needs to be looked at for women in general, and not just at AIDS Action, is that so many women are involved in this epidemic as caregivers and as partners. So it's not just the women themselves that have HIV disease.

k- What are the projects at AIDS Action that are specifically for women?

There is a support group or two and there's Wanda Allen who does education around women. As far as I know there's nothing else geared specifically for women.

k- You used to work at a substance abuse clinic?

The Women's Alcoholism Program of CASPAR, which has outpatient services and two residential programs; residence for pregnant substance abusing women and their newborns. And then a place for just adult women without children. I guess part of what I saw as far as having more contact and more understanding of what was going on in terms of women and HIV is just how really complex it really is, and this is true for everyone. A lot of what women need help with is learning to feel better about themselves and to have more self esteem and be more assertive in their relationships and to be in relationships where they are not fearful of either physical or verbal abuse. Because just talking
about safer sex and just talking about transmission issues or prevention issues or whatever — it's really getting on to over here, when what you need to be dealing with is over here. Because they can't implement information about safer sex if they are in very unhealthy relationships or fearful about what might happen, or if they don't even feel good enough about themselves to care enough that they might become ill. So what it feels like what a lot of women need to begin with is to just be working on those kinds of issues for themselves, in supportive environments where that is possible.

k- I'd like to know some of the issues that might be specific to women involved in substance abuse around HIV: getting resources....

I think what Wanda was saying yesterday is definitely true, at least for the women who are poor and working class, white women and women of color. When you talk about HIV you can't talk about that as apart from all of the other elements in these women's lives. And that there are a long list of concerns that really come before the HIV. There's the substance abuse, there's the concern about money, there's the concern about violence, there's the concern about children, there's a general, you know, what it means to be poor in this country: a lack of access to treatment, to decent treatment, knowing what your rights are, knowing where to get it, to get it from somebody who is respectful and then there are all the reproductive issues, which are a primary concern. In terms of this resource guide I think it will be very good for women and for care providers to have that available as part of more education that women need, because to even be able to take advantage of that they need to know that they need to.

k- Could you talk about your experiences at the clinic with women?

I ran a group for ten years for substance abusing women, but I stopped doing that in about 1983 or '84 at a point when the epidemic was very different. The central motivating force for everything when you are a substance abuser is your substance of choice, whether that is a drug you do intravenously or whether it's alcohol or pills or whatever it is. That's what they are driven by. So people do all sorts of things that they wouldn't do if they weren't under the influence. So their lives become very much disrupted and filled with problems that come as a result of the abuse of the substance. And a lot of people don't know that that's the central issue; a lot of people think that if things got better, if my relationship were better, if my kids didn't give me trouble, if I had a job, if whatever, then I wouldn't have to use anymore. But, in fact,
there are problems of course that predate the use of alcohol or drugs, but that a lot of that comes as a consequence, and until somebody gets clean and gets sober, they can't make the kinds of changes in their life that they need to make. So what people need, what women need, is support to do that. They need to learn to live alcohol and drug free. And to know that there's help for them to do that, and that their lives can get better when they get clean and sober. For some people with HIV it's a motivating force to make whatever years, months they have left better quality. And for some people they can't tolerate the pain, either the psychic or physical pain of the disease, so for them they keep on using. And they will die high.

k- Another interviewee mentioned that if a drug user wants to get tested, they get counseled to look closely at their reasons in case it is as an excuse to keep using.

Right. Everybody that is considering the test really needs to explore what their reasoning is for doing it and how they will cope with the results. But the recommendation in most substance abuse programs is for people to not get tested in the first six months to a year of sobriety. That they are just not equipped to handle that information.

k- It also seems that in the drug using community it is difficult for people to get to appointments. How can you see resources and services accommodating that better?

Well there are some places that have a drop in model. I don't really know. The women's program, we used to have one drop in group a week that could accommodate people who were still active, but they couldn't come under the influence. Mostly our services were by appointment, outpatient care, and a lot of people were able to do it. But, those people were for the most part not active. We had a no-show rate of about 25%. I don't know how that compares to people coming for other kinds of appointments.

k- What women do you see as not being hooked up with any services and why?

My guess is that many women are not taking advantage of.... Part of it is that they are just not paying attention to their health and what's happening with them. They are much more caught up in caretaking for children, caretaking for other family members, partners. Working, feeding, doing all those kinds of things, they are the last one they are
thinking about. It's partly that, it's partly a lack of education, so that they don't even know enough to worry about this for themselves. The other piece is that I think the programs need to be more proactive in terms of reaching the women any way they can. A piece of that I mentioned earlier is that specialized services need to be set up, with women in mind and recognizing that women are not generally going to come to groups with men to talk about issues around sexuality and some of the other risk factors for HIV.

k- In order to set up a model to bring in women what do you see the services needing to do?

I think partly it needs to be done within people's community, although I also know that it is important to have choices and options so that if someone feels that they don't have anonymity going to their neighborhood health center then they can go somewhere else. But it needs to be in a more comfortable place. If you aren't comfortable going to a hospital in a different community then you're just not going to do it. You're not going to come to this area to come to AIDS Action if this is not a neighborhood you feel comfortable coming to. And I think that it's best if women have a choice in providers, if someone is more comfortable with a woman. And also I think the daycare. There's a group at Martha Eliot Health Center for Latino women. I assume it's still running. What they have done is they provide food and transportation, they pick the women up, they take them home, and they do child care.

k- Is that Entre Amigas?

Yes. Does that have enough women in it to still go?

k- It's going as far as I know.

[interview interrupted]

k- It seems that AIDS Action depends a lot on its volunteers. How much of the work force is volunteers?

I just heard last week 1600 people are volunteers, so yes they make an enormous contribution here.

k- What is their make up?
I think it's really a range of people. Unlike probably a lot of other places that get volunteers, because of the nature of the epidemic and because of who AIDS Action has historically been, a lot of men volunteer, but there are also a lot of women that volunteer. They do a whole range of things from educators and they help with fundraising and development, some very skilled people. A lot of mental health people volunteer. Then there's the Buddy program, maybe a few hundred, I'm not sure. There are also people who volunteer to help with copying, answering phones, doing mailings. There's a lot of volume of work that goes on here. There's 75 full-time staff. And just a lot of work gets generated, and there's not a lot of administrative back-up here, so volunteers are used to doing a lot of that.

k- What is their educational, racial, ethnic, etc. backgrounds?

I met with the volunteer coordinators a week or two ago and they didn't yet have that information compiled, but I think they have a lot of it in the computer. If you wanted to look at it, I could give you the extension.

[end interview]
Appendix G

March 14, 1990

Interview with AIDS educator and facilitator of support groups for people who are HIV+.

[begin interview]

k- Could you first tell me what your role is here and who you work with as far as clients?

I'm the AIDS coordinator here. I provide AIDS education and I facilitate support groups for women and coed programs for people who are HIV+ or whose significant other is HIV+, or their children are. I do community AIDS education where ever I am requested in the Mattapan, Dorchester and Boston area.

k- Could you tell me what Dimock provides as far as services in general and services specifically for HIV+ women?

Well generally we provide, we have a medical health center, which provides dental, gyn, an eye clinic, pediatric clinic. It's a pretty comprehensive medical program. We also have a substance abuse program: outpatient substance abuse, detox center, halfway house for men. That's all on campus. We rent out a lot of our buildings to other human service providers like DSS, Metco, Afrik, which is a new program in the communities of color that really works with the family from a comprehensive perspective which means whatever services the family needs, they go out and try to connect it for them. Anything directly related to keeping the family together; that could mean mental health, that could be financial, that could be housing, whatever one might need in order to keep the family together. I'm sure I'm missing a lot. You can look at the listing. There are lots and lots of services.

In terms of what's directly AIDS related, we have an ATS, we have a number of support groups. Like I said we have support groups for women, for men, and for Latino women and men. We have a support group for Black lesbians. We have a group that deals with substance abuse and HIV. We have a peer AIDS education group. We have a substance AIDS group which basically provides testing on site to people that might be in a drug treatment program, and also AIDS education and counseling for people who might be in a treatment facility at this time. We have a BRP program, which is the Behavior
Research Program, that is funded by the CDC. It offers five sessions of information around nutrition, around clinical studies, around whatever emotional support one might need, identifying whatever kind of AIDS services are in the community that the client might be coming from. And it's really targeted for people who have recently found out that they are HIV+ and just need immediate support to help them get through that crisis period, and then plug them into whatever appropriate services they might need, like long term counseling or long term support group, either here in Dimock or wherever else they choose to go.

k- I've heard of the BRP sessions and I've heard that they are being changed to be more geared towards communities of color. Have they been working for this community, or are there problems?

It's the same old thing. It's a matter of letting people know. The reality is that the way many minorities find out about their HIV status is pretty inappropriate at the time, so they need to go home and decipher and respond to the crisis on an independent level. So the idea of the project was to get people as soon as they find out about their HIV status, but what we are finding is that we are getting people two or three months down the line. They come out and seek some support. What we are trying to do is connect with the hospitals and ATS and anywhere where someone might recently get that information and then try to be right there to pick them up so they don't fall through the cracks for those matter of months. Other than that it is working. We are getting participants, we are beginning to get people from the detox centers, people from the ATS in our community. A lot of word of mouth is happening. So it is beginning to work. What one needs to remember is that even though we are people of color, we vary. And so what is working for Dimock and the population that utilizes Dimock might not work in another community. For instance, the other mental health center doing the same BRP has decided to focus on women and their project is totally different, but it's still providing the same information, but the curriculum has to be developed depending on the population. What I think is great about the BRP program is that we are given the opportunity to develop what is appropriate for our community. And I think that's what needs to happen across the board.

k- You said that often people are finding out in inappropriate ways about their HIV status. Could you elaborate?
People of color are not very trusting of the hospital and medical profession in general, so number one you don't go to the hospital or to a clinic unless you have really tried all other alternatives, like the home remedy or some sort of pain killer thinking that that will work. When that doesn't work basically you go into the hospital through the emergency ward with a particular ailment. Once you get in there and complications arise then you are usually tested at that point. So along with finding out whatever the crisis was, you also are informed at that point in time that you are HIV+. The other thing that happens is that most people are not given pre- and post-test counseling in that situation. So they are given that information, maybe somebody from the infectious diseases comes and does a quick little inventory, or a little questionnaire, but you really don't get the emotional support that one might need when you get that devastating information, it just doesn't happen. So usually what happens is that the ailment that you came for is addressed. You might be given a number to call somebody, you might not be, because basically you are healthy at that point, it doesn't seem to be a big issue, if you are not truly truly sick. So you are given that information, you go home with it, you sit there with it. You sit with it for 3, 6, 7 months or longer. And what Dimock was finding was that a lot of people are coming back into our medical system prepared to die, because they got the information, didn't get any support around it, and now by the time they are very sick they come to the hospital hoping their medical problems will be addressed. Usually at that point they have full-blown AIDS and they are really sick and the bottom line is that the people in the AIDS department and the medical providers are now really just preparing one to die. You get kind of sick of that and decide to try to do something to prevent and get to it before that. The other way that people tend to find out that they are positive is they come in on an o.d. — overdose — within the medical facility. One of the positive ways people tend to find out is if they are going through recovery or come from a treatment program or a substance abuse program. They begin to become responsible and one of the things that they do is take care of their medical problems. So we discover at that point. Those people don't seem so devastated because they have established some sort of foundation in terms of support. The people I'm really concerned about are the people that find out going through the emergency room, and that seems to be a large population of people of color.

k- Where are some services for HIV+ women that you know of that are working well?
A lot of them are new programs, so I don't know how successful they are, but they are getting participants, I guess that's a success in itself. One of the projects that I could talk about is the MOMs Project out of BCH. That seems to be one that's working very well. Some of the other ones that are working very well are set up in already established programs for women, for example Women, Inc. plugged in some AIDS services. Boston Pediatrics Program at Dimock is working well, it's working well because it has done exactly that, it has gone out and provided services on site to a captured audience of women. Those kinds of projects are working well. I don't know too many other ones that are just providing services.... BCH seems to be doing a very good job in their women's center and Project Trust.

k- Why do you think it works so much better from within an established women's group....

Because there's already an established support system there. You are just adding more information and support and helping them address another issue within the community that needs to be addressed. If you go out into a population that has no other support systems, this kind of AIDS education and AIDS information touches on a lot of insecurities and a lot of issues that people generally feel very uncomfortable about. So we are talking about, when you go in and talk about AIDS 101 or you talk about how one needs to protect oneself, you are stepping on really private ground. And you have to consider just what kind of support systems are available for those individual women. When you are talking about what they need to do you are trying to empower them, but it's really hard to empower someone when they don't know where they are going to get their next meal from. So there are a lot of things to consider. That's why working within an established group, some group that already has some sort of support systems going, or coming in with a full, comprehensive AIDS program that will address all those issues that women need are probably the best approaches to the goal of trying to provide AIDS education or any AIDS services at all.

k- What are some needs you are not seeing met?

What I've just described, a full comprehensive program that really addresses everything you need to be concerned with when dealing with women. When you deal with women you deal with children, when you deal with women you deal with significant others. You deal with many times them being the head of the household. They may be the lead person in the family system, even in the extended family. So now you
are talking about talking to someone who already has so much pressure on them that to add more pressures on them about the realities of either them being sick or potentially at risk, just is like too much for them to handle.

k- Can you talk a little about what you are seeing in the support groups with these women?

They are women that are really struggling to survive. They are women that have been battered around not only by people that are close to them in relationships, they have been battered around by institutions. They are people that are scared, that want to do the best thing, but may not know how or know the mechanisms to do that. They're women with lots of issues, HIV just being one; "Where do I get work, how do I take care of myself, who's going to take care of my children, do I live or do I die, do I want to?" That's really where they come from. They are people full of hope. People that believe the best will come. They are strong people that sometimes aren't really in touch with how strong they really are. And they need a safe, understanding place to be able to work out those issues. A lot of times all you have to do is provide that place and provide it on a consistent basis, and let them do the work, most of the time that's the way it is. If anything I think what is really needed is a comprehensive program that follows women all the way through the process of what's going on, from being labeled as being high risk to really helping them develop and identify whatever their needs are and helping them learn to advocate for themselves. And that one should not have to be sick to have these services available. There are lots of services available for people who are sick, who fit under particular criteria. If we are talking about making a difference then we need to make a difference much earlier in this virus; we need to make a difference when somebody is HIV+; we need to make a difference when we identify somebody as at risk. We don't need to wait until they are sick and then plug them into all sorts of services, it needs to happen long before that. The intervention process needs to happen as soon as possible.

k- I have heard that there is a lot of money out there for education and not so much for treatment....

I think that education is important. I wouldn't say there's too much money out there for education, but there's not enough out there for treatment, I'd agree with that.
[interview interrupted]

k- Not too much, but that people seem more willing to address prevention than people who are actually sick because they are already....

...dying. I agree. I think that there needs to be more money out there. Yet people are willing to deal with that part if they are willing to deal with it at all – the education part. More so than with some of the medical problems that come up. I agree. There's more money that needs to be put out across the board. I feel like there just aren't enough programs for people who are infected and who are sick. But if you do early intervention and provide the education and support systems one might need when they become HIV+, at that point in time, then one will be able then to advocate for themselves for whatever services are available or then to advocate on a political level with people to the powers that be on what they do need. But if you don't empower them earlier on, no matter what services are available they are not going to utilize them. I think one goes with the other.

k- You said that you think we need a comprehensive system to follow women all the way through. How do you see that being set up and reaching the women it needs to reach?

When I say comprehensive, coming from a community where we have always had to go from the grassroots approach, what I mean is you begin to truly truly network and you look at the kinds of services in the community already being provided and you incorporate what else you need in order to address this virus, so it is not always a separate entity. Because the reality is that that's just not going to happen, and even if it does happen somewhere it's not going to happen within the communities of color, because it has never happened with any other issue, so it's not going to happen with this one. So the reality is for the people working in the community that come from communities of color, what you need to really think about doing is utilizing everything that is already existing and incorporating whatever you need in terms of AIDS related services. And that's what you need to look at. To think about going out and establishing a separate hospice that is not connected with any other existing establishment is not realistic. First of all you are not going to get the money from the powers to be in order to do that. So what one needs to look at is utilizing what's already in the system and try to build on that. Because I truly believe we do not have a lot of time to start all over again, we really need to address it. Maybe there
can be two-fold kind of goals: one where you begin to incorporate now and two where you begin to think long term. For me, dealing with people on a daily basis, that is where we need to go right now.

k- Do you see health centers in the community open to incorporating this?

Some. And some not. But I feel like they are not going to have much of a choice. I feel like they don't have much of a choice now. They are getting clients. They do have to address them, they can't continue shipping them to Dimock or to AA or something. They have to begin to deal with them, and in that I see a response to them in terms of getting AIDS coordinators and AIDS educators. I see that move happening more now than ever before. I think it's a response to the population's demand that they are there, they are existing, and you just can't keep sending them to BCH, because it's overworked. So I think that out of need of the community the health centers are responding, whether they are responding with an attitude of not really wanting to is irrelevant. The fact is that they have no choice.

k- Why do you think they have not been responding before?

I think for a lot of different things. We are talking about people that are already overworked, that are already dealing with stuff beyond what their job is. I think that a lot of people have been assuming that somebody else would be doing that kind of work. Afraid of being identified as a community health center that services AIDS patients, therefore losing their other population. Not realizing, because they weren't getting self-identified or identified with people who were getting infected, that maybe those people weren't in their community or in the population that they were serving. I find that a bit naive, but it's very possible; "We don't have any AIDS patients, they aren't coming here." The bottom line is, you aren't providing any services, so why would they do a disclosure with you to let you know that they are infected. What do you do with somebody who is infected? The bottom line: Boston City Hospital, Dimock Community Health Center, if they are a person of color, those seem to be the two designated places. What's beginning to happen is funding is coming in and along with those grants are particular responsibilities addressing AIDS services. The medical health centers are responding to that. Which is great.

k- What are these grants?
There are a number coming out, that are out, that people are responding to, that say: AIDS education, AIDS health educator, AIDS social worker, or someone that is going to be identified to deal with this population. That means now that they will be able to have a body designated to provide the services. Because like I said, many of the community health centers are already overworked, are short staffed, and then to ask them to take on this piece too is a lot. So with the idea of money coming into the health centers to hire more people to do this kind of work, I believe that it's another way that it's beginning to happen.

k- Another interviewee said they saw a pamphlet in your office about a low cost AZT program, to provide AZT to people without money.

I don't know where it is. I have lots of brochures, but I can't recall one like that. I know that there are places that are willing to respond to what you might need, with as little money as possible. Dimock is one of those places. We will not turn anyone away because they don't have medical insurance. In all honesty I don't know how long one can afford to do that, it's just not realistic. I do know that the Boston Pediatrics Program, which is that blue brochure, covers a lot of services in terms of what you might need and therefore will probably pay for your AZT until you are either put on Medicaid or something that will be able to cover it. Normally that's how things are done. You get plugged into a program that will then cover your expenses until you are able to get disability or Medicaid, or whatever one might need in order to do long term medical services.

k- At a recent BAC meeting it came up that 51as are sometimes filed on babies born who are HIV+....

People are afraid of that. That's why I was talking earlier about people not jumping in to go to the hospitals, because the hospitals are one of the major ways 51as are filed. Say for instance if a baby is born and they have the obligation to file a 51a, then DSS gets involved and all kinds of things begin to happen. And we, meaning this community, has not had a great experience with DSS in terms of being a support system, it seems to be more a type of agency that comes in and intercedes and pulls the family apart without considering other dynamics of what might be best for the family. So those are some of the issues one would have to address when you are talking to women about being infected. It's also why they are so afraid of that, because they might not only be infected, but they might be substance abusers. And they might be trying to get their life together but if the powers that be find out that
information, instead of being supportive they seem to come in and interfere with the process. I understand that their responsibility is to the children, but it seems to me that their process is a bit insensitive, without really considering all the positives of what the situation might be for the children in the family. The assumption is that if someone is HIV+, they are either sick, incapable, or negative. Negative means in terms of behavior, and not really the best kind of parent one might need. And that is not always the case. That’s not always the case. But it is an automatic thing where 51as are filed and it is a major fear of people.

k- Are there other real specific threats that are felt?

Being chastised by either their information or status being gotten out into the community they live in. Not being treated in the best manner by the medical providers. Seeming to be judged in general by being seen coming into the AIDS office, or by being seen with the AIDS lady because she’s an AIDS educator and therefore... you know, you must have AIDS. The other issues are: what are some of the particular problems that go along with this individual that you are trying to help, and that you must encompass them all. It's real hard for me to talk to a woman about implementing safer sex when her significant other who is a substance abuser who tends to be violent, they don't know where they are going to be living next week, they don't know where they are going to get any food, welfare has cut them off because she didn't get down there in time to sign the evaluation papers in order to continue getting her welfare, her daycare is not being paid for, the kid is not in daycare. So there are a lot of things that one has to look at, although there are a lot of commonalities, and those are the ones I've mentioned, there are individual situations that come up with each client, and one needs to be prepared and have an individual there that can walk someone through this stuff. You can provide all of those services to the best of your ability, but if you don't have somebody to walk them through that process, because they've never learned to do that, those services will never get utilized. You can still have a very good program, a very comprehensive program, but you also need an individual for the client to buy into, because they do not buy into agencies or programs. What we buy into is an individual, we trust that individual, so therefore we will follow through on what that individual suggests we do. If you just offer a program with a various amount of people I have to deal with I'm liable to not follow through, so that's a really key piece.
k- Do you see a lot of programs and agencies trying to provide that individual....

Well, that's a luxury that many agencies just don't have, especially agencies in the community of color. We just really don't have that. We probably are doing 2 or 3 or 4 jobs beyond the job description given to us when we came in. It just ends up being that way. Myself as an example, I came in to be an AIDS educator, I am a group facilitator now, beyond my AIDS 101 I do, I have a client load.... And all of that comes from doing the education. That's what I'm saying, people buy into individuals. Therefore I go out and do my AIDS 101, people buy into me and stick with me even though I may refer them to another agency or a place that can provide them with particular services, they still need to stick with me for a while. I need to be the place they come and complain to because so and so wasn't there when I sent them there, or they didn't like the way the service was, or that building was just too far down town. I still need to be the person, for an appropriate amount of time, maybe 2 or 3 months, I'm still the person they come bounce stuff off of. And now what could happen is as I do my AIDS education, if they buy into me, if I had an individual that was also a part of what I was doing that I could transfer this person to immediately, that would alleviate a lot of the work, but it doesn't really happen that way. Transferring from one agency to another agency, or transferring from one individual to another individual just does not happen quickly, so it's real hard to do that piece, and it's almost impossible to get enough money to hire enough people to do that stuff. So you end up doing a lot of jobs that you would not have considered doing, or would know that needed to be done, but it becomes incorporated in your job.

You are talking about people who need everything. It's not like I can call one agency and get all of that work done. There will be a number of agencies that I'll have to call, a number of individuals I'll have to call, and they'll have to return my calls back, and then I'll have to find what the criteria is that the client would need to go down there and get that service. And then I'll probably have to do all of those phone calls over again to find out what's holding up the service. It can get really into detail, and the worst part about this is that there is no agency that will do all of this work. There are some agencies that will do this work once the person is really sick and bedridden, but why wait until that point when you can begin to plug the person into what they need now, so that when they are sick the focus can be on taking care of their health rather than that while they are exhausted and too sick to get out of bed, but they still need food and there's nobody to bring food to them. They still have to worry about who's going to take care of
their kids, because it's not a piece that they were able to be prepared for. And if they end up not getting sick, that's great, at least they have this information and they've learned to empower themselves, they still have identified the needs that need to be addressed, and their children can still be taken care of. So either way you don't lose, but at least they've begun to learn how to empower themselves.

k- Do you see a really successful way of empowering people to get through this?

It's a long term process, and it encompasses more than just AIDS. It encompasses cultural sensitivity, women's issues, sometimes it encompasses simple things like doing a resume. It's such a broad spectrum of things, that's why I say a comprehensive place or a place that's already doing some of the pieces that you know are related to the individual that might have the virus. I think that the whole thing we need to understand is that we are not dealing with people with one problem. We are dealing with people that have lived a while and have a number of other problems. And we need to stop treating them like this is a separate thing, and like this is all that is existing. People don't live that way, at least people of color don't live that way, things are not separate like that. Everything is very much encompassed in what is going on and we service providers need to stop thinking of providing a particular service, because that's really just not the way it goes. It just isn't. We need to look at the multiservice kind of model, where everything is available to the best of one's ability, or agencies ability, of what one might generally need, whether they are HIV+ or not. And go from that. It's just not a separate thing.

k- Is there anything else you'd like to add?

No, except I'd like to see your final paper. I'd like to get a copy. I just think if we are to really make a difference we need to stop looking at limitations. We need to be a lot more creative in our approaches. We need to understand that there is no one particular method to do this. We are dealing with lots and lots of different kinds of people, so we need lots and lots of methods to get this information out. Like there is no one particular way to do this, we need to keep that in mind. We also need to begin to look at a volume of services that are encompassed or incorporated with a lot of other things. We cannot keep doing this like it's a separate entity, because it isn't.

[end interview]
Appendix H

March 20, 1990

Interview with an HIV+ woman.

[begin interview]

There really aren't any resources that I know of, and I think this
disease effects women differently than it does men. They don't know
anything about that. The only information I've gotten is that there's
been a couple of women's HIV support groups where they can compare
notes. Other than that there aren't any women's resources. I think the
biggest mistake you can make is giving a resource sheet to women and
then when they get there people don't know what they are doing.
That's a real injustice. There's nothing worse, because there is so much
stigma with this disease. Like 25 years ago it used to be the big "C",
cancer. There's such a big stigma with this disease that to send you
off.... I work in a private hospital, I know how doctors and nurses feel
about this disease. And 70% of them don't want to come close to people
like me. I've heard what they say, because they don't know that I'm
HIV+. They don't want to have anything to do with it, so it would be a
big injustice to send a woman out to a clinic when they don't have
anyone there that knows what they are doing.

k- So you don't know of any clinics? Like Dimock has done a lot...

Well, Dimock is over in the Black section, so I don't have any reason to
 go over there. I don't think that this disease effects just Black women.
 As far as resources I know in the North Shore, there's AIDS Action, but
 specifically for women, not that I know of.

k- Have you been dealing with AIDS Action a lot?

I really don't have any need to deal with them. I have an advocate
there in case I want to tap into some of their holistic healing. At this
point financially I don't have any reason to tap into them. I think they
do a good job, but it's definitely a gay organization. So for heterosexual
women, like myself, we have been set over here. I mean most of the
people that work at AIDS Action are gay and that's where their politics
are. So heterosexual women are left over here someplace.

k- Could you give a little background about yourself?

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I'm a white woman. I'm 42 1/2 years old. I've been in and out of a long term relationship, currently in. I'm one of ten children. I'm in recovery from alcohol and drug addiction for 6 years.

k- What did you know about AIDS and the virus before you were HIV+?

Only what I read in the newspapers, that if you got it you were dead.

k- Who did you learn....

I knew I had lived a high risk lifestyle and I felt it was my responsibility to find out, and so I went to a doctor I had been seeing at Mass General. He tested me anonymously. He called me up on the telephone. He said, "You are positive." I said, "What do I do?" He said, "I don't know." I think my experience is very typical. A lot of people.... It's changed a lot. Like I said, when I found out in '87 it was a death sentence. We are now talking about it as a chronic disease. So, it's changed a lot. That's why the suicide rate was so high. People would get tested. The doctor would say they are positive and "I don't know." If I hadn't been educated; if I hadn't been working in the human services field; if I wasn't an aggressive assertive woman, I would have been shit out of luck. But I did a little bit of research. I found a doctor through my therapist that gave me my first message of hope, and that was John Mazzulo.

k- So what have you found as far as medical care?

Well, I went on AZT. What I did was what I'd advise anyone to do which is keep it off your medical insurance record until you get disability insurance in place and a $100,000 life insurance policy. I found a doctor who would do my T4 count under the table. I would pay in cash, I gave him a phony name and he kept track of my T4 count. Until it reached 300 and I went on AZT. Now they do it when your T4 reaches 500. And I take one every 4 hours, I take about 5 AZT pills a day. I've been doing that since December or November '88. And I take pentamidine every other week, aerosolized pentamidine. Other than that I just take good care of myself.

k- You are getting this through a private hospital or....

I have insurance. I have a private physician.
k- You said that you had to be very aggressive to get the information. What did you do?

Just talking to people. It's a very touchy subject. The reaction I got, even from the people close to me, was really very negative. I got a negative reaction from my family. Just by talking to people. Just by being in the human services. If I had been a secretary or a livestock dealer, like I used to be, I don't know what I would have done. Just talking to people, networking, finally my therapist is the one that came up a doctor that I went to, and that was John Mazzulo.

k- Do you see any outreach out there in terms of women?

No. Not that I'm familiar with.

k- There's a three week program in place for people who have just found out that they are positive. It gives an introduction to the resources and....

I think that that's available now. I don't know if it's specifically for women. If it is that's a new program.

k- Actually, they are just working on that now.

I think that they are starting to get some resources together. But in reality, if you talk to the doctors they cannot tell you how this disease effects women differently than men. Gynecologically it definitely does. That's where some of my first problems have shown up.

k- Could you tell me a little about that?

Well, I think that women have candida. Some of the women in my support group have had real serious problems. That's not a problem men generally have, obviously. Any women that have the papaloma virus, with HIV it's much more dramatic. I had surgery for that last January. That's HIV related when the papaloma gets worse because your immune system is down so the papaloma virus is able to take over. And they don't know anything about it. They don't know anything about women with the papaloma virus and HIV, what kind of effects there are. Where do you find a gynecologist that works with HIV+ women. I don't know of one, do you? That's where we are significantly different from men. We are much more complicated than
men are. That's where women I have talked to, myself included, have much more difficulties.

k- What are the barriers you see to women accessing the resources already out there?

I think, for example, the doctor I see is gay, his secretary is gay, his med technician is gay. He's a very good doctor, but I'm a heterosexual woman. And I go to a gay office. Fortunately I don't have any hangups about that, but I can see where for a lot of women it would be very uncomfortable as a female to go to an all male office where there are pictures of men hanging on the wall. If you go to one of the healing groups, most of the people there are gay men. And gay men are frequently sexist. So when, as a heterosexual woman, you go into one of those groups you are set apart. Much like how gay men have been set apart. But with respect to this disease, you go to a healing group, you go to most of these functions, it's gay men. And some of them definitely have an attitude about women.... I don't know of any resources. I don't know where women go for help. I just know where I have connected, and that's as good as I can get. I don't know where else to go to. There's not much to discuss in respect to that because I've been boxed in anyway.

k- Could you talk about how you see things changing? What would make it better?

I think it's starting. Like you mentioned the three week program. I don't know if AIDS Action has zeroed in on that or not. Since it's state funded, the Department of Public Health seems like the most reasonable area to start a program specifically for women. How would you network to find a gynecologist who is familiar with this disease. I don't know.

k- When you went on AZT was it approved?

No. It wasn't approved by the US government, but it was real obvious to the doctors who had been working in this field that it worked. It was also real obvious to them.... For example some doctors are recommending – I have some women in my group that are taking AZT every four hours. My doctor says that is too stressfull. Why would you want to get up in the middle of the night to take a pill? So every doctor is treating this a little differently. I feel very fortunate that I am connected with two of the doctors that are very familiar with this
disease. There are a lot of physicians out there treating women who
don't know shit about this disease. Nothing. But the women don't know
that.

k- You said you talk to other women. Are you in a support group?

I tried a support group. But since I am a counselor myself I didn't
really feel that I was getting that much out of it. I also felt that I was
light years ahead of other women on some of the issues. As a member
of Alcoholics Anonymous I have a support group. So, I drop in now and
then to say "Hi." Occasionally I'll talk to some of the women on the
phone. But I found that group by accident. I can't remember how I
found it. There are a lot more HIV women's support groups now, but at
that time there were only three women in the group when I started
with it. There are more resources now than there were three years ago.
So this disease has come light years in three years.

k- It does seem like there are some resources available, but why aren't
the women getting them?

Well, how are they making the community aware of them? For
example, the substance abuse hospital I work at, they haven't got any
information on resources at all. Substance abusers have a very high
rate of AIDS. With needle users it's going up. It's certainly not reaching
these substance abuse hospitals where some are testing, some aren't.
I'd certainly ask care providers about that. Have they sent the
information to places where people would need it, for example
substance abuse places, detoxes. Do they have all this information. If
they are providing these things and they are available they need to let
the community know about them.

k- So, does it seem that you just have to get lucky and run into these....

That's my feeling. Like I said, I haven't had any real need recently to
look for these kinds of things. Because I'm involved and I read,
ocasionally I'll hear about one of these, but I'm going on a reference
point of when I found out and in the last 6 months maybe a lot of stuff
has come up. I'm not familiar with it. Certainly the advocate at AIDS
Action hasn't said, "There's a program here for women."

k- Could you talk a little about your experiences with AIDS Action?
Well, I have mixed feelings about AIDS Action. I think it's becoming a real political organization. I haven't had that much contact with them. I went over and got an advocate so I could access into the yoga classes and some of the wellness classes. I have a gay friend that they have been very good to. But, as I said, he's gay. So I don't know how they are doing with women. I have really mixed feelings about the gay community and their feelings toward women in respect to this disease. I am very grateful that the gay community was active enough politically to attack this, because if it hit substance abuse first it would have been rampant. But they were already organized, so they were able to get things moving. And they have some political clout and they have some money. But, AIDS Action is run by gay people; I don't know how they are treating women. Certainly my advocate is very nice to me. I've only seen him once. I don't have a real need to tap into them. Some people they have been very good to.

k- Do they have many women volunteers?

They very well might be. Women are caretakers anyway. It wouldn't surprise me if they have more women volunteers than men. But it does not necessarily mean that because you are a woman that you can be sympathetic to this disease as a woman.

k- Could you talk about the reactions you see in the public to this disease?

You don't tell people. I think that's changing. More people are becoming educated about this disease. If you believe what you read in the paper, if you even get close to someone with the AIDS virus you were dead meat. That's what we heard about: dead, dead, dead. When I found out I had not long to live, from all I read and all I knew. From what I know now I know that's bullshit. But how do you know that when you read that in the paper. Let's put it this way, most people don't know and I don't tell them. I know I'd be discriminated against. So what's the point in telling. They don't know that I am positive. I hear the way they talk about it: "He's dead meat." Not wanting to be close to them. Health care workers are some of the worst as far as not wanting contact with someone who is HIV+. Doctors in particular. I'd be afraid to tell somebody in the emergency room that I was HIV+. I'm afraid they'd let me die. I would tell them because I don't want to infect anybody, but that's the kind of stuff you deal with. You have to go to the dentist. Should you tell your dentist? Do you have to go to an
HIV dentist? I don't tell them. I watch what they do and make sure they are protected, but I don't tell them.

k- Are there any policies on that?

That's an ethical question. Is it my life or your life? I have a sense of survival. If I'm injured and I need help and if I tell you I'm HIV+ you won't give me the help, what do you think I'm going to do? I'm not going to tell you. It's that simple.

k- It's often said that the attitude has changed from dying with AIDS to living with AIDS. How have you experienced that?

Definitely. Obviously it is much more positive. My health has been good. I take care of myself. I just had a 600 T4 count. I was down to 250. It's because I take care of myself, take AZT, meditate, that kind of thing. It's definitely a chronic disease now. I think it's very hopeful for the future.

k- In doing the resource guide and this research it seems that it is very hard to get access to HIV+ women. Going into support groups can break the trust there. There are lots of issues of confidentiality....

I think if you asked women with this disease to participate in this study I'm sure they would be more than willing to. Just because they know that there is a need for their issues to be addressed. Anybody that is in a support group that has gotten comfortable talking about it won't have a problem discussing it, as long as you don't use their name. The only reason they are concerned about their name is because of discrimination. Not because they are ashamed. They work through those feelings. The guilt feelings of, "What did I do wrong? I never should have done this or that." Especially when they get it from men. Women tend to feel guilty, especially around those issues. I don't know if it's a socialization process or what, but we really do carry more guilt. That carries right over into HIV and this disease. I'd be interested to know if suicides are higher among women when they find out that they have this disease. It's changed a lot even in the last 6 months because more and more the public is finding out that this is not as scary as they thought it was. There's a whole lot they don't know about this disease. There's a biologist in California that's been studying retroviruses. He claims that there's no relation to HIV and AIDS. A very respected member of the academic community, too. He's been studying viruses for 25 years. The most recent article about him is in the SPIN magazine.
He's kind of interesting. Does everybody who has AIDS have HIV? No. There's a lot they don't know about the disease. And they know a lot less about women than they know about men. When somebody is going to start accumulating some data on this, I don't know. They ought to consider it since they are going to see a lot more women.

k- It seems that there are a lot of "women's issues" tied into this disease. How do you feel "as a woman" in respect to this disease?

Well, where do you go for support? The gay community has been dealing with this for 10 years. They are very open about discussing it. If a man comes up HIV+, he doesn't have to keep it a secret – a gay man. He knows a lot of other people have had this disease, it's very easy for him to talk about. Where does a woman go? Where in reality does she go? If she tells some of her best friends, some of them are going to do what mine did – totally freak out. Where do you go? I'm 42, I've been around the block, I was self-employed for 10 years, I'm a pretty aggressive woman. I'm not a typical woman in that respect. I've always been politically active. But most of the women in my group aren't like me. I think when you come up with a disease like this all of your other issues come up too, that you haven't dealt with. All your fears, doubts and insecurities as women. Women do have issues and they are magnified. They are the caretaker, now they have to figure out, "Who is going to take care of me?" How many women can say, "I know this man will take care of me." Who is kidding who? So you don't have anybody to look to to take care of you. Some people's parents don't want to have anything to do with them. So women don't have caretakers to take care of them. They are isolated from other women because of the dynamics of being socialized in this world. Some of this has changed. Going to school now is entirely different than when I was in school. When I was out there in the '60's campaigning for a right for a woman to have an abortion. That was big stuff. We had to go out and do a lot of politicking to get that passed. Like I said, I think I'm a different kind of woman than the average woman that deals with this disease. At least that's been my observation in my group. Especially with women that got it from a man.

k- Why especially if they got it from a man?

Because, for me I may have got it from a bisexual man, but I might have also got it from needles. Anyway, my lifestyle was conducive. I lived on the edge. I know my way around the streets. Some women, they just got involved with a guy who was an addict. They aren't
familiar with the drug world, all the insanity and crap that goes on out there. So when they come up with the disease they are not prepared to cope with it. They don't have caretakers in their life, some of them have children, and that complicates it even more. If they have children and have this disease that's a double-whammy, who's going to take care of their kids when they aren't up to snuff? I don't know too many men who are good at that, do you? Speaking realistically, you are dealt a different deck of cards. You have different dynamics in your life. You might be a mother. It's a much greater likelihood if you are a female than if you are a gay male, right? It's different issues, and nobody addresses them. They may be starting to. I hear things, but I don't see anything of substance. When I was out looking there wasn't anything there. So I built up my own support. Some women who think they are positive are not going to get tested because of that. They don't know who to go to, or what to say.

k- I'd like you to look over the rough copy of the resource guide and see what you have to say.

A lot of these places are running HIV testing and counseling. I don't think a lot of people are qualified to be doing what they are doing. I would not have wanted to have to go to some of these people I know are counseling in this field. If you are going to be fair to the HIV person you are going to make sure it's anonymous and tell them, "If you come up positive, get some disability insurance. That way you know that you'll be able to take care of yourself. Get $100,000 life insurance. Then when you kick the bucket your children will be taken care of. At least the money will be there to plant you." That's what these people should be told, but they aren't. So I got all that stuff in place. I was aggressive. I asked a lot of questions. I got the right information. But you are so emotionally devastated when you get this news, most people aren't able to do anything.

Abortion, pregnancy issues. I got pregnant when I was 40, unexpectedly. At that time I was told it was a 70% chance that my child would be HIV+. Now it is 30%. They are switching all over the place. I had to get an abortion. Do I tell them? No I didn't. But those are the kind of quandaries you get into. Should I tell these people before I get the abortion performed that I am HIV+ because they are going to treat me like shit. Will I get quality medical care if I tell them? Maybe not. Like I said, I have a sense of survival, so I didn't tell them. I did go and have my tubes tied.

k- How do you feel about the percentage changing?
I don't care. At my age it doesn't make a lot of difference. If I had been 25 I would have been pissed. I would have been real goddam angry. That's what I mean, this is the kind of information they are giving to women.

k- How do you feel about the issue of pregnancy for HIV+ women?

It's a personal decision. You have to decide for yourself whether you want to bring a child into the world with the risk of having this disease. It's very individual. I would not venture to make the decision for anyone.

(Looking at the AA, etc. listings) Trust me when I tell you that you aren't going to walk into these groups and tell them that you are HIV+. You aren't going to do it. Alkies and junkies are just like everybody else. They are just as discriminatory. I can tell you that I work in the field of substance abuse and I would say that out of the ten counselors I work with, eight have fear of AIDS. These are people working hands on with a very high risk group. So, when I see with my own eyes that 8 out of 10 of my peers are discriminatory, and are frightened about this disease, I am going to tell women to be very careful about who they tell. Because you get poor treatment.

(Looking at the Legal AID section) See I tried to tap into the the AIDS Law Project. I called twice and the guy never returned my call. So, it looks good on paper, but in reality it isn't there. I wanted to find out about a couple of issues. I thought they would be able to tell me. They never bothered getting back to me. Looks good on paper, but....

AIDS Action has done really good with this Buddy service. Boston City has done real good with home health.

At any of these I would tell them to be very careful who they tell about this. It's going to come back and hit you in the face.

k- What do you think would be very helpful to have in the resource guide?

See, gyn is one of the areas where some of our serious problems come up. I'd suggest talking to some gynecologists who work with this, I don't know where you'd find one, and see what they recommend. My recommendation is to get a pap smear every 6 months. If you have the papaloma virus you are at much higher risk for cancer if you are HIV. So I get one every 6 months. Since lymphoma is a big issue for HIV people, how does that effect you gynecologically? Does it put you at high risk for other kinds of cancer? Nobody seems to be able to tell me.
No gynecologist I have talked to has been able to tell me. They don't know. They don't have a database large enough to draw any assumptions. Doctors are taking care of women who are HIV+ and don't know anything about the disease.

k- Any other information you feel is important to pass on to other women?

Question and request. Make sure your doctor knows about this disease, because most of them don't. I think that's very important. Make sure he's compassionate about it.

[interview interrupted]

Once you are put down as HIV+ in your medical record, it is sent to that great computer in the South Shore. Banks can access that. They red flag you. Anytime you have a fatal or chronic disease they red flag you. All the health care workers send their information there. I'm sure my name is in there.

k- So if you go to an anonymous site that won't happen, but if you go anywhere confidential then that happens?

Yes. I would recommend anonymous testing, period. Then you should give them information about disability, life insurance, the effects stress has on this disease, how it can and cannot be passed on.

I haven't found the need to look into resources in the last year. I found my own, but it was only through a lot of effort and talking and this and that. I was pretty aggressive about it. I don't know what other women are doing.

Tell women about disability, life insurance. Tell them to cover their ass. Above all, don't let your insurance expire. Those are the issues important to people like me. How can I continue to take care of myself with this illness. You can use all the esoteric bullshit you want, but dealing with the realities of life, how can I get these things in place before I get sick. How can I protect myself so I don't end up as a ward of the state?

I'd ask these health providers, "Where are you referring the women?" So they find out their HIV+, then what? Are you patting them on the head and saying, "Take good care of yourself." What are you doing with them? That's a question I would ask. Sending them on their way and telling them to call AIDS Action? People get that kind of news and it almost immobilizes them. You can't expect them to be
doing a lot when going through that kind of shock. I think that expectation they have is that you should take the bull by the horns when you just got the news that you are dying. You are supposed to go out there and go for it? Six months after I found out I was in a state of shock. I didn't know what to do. I didn't know of any resource. I called AIDS Action and they basically gave me the run around. I talked to some nut on the hotline. I knew more about the disease than he did. I think that has changed a lot. We are going back three years.

If you are going to tell them you should have a support group right there that they can access right into. If you are going to test, have a support group right there. Don't tell them to go off over here or off over there. Say, "You are positive and guess what, we have a group tomorrow night with 6 women who all have the same thing in common. Why don't you join us?"

I think a lot of people stand on the outside and debate people like me. That gets to be a bit much. Instead of standing around debating, why don't you ask me how I feel? Why don't you ask me what I need? Instead of sitting around in board rooms and talking about a lot of crap that doesn't really mean anything. Why spend a lot of time and energy on something that won't help anyone. If you are testing, have a support group right there they can access into.

k- One of the needs that comes up is that women need an advocate, one person to help them through. But there aren't enough to go around.

Yes. But it's not just that there aren't enough, they also don't know what is going on. I think a lot of people get into advocacy because they feel sorry for people. The last thing you want from people is pity. Thinking back, if I had just had somebody empathetic to talk to about it. And I did. I had my therapist, she's the one that saved my ass. I had been in therapy for a year and a half. I didn't need to start a new relationship. She was already there for me. She hauled my ass through.

Could you imagine if you got this news, are you going to get on the phone and call all sorts of people. Of course not, you are devastated. Why somebody hasn't figured that out is beyond me. If you are going to have testing, you need to have support groups right there immediately available, not three weeks from now. And maybe, ideally give them one-on-one counseling sessions, maybe five, to process some of the feelings. And then move them into a group. Give them somewhere to talk about the fear. Someone that can answer all of the questions that come up and not have to wait, because that just creates anxiety and stress. You are in a fragile emotional state as it is. So what do you do from there. Some people just get shitfaced all of the time and
hope it goes away. Some people crawl into a corner for 6 weeks or 6 months, or whatever and don't do anything. Some people kill themselves. So, if you give somebody this information, have something else to give them, besides, "Guess what, you are HIV+, gee I'm sorry to hear that." Have someone there to talk to in order to process these feelings. The sooner somebody processes the feelings, the sooner they will take the bull by the horns and take care of themselves. It could work a lot like Alcoholics Anonymous works, where you come in and people take care of you without expecting anything in return. And then you pass it on later on. If somebody comes up positive, I have a lot to give them. A message of hope, you aren't a dead duck. There are things you can do to protect yourself. Spend time with them on a daily basis while they process the feelings. Do some crying, being angry, all of the things you have to do. All of these testing sites who say there's a group at AIDS Action, that's unreasonable to expect someone to do all of those things when they get that kind of news.

[end interview]
Appendix I

March 21, 1990

Interview with a provider of prenatal care for HIV+ women.

[begin interview]

Right now I am director of ob/gyn services at the Dimock Community Health Center. I'm also coordinator of prenatal care for the Department of Corrections out at MCI Framingham. So I work in prenatal care with women who are incarcerated one day a week. I am also the medical director of Neil J. Houston House, which is a residential treatment program for drug addicted women who would normally be in prison, but instead of being in prison they are completing their sentence in the Houston House while receiving prenatal care, having their babies, keeping their babies, and working on addiction issues. That's what I do on a day to day basis.

k- Could you talk about resources you know of for HIV+ pregnant women or women dealing with pregnancy issues?

Resources that are available to them? There are a couple of things that are going on right now in the city for HIV+ pregnant women that didn't exist a year ago. Because HIV+ women right now are coming into the prenatal population, programs have gotten together and decided that this is a special needs woman. First off, in her fertility decision. Then if she decides she is going to carry her pregnancy to term, then you have the pediatric component. And also subsequent pregnancies. Counseling women around that. One of the big things that has happened is the NIH HIV transmission study, which is looking at the natural history of the HIV infection in women. The truth is that we do not know what the natural history of the HIV infection is, and it is different for men. It's different in pregnant women. So there is a three year study that includes 6 hospitals around the country, and Beth Israel and Boston City Hospital and Children's Hospital are involved in this. A woman can get into that study and get her prenatal care and receive health services and it has a couple of other incentives in it. The baby can also get pediatric care at least for three years. That doesn't mean that at the end of three years they are dumped from the health system, not at all. But for three years that will take care of women who are HIV+ and women who are high risk, high risk and negative. So that's happening and Dimock is involved. We already have several women who have
signed up for that project. They have just started taking subjects for that project around the end of January and will take them for the three year period. So that's exciting. So we can begin to get some notion about medications during pregnancy. They've put a hold on AZT, using AZT on women in pregnancy, until they deal with this controversy around vaginal cancer that they found in rats with the use of AZT.

Dimock and Boston City Hospital, because we have been dealing with HIV+ pregnant women, have developed comprehensive programs. We have a high risk pregnancy clinic that is run on Tuesday and Thursday evening. We have our substance abuse program which is tied into Dimock, and detox for women who are drug addicted. We have the acupuncture. We have our affiliation with Beth Israel Hospital. We have the pediatric component. So we have a pretty nice set up here in terms of taking care of and dealing with HIV+ women. We have a strong counseling/advocacy program, one in which D.E. Dale does a lot of counseling with women who are HIV+. And we have our Boston Pediatric AIDS Program right here on campus. So we are a little lucky and a little special. We have all of these concentrated services in one place.

So I do think that there are resources available for HIV+ women. I don't think that there are a lot because people are still learning about HIV+ women. When you talk about HIV positivity, almost always when you talk about women you have got to have a program that deals with their addiction. You've got to have some way of helping them deal with their addiction issues, or you don't have a program. You've got to have some way to help them deal with how they got to where they are: bad relationships, incest relationships, abusive relationships. What happened to them. Dealing with being mom's. They may not live to see their child's third birthday. Their child might not live to see their third birthday. So this is a real special needs population. You can't just dump them in your regular prenatal services. They will fall through the cracks, because they need special help.

k- Could you talk a little more about the NIH study?

The study is basically looking at two populations of women, HIV+ women and HIV- women who are at high risk. What it is looking at is the natural process of the infection: what really happens to them. When do they go from being HIV+ to showing symptoms. What effect does their high risk activity have on how soon they will become symptomatic. There was a thought that women who were still drug abusing and were HIV+ tended to succumb to their disease within 13 months of their diagnosis. Nobody has looked at that in a large
population. If she continues to use drugs, is she going to die sooner? The other question is which drug – heroin? If she is a heroin user will she live longer. They tend to live longer than cocaine abusers. And looking at the symptoms; when they show up. What do you see in women first? Do you see thrush? Do women get Kaposi's Sarcoma? Not usually. Women don't usually get Kaposi's Sarcoma. Pneumocystis. How soon does it show up? Does it show up sooner in women who are pregnant? Is it as bad in women as in men? How many bouts of pneumocystis does it take before someone succumbs to the disease? Do women respond to aerosolized pentamidine the same way that men do? So basically it's looking at the whole thing. If the infection goes dormant, how long do women remain asymptomatic compared to men? Since we know it's transmitted through the placenta, the interesting thing is, depending on who you read, you'll get some babies who are HIV- and remain HIV-. Why? Have they built up an antibody to it? You'll get some babies who are HIV+ and will succumb to the disease in three years. Why? That's what that study is all about.

k- How do women get channeled into it?

There are nurse liaisons for the study who contact various health centers. Since Beth Israel is the hospital that we send all of our HIV+ pregnant women to, it was natural for them to contact us and ask us to send high risk women their way. So I identify women who come in either for prenatal care or gyn care, and I know they are high risk, or that they are using, and I capture them and tell them that there is a study going and that the study will offer them some perks. And then I identify them to the nurse liaison. She comes over and does a very long, extensive two hour interview introducing them to the study, doing her questionnaire. And then she signs up.

k- What about the women who don't enter the study?

Well, if they aren't going to be channeled into the study and they are HIV+, they can remain here at Dimock and continue to be seen. We have three internal medicine docs who now have gone out and learned about AIDS. So we have three internal docs who will see all of our HIV+ women. And we will render them care and admit them at Beth Israel when they need to be admitted and take care of them. They become part of Dimock Community Health Center.

k- What about women who aren't here. How are other resources?
I think that some people are realizing that they can't take care of HIV+ women, which is appropriate. So they are referring them to places like Beth Israel. There is an internal medicine person there. Or you can send them to Boston City Hospital. So it's not like you can't get them some services if you can't take care of them. I don't know what other health centers, like Roxbury Comprehensive and Harvard Health Plan, are doing with their HIV+ women. But I know that you can utilize Beth Israel or Boston City.

[interview interrupted]

Basically what I have heard is women being unable to get shelter, unable to get an apartment. Being unable to tell her family about her diagnosis. Being unable to pay for expensive medication, because of her diagnosis. Then hooking women into some sort of advocacy to deal with those sorts of things. I've heard of women going in to get Medicaid with an HIV+ diagnosis and having terrible, long delays in the process. But I have yet to hear of anyone being totally denied care. I've had some women come in here and say I'm HIV+ and I have no money and I need to be taken care of today. This being a health center, we are also in the business of getting our bills paid. We don't turn anyone away, but we will find alternative insurance services for her, or we will get her to Medicaid. We have a neighborhood health plan coordinator right here on sight that can get her referred. We have Centercare here, which is $5, basically a type of HMO, each time you come. We have a lot of sales reps that come through here. We can get medication free and give samples. I have heard about women going to suburban hospitals and being misdiagnosed because they simply didn't know what they were looking at. I have heard of a couple women dying in the early part of pregnancy because the hospital just didn't know what they were dealing with early enough to at least prolong her life or get her to a point where she could have a viable pregnancy. I think people are working very hard to have those horror stories not happen.

See, it's not the HIV positivity, it's the drug addiction. When you are looking at HIV positivity you cannot separate it from drug addiction, which is extremely difficult to treat. I have been working with the Houston House for a year and a half. Yes, we have some success stories in terms of babies, but our success stories in terms of mothers is not that great. We do not know how to get women off of drugs and keep them off. I don't care what anybody in the country says, you can dump millions of dollars into it. Certainly you need more residential treatment programs. You need more treatment programs because we don't have a lot of beds in Boston for drug addicted women. Most of the
beds are for men, 83% of the beds are for men and not for women. So you could open treatment centers because women are asking for help, but we don't have the panacea. We don't know what makes people stop using drugs. It is the drug addiction that leads to HIV positivity. So, it is the resources that are available in helping women deal with their addiction that we need to be pushing for, we need to be talking about. Once they are HIV+ you have a diagnosis, you have something to work with. As premature as it may be, most places have a plan, a protocol, for taking care of an HIV+ woman. Except some of the smaller suburban hospitals who tell you, "We never see HIV+ women. They don't come here." They are coming there, they just don't know it.

[interview interrupted]

k- What kind of counseling are women receiving around HIV and pregnancy?

They can get counseling here and at Department of Public Health, the HIV hotline that is run out of the lab at Jamaica Plain. We talk to women about pregnancy and being HIV+. We also have an anonymous testing site here that treats on Thursdays from 1 to 6, which will counsel women and talk to them about HIV positivity and pregnancy. So basically that counseling includes, given the latest research and what we know about this disease, this is what you can expect. You have a 60/40 chance of having a baby that is HIV+. Given those odds, what do you want to do? I think more and more people recommend to women who know they are HIV+ to suspend having a baby until there is more research, until we get closer to developing drugs that will prolong her life, that may inhibit the transfer of drugs across the placental barrier, that may prolong the life of the infant, just until more is known. I don't know what others are doing. Dimock Health Center, once a woman is HIV+ and finds herself pregnant, almost always she will not terminate the pregnancy. It's not Dimock's recommendation that she do so.

k- Do you talk about the risks to her health?

Yes. Very much so. It was once thought that pregnancy would exacerbate the infection. The studies are proving that that is not true. There is very little effect. You generally don't get sicker faster when you are pregnant. The NIH transmission study will be looking at that.

k- Do you know of any cases of women being told that they should do one thing?
I sit on several task forces that look at developing standardized protocols for HIV+ women, HIV+ pregnant women, so it's hard for me to say what other clinics and other hospitals are doing. I know that at Beth Israel a woman is given the opportunity to talk about the fact that she is pregnant and HIV+ and recommendations are made. I think what people are doing, and what I have found from going to local conferences and regional conferences and listening to what people are saying, is that most people are giving women the facts and letting her choose for herself. I have heard of a couple places that say, "Therefore we recommend that you get an abortion." We are not in the position to say that because we don't know enough about this infection. What we do know about it is that it seems to be devastating, but we really don't know a lot about this infection. Especially when we are getting some authors quoting a 60/40 chance of having an HIV infected baby and some authors quoting a 40/60 chance, a 50/50 chance. So how can you turn around to a woman and say that the baby in all likelihood will be HIV+ and die by its third birthday. You can't. You definitely can't tell her that if she's HIV+ and pregnant she's going to be sicker. If she's HIV+ and continues to do drugs she will be sicker. That's about all you can say. You can tell her something about the drug addiction. I know that all the health centers and all the hospitals are definitely talking to women about the use of cocaine and the use of crack in pregnancy, the devastating use of that. And what kind of baby they can expect if they continue to do coke and crack. That's basically what I'm dealing with on a day to day basis—trying to get women to stop using crack and cocaine. Then, once they aren't high and they are listening to me I can talk to them about their high risk behavior and getting them tested. Some of them are sexually active with known HIV+ men, not using safe sex at all.

k- A woman I interviewed said that a few years ago when she found out that she was HIV+ there were no resources to help her.

I would concur with her that two years ago nobody knew what to do with her. My first HIV+ patient walked in here three years ago and she knew she was HIV+ and we didn't know what to do in terms of putting resources together for her. We didn't know where to send her. We didn't know what to do with her medication, what to do with her regarding a new baby. Consequently she had a very sick baby. When she delivered she came back here for her prenatal care, but she was the first one we had seen. We were kind of hoping that HIV positivity was
going to go somewhere else. But the fact of the matter is that this health center is in a community that has a very high rate of it.

k- What kind of medication are they giving women who are HIV+ and pregnant?

Right now, basically they are using an antibiotic regimen. You can't use acyclovir, which is used for recurring herpes infection, but you can use Bactrim. As soon as the FDA can clear up this stuff around AZT we will use AZT. There is one other drug that slips my mind that has gotten a lot of good press and the trials for pregnant women are going to start soon.

k- Are these medications enough, considering AZT can't be used?

Is it enough? We don't know. Does it help? We don't know. We just started and we are only into it a few months, giving pregnant women medication during pregnancy. Does it look good? We don't know because we don't know what the natural history of the infection is.

k- Do you know what symptoms, such as gynecological problems, are common for women?

I'm not seeing anything a whole lot different. Basically when they get sick they come in with respiratory distress, generalized rash all over their body, excessive fatigue, diarrhea.

k- You mentioned that most women here don't get abortions. Why do you think that is true?

Well, when they get the diagnosis of being HIV+ they have a feeling of finality that the disease is terminal and if there is a possibility to bring a healthy child into this world, it renders you a piece of immortality. Plus, addicts play the odds all of their life: "I'm going to get away with it. Being drug addicted and doing as much drugs as long as I want to. I'm going to be the lucky one. I'm going to get away with it." Getting pregnant and having the baby is playing the odds. There's a chance that this baby will be alright. And I want to leave something behind.

k- Do you know anything about 51a's being filed for baby's born HIV+?

A 51a will get filed if she continues to use and if her toxic screen is positive when she goes into labor and if the baby's toxic screen is
positive, then a 51a gets filed. A 51a is not based on her HIV positivity. Her HIV positivity is confidential, at least it is supposed to be. Dimock’s policy is not to notify DSS that she is HIV+. You’d have to do that on every single mom, and why would you? I could see it getting really sloppy and real touchy if some wife of some Red Sox baseball player comes in and is HIV+ and you file a 51a to the Department of Social Services. I don’t think so. What would you be doing that for? All you would be telling DSS is that there is a problem they need to go out and investigate. It’s not happening in this clinic. It’s not happening for women delivering from MCI Framingham or Houston House. Those three places specifically I can talk about.

k- Even though most women here aren’t getting abortions, do you know about access to abortions for HIV+ women?

Nothing has changed whether you are HIV+ or not regarding access to abortion. Your access to abortion is dependent on your insurance service and ability to pay. The three abortion services we refer women to, none of them have special policies regarding getting abortions and HIV positivity. You can have one whether you are HIV+ or not.

k- Do women generally not disclose?

My sense in terms of talking to women when they come back for the post TAB check up, is that they are not telling people when they go for an abortion. That should not be a problem for the provider who is doing the TAB since we are supposed to be using universal precautions on all patients. One of the things that health care providers have to be concerned about is not so much HIV, but picking up hepatitis. We are all supposed to be using universal precautions, so it shouldn’t be an issue.

k- I was reading that women who are incarcerated and pregnant are often finding out too late about their HIV status to be able to make decisions. What have you seen happening?

We are now trying to identify every single pregnant woman in the institution. She comes in and says, "I think I’m pregnant." This is when she’s doing drugs so she knows she’s going to be drug sick or on methadone, or whatever. Now on intake, the guards or the physician that sees her the next day asks her when she had her last menstrual period and does she suspect she is pregnant and the beta sub-unit is done exclusively to identify pregnant women. There are women who
come into the system and don't get diagnosed with pregnancy until three weeks later and are no longer eligible for abortion in Massachusetts.

k- Could you talk a little about the needs you are seeing in this population and how you think it could be dealt with?

The needs I'm seeing in this population are treatment issues. Treatment around addiction. Either day treatment programs or residential programs for women. Then the counseling support that is going to be needed once somebody finishes a treatment program. We are finding that we cannot simply take the woman that has been in a treatment program for 9, 10, 14 months, put her back on the street and say, "You are cured. Now go run your life." It doesn't work that way. There needs to be some sort of half-way house, a second step before getting back out into reality. The primary need is treatment. After treatment, a half-way house step. And then counseling. Emotional, psychological counseling. Issues around being depressed, feeling ashamed.

k- What half-way houses do you know of?

None. There is counseling available, but not programs specifically for women. At Dimock I'd like to see a women's center where they can come with counseling issues: surviving as a woman in the 1990's, being a single women with children, being in an abusive relationship while being in a relationship with somebody who is a drug user. That kind of model.

[end interview]
Appendix J

March 23, 1990

Interview held with a coordinator of AIDS services in the Latino community.

[begin interview]

The Latino Health Network was founded in 1987 by a group of Latino professionals to address the impact of AIDS in the Latino community specifically. Latino agencies were reporting a steady increase in the HIV+ cases in the substance abuse community and the agencies that were already set up, like AIDS Action, were coming to these people and asking them, "How do you handle this? What do you do about that?" That's how it first developed. And like I said, it was first developed by a group of Latino professionals. It was run out of their houses and then it was run through IBA, another agency. Now we just moved here in August of '89. So we are pretty new. Also at that time a prominent community leader had died of AIDS, so that was a real shock to the community. That's what really started the agency moving. That's basically the background of how it started. So it started to address the epidemic in the Latino community specifically.

We are not a direct service agency. We are kind of a clearinghouse for all Latino agencies or agencies that are dealing with Latinos and AIDS. So we are pretty much known. We do a lot of media exposure. We work in collaboration with other agencies. We have the hotline also, which the community uses and talks to us about their symptoms or their anxieties or testing. We direct them to Latino specific services.

k- Could you talk a little about the services you direct them to?

There aren't many services in place for Latinos and that creates a problem. That's my personal opinion. This has nothing to do with the agency and I want to make that clear. I feel that the push for testing puts the community in crisis, because there aren't enough services set up once you know you are HIV+, such as support groups, mental health counseling. Even counseling at ATS test sites, there are hardly any bilingual counselors. Even though there is a push from the mainstream society, there is that concern. This has pushed us to work in collaboration with other agencies. Other people who are being funded, other Latino agencies, other agencies that serve a large Latino
population. It has pushed us to work in collaboration, and I think that is a very positive thing. So that we share resources. Anything that we develop is to share with other agencies. So we are pretty up to date with all of the resources. I have that reference manual which I use on the hotline to direct them to Latino specific services if that is what they need and want. So, it's mainly networking and coordinating services. Because they are so scarce we can't afford to not be in collaboration.

k- You have been attempting to get the Latino specific resources to deal with AIDS and the AIDS specific resources to deal more with bilingual and cultural....

Well, that's part of it. We don't make them do anything, but we do let them know what the needs are, and we do have curriculums that we modify, and that we feel should be modified for the Latino community. There are a couple of agencies on the west coast that have a lot of curriculums for Latina women and AIDS and health. Because I think in order to address Latina women you need to address health in general. You can't see AIDS in a vacuum. You have to address the whole health concerns of Latina women. And in that you have to address the history, barriers to getting services and so forth. So anytime we do our presentation we don't see AIDS in a vacuum. We talk about Latina women's health in general.

k- You mentioned modifying curriculums. What barriers do you see there?

Well, what I think the large barriers are is a history of abuse towards Latina women in the medical system. If you know anything about the health history of Latina women, we have been guinea pigs, we've been sterilized against our will, all of this stuff. So Latina women tend to access health care really late, almost on a crisis basis. We tend to access when we are pregnant, pretty late in pregnancy. It's not that we don't use any health care, there's a lot of nontraditional health care that we do use, that's becoming so famous here in the US. Accessing more holistic and more natural, herbal kinds of stuff. A lot of it comes from different religious sects, such as Santeria, spiritualism and spiritualists that will help you know herbs and prayers and all that stuff. So when addressing the women.... Well, take for example Safetynet. I think that you cannot assume that the women feel comfortable enough to address sex in their discussions. We use the Paulo Freire method, which is to empower women to talk about and then to educate, and in turn they empower other women, so it's like a chain, instead of me going in and
giving all of these Safetynet parties. It's more to empower these women and continue the chain of empowerment throughout the community where they can share this empowerment with other women. It's more on a horizontal level than a vertical level. That's the way I see it. So when we talk about women's health and Latinas we have to realize that a lot of women have problems making their bodies their own and realizing that this is my body and this is what I am going to do with it. So you cannot assume that they are going to carry out this message effectively if you have not assessed how they feel about talking about sex, about their own bodies, about rights to their own bodies and so forth. So we deal a lot with the self and a lot with self-esteem issues. A lot of sexuality issues. A lot about lesbianism and making your body yours, and sexuality in general. We make sure we talk about all of this before even addressing AIDS and addressing prevention, so it's a job, it's a task. If we were to do Safetynet I would certainly modify it in that way. Not major modifications, I think it's an excellent idea. But really make sure that the women feel comfortable about talking about their bodies and being more explicit, and talk their language, and giving them information about their rights and so forth.

k- Could you talk a little more about the holistic medicine?

It's accessed a lot in the Latino community. I'm not aware of using it regarding AIDS or being HIV+. But I can just tell you that the history has been, like they say, Latina women don't access health care. Well, they don't access the existing western health care. In the past they have accessed nontraditional medicine; healing, herbal teas, massages, and there's some mix with religion, Santeria which combines African sect religion with Catholicism. I don't know much about it because I'm not a Santera myself. I have seen it, as a Latina woman. But I know that it is very common if you are suffering from some ailment. You go to this person who would be like a priest or priestess and they would help you out either through prayer and massage or through teas. They have botanicas which are their pharmacies, where you can buy everything you need to take care of that particular ailment, whether it be physical or emotional. So that does exist and it is accessed pretty much throughout the states.

k- Do you see a way of reaching into them and training them about AIDS?

That's what we are starting to identify. That's interesting that you bring that up because we know that there are people in the community
that are like the Santeros and Santeras, and we thought that a good way of doing effective outreach is reaching these people and educating them. But this is all just starting because a lot of things are new for the Latino community. That's a place to begin to do outreach.

k- Could you tell me a bit about the resources you have been referring people to?

For Latina women specifically? There isn't much. The WARN Project has support services for women who are HIV+. It's a closed group and it is very short term. Martha Eliot has a support group for women who are HIV or whose lives are affected by HIV or have AIDS and their children. This seems to be a very comprehensive group. They even do art therapy with the children involved. The MOM's Project at BCH deals with pregnant and parenting women who are HIV+, or I believe at risk for being HIV+. That's about it, there isn't much. When you address support groups you have to take into consideration that there are other needs that have to be met. You cannot expect that if you have a support group all of the Latina women will get there, because they each have different needs; they might have childcare needs, they might have transportation issues, there are a host of things you have to take into consideration in order to make the support group a viable one. You can't expect to have a support group in Newton and expect the people to get there. It has to be in their community, somewhere that is easily accessible. I thought that the Martha Eliot one, Entre Amigas was very successful. They go out of their way. They give the kids food, they feed the women, they provide transportation and so forth. We don't do direct services, we provide technical training, or technical assistance to other agencies. We train trainers. Right now we have a consultant working with us. Her role is to develop a seropositive support group statewide, very Latino specific, very culturally specific. She'll be piloting that in May. So we've been getting some ideas from seropositive groups from DPH through Behavior Research Program. We've been getting some sort of training, but we have to adapt it and modify it to the needs of the Latino community. So that is going on. We are going to pilot that and then train trainers to do their own support groups, develop them.

k- You mentioned having resources inside of the community. I have also heard concerns that if some of the programs are inside of the community people will not want to go for fear of being identified.
I don't know. I think that could be a concern, but we don't know much because we haven't had enough support groups to make that conclusion. I know for the Anglo community it has been like that. Even the AA program and NA, all of these 12 step programs. You go anywhere but Boston if you live in Boston. That happens a lot. That could be a concern, but I can't make that assessment now because there have not been enough support groups to say that is true. I could imagine that that would be a factor because of the taboo around AIDS and around sex and a lot of things.

k- Women tend to go to the community health centers when they are sick?

Yes. They tend to access the health centers.

k- How do you think their treatment is there?

I can only talk about the history and the barriers. There are a lot of cultural barriers. I've heard of a lot of insensitivity. If you are going to tell somebody that they are HIV+... Women have said that they just say it, they don't regard confidentiality. I think that there has been abuse. Latina women are very stigmatized by the health professions in general, and that is a barrier to our accessing services. It's a history. Populations of people who have been, don't quote me on this, but I think 38% of Puerto Rican women of childbearing age were sterilized. That says something about attitudes towards women and towards Latina women specifically. I think the world is misogynist, but being a minority woman – I hate that word– I think the odds are against you even more because traditionally women in the third world have been used as guinea pigs. So it's a trust factor involved. So we try to empower women, let them know it's their body and they have the right to refuse medication, to refuse treatment, or to access treatment.

k- There are resources for women starting up. How do you think they can best reach out to these women?

I think that they have to extend their outreach strategies. When you work for an organization you are usually given an outreach plan. I think you have to go beyond that plan. Go to the shooting galleries, go to where the people are instead of expecting the people to come to you. You have to know the community, you have to have a lot of not only bilingual, but bicultural people. Because the system gets away with, "Oh yeah, you are bilingual. You came from Utah. Go ahead." That doesn't
make them bicultural also. They need to hire more Latina women in this case to do the job and do it well. You can't expect to just suck the resources of one organization and that this will give you an excuse not to hire your personnel that you really need. That's what they tend to do. They see us, for example, and that is our job to a point, but I feel that that doesn't take away from their responsibility to hire the proper personnel. And then when they do the turnover is so incredible because the people get so burnt out because they are hired to do AIDS education, then they have to do translations, they have to interpret, they have to be outreach workers. They take this one Latino worker and they stretch so much that the person gets burnt out and just leaves. So don't just hire one token Latina, hire a staff at different levels to do the jobs. Like I said, the strategy in outreach is go where the people are. Don't just expect that there is this great outreach plan, you have to modify it if you genuinely want to get to Latino women. And there is a crisis in their community. We are the fastest growing AIDS population statewide and nationwide. I think that there is a crisis and we need to face it because the shit is hitting the fan. If there is a genuine interest we want to see it put to work, not just lip service. At least I want to see that. I want to say I'm not talking for the agency, I'm talking for myself as a woman, as a Latina woman, as a women's studies major, as a lesbian, as a feminist, as a lot of things, this is what I see.

k- Could you talk about work you have done with the Multi-cultural AIDS Coalition?

I know we get some monies from MAC and we work very closely. We developed an advisory group, for example, which is composed of different people in the Latino community who are Latino, who are working in the area of AIDS and health. Our advisory group was developed to have collaboration in effect and now we are working together to look at what services are in place in order to meet the testing crisis in our community. We are talking about checking out what is available. It's a place to meet and vent your frustrations or your successes. We made sure we developed our own outreach strategies. We developed our own education strategies. Now what we are doing, given the push for testing, we are coming together to talk about the services that are available and to get a little more political and say, "This is what we need as a community." The only way we can do that is coming together as a group. I know there are other monies we get from MAC, but I'm not sure what we do with them. It's AIDS specific money. Our focus is on prevention. We are a Latino health organization, a network, so all the monies we have are AIDS monies, but
we do address health in general. We want to extend our services to more health related, not specifically AIDS, of course do AIDS education and prevention, but we want to extend to other areas. I love women's health issues, so whenever I do a presentation women's health is all over the place. Like I said, you can't see AIDS in a vacuum, you have to relate it to what is going on in the history of women's health, the history of Latina women's health, where we are, where we were, where we are going, what's happening, what we need to do. Because it's a question of life and death. So we always do our women's thing. But, it so happens now that all our funding is AIDS money.

k- A lot have people have also said that you can't address just the woman, you have to address the....

...family. A lot of agencies that have been set up to address the AIDS crisis tend to address the patient, and in our community we are very tied to our families. They take part in our health, they take part in our healing process. I think that has been one of the major concerns of our community. "We are here for services, but they see me as an individual and I have my whole family that is involved or a large group of my family is involved in my health." I think that is certainly another issue in making support groups work, accessibility to health care. I have this woman who came from Puerto Rico. She had full blown AIDS. The agencies saw her as a person who needed help, when her mother was there, her son was there. They all needed help because she was very much involved in taking care of her and taking care of her son, and the financial situation also. I think that needs to be looked at, you can't just take care of the individual, you have to take care of the family.

k- How do you see the Latino community reacting to AIDS?

I don't think you can generalize, but I think there are a lot of factors. For example a lot of transmission through IV drug use. And also the risk factor of bisexual and homosexual contact between men, which many men will never admit to being gay. They will say, "I'm not gay," while having sex with another man. I've heard of cases where men would rather say they are IV drug users than say that the risk factor was having unprotected sex with other men. I guess the whole issue of a lot of men in this culture having sex, which is a good and a bad thing because they are throwing labels right out the window, sort of "Don't label me." But the homophobia is incredible. The homophobia is rampant. There are Latino men that very much identify as being homosexual, as being gay men. We have a Latino gay men's group here.
But a lot of them are not and they put up all kinds of excuses. I've met personally a man that told his family he got it through IV drug use, would never say he was sleeping with other men. I think that is an issue. And in terms of lesbian women, I think they are totally invisible. Our women are getting infected mostly by having sex with IV drug users. So that's a factor, educating our women. We conduct our own community based research. The focus groups I have done with the women tell me, "I am sick and tired of doing the education. We need men as role models to educate other men, because the men are not listening to us." There's this whole thing about using condoms, and the Latino community is very much attached to church. There's all this stuff. And we do need more men to educate, positive role models. I'm getting this directly from the women.

k- What kind of role do you see the church playing in the community in regards to AIDS?

Well, there are different kinds of churches. Some are more progressive than others. Our community tends to be Roman Catholic, and their policy on using condoms is "No way, we won't do it." There's all this stuff about procreation and all of this misogyny. That's my personal opinion. There's all this misogyny and the ones who get the short end of the stick are the women. There are groups working with the churches. There was a meeting about two weeks ago with reverends and all of these people who are involved. We got a call last week from a Roman Catholic priest who was really pissed off and asked us our policy on condom use and all of this stuff. Just getting through all of that is a hassle. People are very connected to church. They are very resistant to using condoms. That is something you have to respect if the person feels strong enough. I think our job is to educate and tell them that this is what is going on. This is how you can best protect yourself. There are groups getting together with the priests and reverends and letting them know our concerns about the spread of HIV in our community. Like I said we are here to educate. We can't tell women what to do and we would never do so. When you do outreach and education you have to keep in mind the communities ties to the church and how that effects their accessing services and how that effects them taking care of themselves and prevention.

k- Since women are usually the caregivers, how do you see that effecting their accessing of resources?
I think women in general have been caretakers all through history. I think that for Latina women that is even more internalized for them. They are, not all of them, but a great number of them would sacrifice their own needs to take care of their children, to take care of their husbands, because that is expected of them. It is very ingrained. It's so socialized. Your children are first, your husband is first. I think Latina women have a lot of strength and they are starting to wake up and say, "Hey, I'm sick of being the educator. I'm sick of taking care." I've heard this in the focus groups. I think nurturing is a very positive thing, but I also think you have to nurture yourself in order to provide anyone else with nurturing. We try to get this across. Women are very good about talking about their needs and their feelings. But again, it's socialized roles and we can't change socialization, we can just tell them that they have the right to take care of themselves and make them feel that they own their bodies. Make them feel like they owe themselves to take care of themselves and they can't possibly take care of their children if they themselves are not well. But sometimes even the woman is HIV+ and the male is and they have to take care of the male and they have to take care of their children. That certainly is not good for keeping healthy, it just drains them. I think that is an issue for all women, particularly the roles are so ingrained in the Latino community. You are the woman and you do this, and you are the man and you do that, even if it is all a fantasy anyway. I facilitated a workshop the other day with Mujeres Unidas. They are a group of women called Women United. It's composed of Latina women. We talked specifically about taking care and how that feels to them. They are pretty empowered and they know what they want. Anytime you bring women together and you give them a chance to be together there is an incredible empowerment that goes on. I think that is the best way to empower women, just bring them together and let them break the silence around mothering and all of these myths you learn since you are a child. Mothering is the greatest thing and every woman wants to be a mother and this is the way you are supposed to feel. So I think that we need talk specifically about roles. They were very open, very open with their sexuality and machismo and how they were sick of it, how they weren't going to put up with it, how it's a fantasy a lot of the time. We should burn the storybooks, I think that's where we should start. Burn all the Cinderella's and all that stuff. It's all fantasy and it really impacts socialization. We are talking about feelings of rejection and abandonment. We showed a film in Spanish and the film was about a woman who had to make a decision about not having sexual relations with her partner because he was very macho and he was very resistant to using condoms. So she asserted herself and she said, "No condoms, no
me." We talked about that and how that's not so easy to do. Sometimes there's a real fear of abandonment even though you are the provider and the nurturer. There's this whole fantasy, because many times men don't even provide for women. Most of the time women are single parents anyway. There's still this fantasy, if I don't do this he's going to leave me. And that's a real threat and we need to address it. It is real, but where does it come from. Is it in fact a threat or is it something that is created and perpetuated. A lot of women said, "Yes, it is a fantasy. They don't really take care of us, not economically, not emotionally." But it's still there. It was fun discussing socialization in a way that they could understand it. It's very empowering. We even talked about lesbianism. One of the older women said, "I've been considering it. I feel like this and I feel like that. And I really feel for women. I feel sexually attracted to women." So they felt very comfortable. That's very empowering, just bringing them together and letting them be themselves. Just throwing out some questions and letting them play with it.

k- Is there anything else you want to add?

I think I covered everything. The trust factor regarding health, accessing health services, has to be dealt with. I think the main thing is not seeing AIDS in a vacuum. I think you have to address so many things. You have to be more macro. You want to educate in terms of their needs. You have to look at the history of women's health and address issues of socialization. Address the myths regarding mothering and all of the myths regarding marriage, gender role issues, etc.

[end interview]
Appendix K

March 29, 1990

Interview with an HIV+ woman.

[begin interview]

k- First you could tell me a little about yourself.

I'm 35 years old. I'm a recovering alcoholic and addict. I've been clean and sober for almost six and a half years. I'm originally from California. I came out here to go to school and liked it a lot and ended up staying. Bouncing back and forth a lot. But now I've settled in the area, it's home.

k- What did you know about AIDS before you became infected?

I didn't know anything because I got infected before anyone knew anything pretty much. I got infected, I believe, through intravenous drug use. The last time I used a needle was in 1983, so it had to be sometime in those last couple of years in Los Angeles where I was living at the time. I had been in a rock and roll band for a few years professionally and was running with a real fast crowd. We never heard anything about it back then. It was 1981, '82, '83. Maybe some people in the gay community had heard of it. It was called GRID back then, but people who were addicts didn't make the connection. I didn't hear about it until I left Hollywood and came to Boston. Basically my whole life had fallen apart completely. I was hitting bottom in the process, a very painful process. And while I was trying to figure out what I was going to do with myself here I started to hear about it and read about it in the paper. Something clicked, it was like, "Wait a minute, I'm in this risk category because I had been a heroin addict for a while." I got concerned about it. And one time I came down with a sore throat and my lymph nodes were all swollen, which had never happened to me. I got really worried. I went to Mass General. I remember this very clearly. It was in the summer of '83. I went in, into the emergency ward because I didn't have any insurance or anything. I talked to this doctor and he just looked at me like, "You don't have to worry about this," because of the category he put me in. I said, "Are you sure?" And he said, "Yeah, get out of here. You're fine. All you have is a cold." Something in the back of my mind said that this is not the end of the story here. That's when I pretty much first heard about it. And I didn't
do anything about it after that because there wasn't anything I could do and I didn't know what to do anyway. Nobody seemed too worried about it. So I just went on my way and got sober, which was the most important thing.

k- When did you find out then?

In 1985, several years later. I got sober in January of '84. I focused all of my energy on that, getting my life back together, working with the program, AA. I was going to NA, too, Narcotics Anonymous. And wasn't hearing much about it in the media. At least nothing that made me think that I needed to deal with it. But it was always somewhere in the back of my mind. The awareness was there. Then I got sick. I came down with mono and pneumonia at the same time, not pneumocystis pneumonia, but just pneumonia. I never used to get sick like that, even when I was using. Something made me feel real uneasy, like there's something wrong, I better look into this. I was working here at the time and I asked the health center if there was a test or something or any way I could find out if I had the virus. They didn't have access to it at the time. It was early 1985, right before it became available, a good reliable test. So they said, "Keep an eye on things. We know you are concerned. We are concerned. We'll let you know when there is a test available." Because of the health plan and all that. So I had to put it aside again, on the back burner. In the meantime I met the man who is now my husband and we started dating. Three months after we had been together I became insistent that I had to get tested because he never used needles and wasn't particularly promiscuous. He's also a recovering alcoholic and addict. He didn't do the same things I did. He was in a lower risk category than I was and I was really concerned about him. I said, "I have to do this. I have to know." So I pushed to get the test and they set it up so I could get it. That was in October of '85. I came out positive and it was like.... My whole life changed.

k- When you were tested did they give you information you needed to know?

They gave me what they could. They didn't know a whole lot at the time. The stuff that they knew they had a hard time translating to me because it took me a real long time to understand how this works. The saying back then was "You only test positive. You only test positive." Which gave me the impression that there was a problem, but it was only a vague sort of problem and nobody knew what was going to happen. "We don't know whether you'll get sick or not." What I didn't
understand, it took me years to figure this out, was that I had the virus, it is in me, it's in my body. And the question of whether I get sick or not is a matter of degree of whether or not I get infections that come from somewhere else, that have nothing to do with AIDS. All the AIDS virus does is destroy my immune system, make my body not work normally. But the stuff that gets you is the outside infections, the opportunistic infections. And I did not understand that. So I kept saying to them, "Is there another test I can take to see if I have AIDS?" Because I didn't get it. They kept trying to explain it to me. It took me a while to really understand, for it to really sink in, into my consciousness of what was going on with my body. So they gave me as much information as they could, but it was really a wait and see kind of thing. "We just have to wait and see." So they monitored me really carefully. I had a really good doctor and nurse practitioner on the health plan who really just took me under their wing and they were concerned for me, and still are, and have been following me very closely every step of the way so if something does come up they can handle it. They know a whole lot more now, too. So, I'd say I've been very lucky that I have the coverage I do here. Because I have access to just about anything I need.

k: What about when you were in the situation of having no insurance. What would have happened?

Oh God, I can't imagine. I think that when I got sober.... We have an expression in AA, we believe in a power greater than ourselves, it helps us get through stuff. I came here as a temp. I wasn't looking for a job. I still had delusions that I would be back in the music business once I got my shit together. I came here as a Kelly Girl. I had no idea what it was like to have a normal job, a full-time job and be responsible and all that. And they just hired me here. Because of that it was like an accident. I just stumbled into this incredible job and this incredible health plan with a really great doctor. So I really don't know what it would be like for me. I know what it is like for some friends of mine, it is very difficult for some people I know. People give them a hard time. They have difficulty getting access to things. Here everything is in-house. If I need to go somewhere they can send me to Mass General where they already have connections. They can send me to Mount Auburn or whatever. Other people who aren't on a health plan, it's like they have to go through the whole process of people getting to know you all over again. It's uncomfortable. If people see you enough they see that you are doing okay or not doing okay. At least they know you, so it is different. You have a safety net to fall back on. A lot of people
have to go to strange pharmacies or strange places for particular care. It's hard for them I think, real hard. I can't imagine. I'm just really lucky. I think my higher power is looking out for me, that's what I think. To tell you the truth. Because I did not do anything to get here, to get to this point, except show up.

k- What infections have you found specific to women?

Yeast. Most of the women I know, we have a lot of problems with vaginal yeast infections. Abnormal pap smears. I've had several abnormal pap smears in the last two years. They finally decided to do a colposcopy and a biopsy. They were looking for human papaloma virus, they were looking for cancer, and there was nothing. It was just abnormal cells. And my personal theory – see I have to develop these theories for myself because a lot of stuff people just don't know, they have ideas, but they just don't know – I think I get so many yeast infections that it has changed some of my cells and when they do a pap smear the cells show up abnormal. And when they count them that way, you get an atypical return on your test results. I've decided just to keep an eye on it and do regular pap smears every six months I guess. But I'm not going to get hysterical about it, unless they have something definitive to tell me. That's just an example of some of the problems. My periods have been normal. They've been okay. The rest of the stuff is hard to tell because I don't know what's the virus and what's being on AZT and I don't know what's making stuff in my body change. It's difficult to tell sometimes.

k- Are you on a trial for AZT?

Well, I've been on AZT since May of '88. That wasn't part of a trial. They just put me on it because my T4 counts were very low, under 200. They felt that it was time. Then I got involved in a clinical trial, which does involve AZT as part of the protocol. They are testing AZT, Dapsone, Bactrim and aerosolized pentamidine as a prophylaxis for pneumocystis. And to see which drug works the best. I started in the summertime of 1989 at Mass General and I couldn't handle the Bactrim, I got real sick. I had a reaction to it. Then they switched me to Dapsone and I had a reaction to that. So now I'm on aerosolized pentamidine, which I've been handling pretty well. Once a month I go in and they hook me up to a machine and I breathe out of a tube for 20 minutes or whatever. It's easy. I come to work a little late that day. I have a schedule worked out so that I can meet those obligations as well. And the AZT is part of the study, so, yes.
k- How do you feel about being in a trial?

Fine. I think it is great. Anything I can do to help. I'm on another trial, too, for Chinese herbs that my acupuncturist is involved with. It's not a hospital trial or anything, it's from a holistic institute in Portland, Oregon. It's a holistic thing. I'm doing the Chinese herbs now. It's a hassle. Sometimes it is time consuming and I have to remember not to spread myself too thin. But, I think, anything I can do to help. There has to be some positive stuff you can do with having this virus. It's not a completely negative, bad thing. There's a lot of good things you can do with it. It's a way of giving back I guess. Anything that helps.

k- How do you find out about these various resources?

Well, the Mass General study was through my doctor. These guys all know each other and they are connected. They talk to each other a lot. Plus I think Massachusetts now publishes a list of all the protocols that are going on with a hotline number. That's not how I found out. My doctor just suggested I do it. As far as the herbal one goes, it's almost like I was on the outside for a while, because when I was HIV+ and my T4's were above 200 I didn't qualify to be a client of the AIDS Action Committee. When my T4 counts dropped, that's when I qualified because I fell into the ARC category I guess. So I went to them to become a client. That opened up all sorts of stuff for me. I went to see the wellness coordinator there who referred me to an acupuncturist. And she's the one, she was doing the study with her other patients, so she asked me if I wanted to participate, and I said, "Sure." I'd say the AIDS Action Committee has opened up a lot of doors for me as far as resources go, definitely.

k- What about during that time period before you entered AIDS Action?

Well, during that time I didn't need a whole lot. I think I was focusing a lot more on my sobriety and getting my life together and my boyfriend and I were trying to work out our relationship. I was involved in some of the AA (Alcoholics Anonymous) activities, AA conference planning and stuff like that. I really just didn't dwell on it too much. I was aware, but I was feeling okay and I wasn't having problems with my energy level or anything. The things that have been happening in body have been very gradual. So I didn't have to deal with it because there wasn't any real reason to, that I could see. I did quit smoking early on, that's one of the first things I did. I didn't dwell
on it too much, I focused on AA for the next few years and then things started showing up in my blood, like the lower T4 counts. Stuff started happening. When I was ready, I started to look for information. I do remember in the beginning when I first tested, trying to get more information, especially about women and having children, because I was really concerned about that. I couldn't find anybody who could tell me anything. I went to a Women and AIDS conference in October of '86 at Suffolk University. There were some people there, one woman from Boston City Hospital, Janet Mitchell, who seemed to have some information – this was a long time ago, so you have to realize that over the years information has really accumulated. But, I have a scratch pad that I had with all of these phone numbers that I would call, and people would keep saying, "We don't know, but try these people." So, I was talking to Deaconess and Beth Israel and Mass General and Mount Auburn. Basically I think I was on a panic thing about what was going to happen to me, and if anyone knew what was going to happen to me. And nobody could tell me anything. I think that part of that was me grasping for straws. I wanted some kind of guarantee - am I going to be sick or am I going to be okay? Nobody could tell me one way or another so I had to resolve that on my own self.

k- How do you feel about the issue of pregnancy?

Well, I don't know. I just saw something on television last night that said it was 50/50 that you could transmit the virus to your child. I think enough time has gone by that they have been able to see the results. They suspected it was around 50/50. But they have some real data now because a few years have gone by. That and the knowledge that a child has a harder time with this virus than an adult, usually, they have many more problems if infected than an adult does for the most part. I don't think it's right. It's not to say that in the future we won't try it, if they can come up with some things to make it better. But the way it stands now I just don't think it would be fair to a baby or to us to do that.

k- Have you been able to talk to somebody who knows more for counseling?

I haven't. Well, actually, yes I did. Some friends of mine who work in the field I have talked to informally. But I have not gone for official counseling because it's not really on my agenda right now. If it gets to the point where it becomes something that me and my husband really want to do, or go for, then we will be able to get information either
through here or Mass General or AIDS Action or somewhere, I think. But just the thought of it right now doesn't sit well with me. I just don't think it would be the right thing to do at this point.

k- In looking back at your situation, what do you think women need to know?

I think that women need to think about what they do. Especially women in their teens and twenties. I know for myself that I had no understanding of the consequences, the long term consequences of my behaviors back then. It was almost like the old "I think I'm invincible" thing. I was a child of the pill generation. It was the '70's. It was suddenly, anything the guys could do we could do better or do the same. Everybody was suddenly on equal footing. The pill was a great equalizer for a lot of us. I think that a lot of us didn't understand the long term consequences, not just from picking up sexually transmitted diseases, but emotional consequences of slowly chipping away at your sense of what is important, values and stuff like that. Not morals, because I don't like that word, but values. I think women need to think about the long term consequences, even if they can't internally understand, because most people don't internally understand long term consequences until they have something happen to them. And then it dawns on them, "Wait a minute, if I had done such and such. If I had made a different decision I may not be in this situation." Which I have gone through a great deal of turmoil with. But I just didn't know. I didn't really know. When I was running around like a maniac in the rock and roll world I really thought that when the time came, when I got tired of it, when I got burnt out, or when I just didn't want to do it anymore, that I had a choice to just stop and change my life. It didn't work like that. I was caught. I was stuck and I could not get out. I eventually did get out through a lot of suffering and a lot of luck. But it wasn't like, "Okay, I don't want to do this anymore. I think I'm going to change the channel." People do things with their lives and they make some very bad decisions and they can pay high prices for that. I think even more than all of the pamphlets and all of the things that they can get in the mail and all of the resources they can talk to they have to make a decision that they want to take a look at the consequences of their actions. Take some responsibility for themselves to know who their partners are and to care about themselves to think about those things in the first place.

k- How do you see getting this information to people, because they need to know that it is an issue to consider?
PWAs need to talk to young people about their experiences with HIV. They need to talk to everyone about it; every age group and demographic "class." There are some disturbing statistics about how it is isolated in the inner city. I feel uncomfortable when I see news reports like that because it focuses again on class, race, types of people that are in the risk categories, which makes all of the people that think they're immune from it think that it is somebody else's problem. "I don't have to deal with it. It can't happen to me, or it won't happen to me." Things like that. I think that is dangerous thinking. It's a virus. The virus doesn't care. The virus doesn't know the difference between who you are and what you are doing. All it cares about is means of transmission. I think that women who are sexually active have to take a good look at safe sex. They need to think about this. And that brings up another whole can of worms. Just from my own relationship with my husband.... We don't know for sure, but it seems that it is harder to transmit this virus from woman to man. He still doesn't have it. He tests negative. And, well let me put it this way, we are not exactly religious with safe sex. We practice it but, I don't know, it's hard to explain. It's very difficult to explain something that a lot of people won't understand, but we've made some informed decisions and we are finding that the diaphragm and the cream with nonoxynol-9 seems to work very well. Condoms. There are different ways to do it. We are also monogamous and know our situation and we have also taken responsibility for whatever happens. We know we are both at risk. Somebody who is just having a good time and partying a lot, use a condom, it's not worth it not to. If you get involved with somebody who you can really get into this stuff with and learn different ways of practicing safe sex, then great, then you have good communication and whatever. But if you are just going to be bouncing around a lot then bring them with you, put them in your purse, whatever. It's true. But so far the other stuff has worked well for us. I can't explain it, I don't understand why, but I'm glad. So far, so good.

k- How does it feel to not know, since there have been so few studies on women and AIDS?

It's frustrating. It goes through the grapevine. I talk to my girlfriends that are dealing with this. "Do you know.... Do you ever notice...?" "Yeah." "Does your doctor know anything about it?" "No." Nobody knows what to tell anyone else. It's all word of mouth. One of the things I've always felt is that my blood work doesn't do as well when I am premenstrual. I think when I have PMS — and I know when I have
PMS because since I've been sober I can actually chart it, take my
temperature every morning, fill out a little graph, so I know I have PMS
I swear I feel worse, not just from the PMS, but I think it aggravates
the HIV condition when I am premenstrual. I tend to be more
vulnerable to things. I get tired faster. If there is an infection floating
around the office I am more prone. I have believed this for a long time,
but I never talked to anyone about it because nobody ever said
anything or knew anything or done any studies. I talked to my
acupuncturist about it when I went into see her when we were first
mapping out a strategy. And she started treating me first with herbs
for PMS, not for immune enhancement or anything. Because she also
agreed with me that it seemed that we didn't do as well in those five
days or week before our periods. It was harder for us. So I've been
getting a double benefit. Not only do I get relief for my PMS, but I feel
better. But where are you going to get documentation on something like
that? That's the biggest example I can think of.

k- What are you getting through AIDS Action and how do you feel about
working with them?

A lot. I think they are really excellent. I am on the client advisory
committee. They have a little committee of clients who give them
feedback. That was an honor to be asked to be a part of that. I
especially think that Wellspring and the Wellness Coordinator, have just
been wonderful. He's like a dynamo, this guy. I had a question. I was
worried about a terrarium that a friend gave me. A well-meaning
friend gave me a terrarium with plants in it and soil and it made me
really uncomfortable. I couldn't figure out if I just didn't like it because
it was so big or if there was a reason why I didn't want it in my house.
So I called him because I knew if anyone knew anything about
anything, he would. He said, "Well, there are some infections you can
get from soil." I said, "Good," because I didn't like it anyway. So I have
to give it back to my friend and explain, "Look, I'm really sorry. I don't
mean to hurt your feelings, but..." All those funny questions you
wonder about, you can get information about. Their resource library is
great. The guys that work there have been good about sending stuff if I
need something. I wanted information on Dapsone when I was on the
first part of the trial at Mass General because it was making me feel
funny for three weeks before I broke out in a rash. I felt weird. I
wanted to know more about the side effects. I got something in the
mail right away. It's wonderful. I don't go there very often, I only use
them when I need them. I don't want to overload the system. I know
that they are already overloaded as it is. So when I am holding my own
I am always on the fringe, I'm always sort of around. They are doing a great job. We do The Walk every year. My husband runs around and gets money. He really gets into it.

k- I would like you to look at the resource guide and tell me what you think.

Oh great. So this is what you put together. Yeah, money, that's another thing. Sliding scale. A lot of this stuff is expensive. I don't buy clothes anymore, I buy vitamins. It's okay. It's okay most of the time. That's another thing AIDS Action helped me with, getting discount cards and what not, because I'm doing all the vitamins and nutrition and that stuff. I'm telling you, that stuff really adds up.

k- You are mostly covered through here though?

Yes. The health plan. But you know vitamins and the acupuncture aren't on the health plan. So I'm on a sliding scale with the acupuncturist. The vitamins I just pay for out of my pocket. It would be nice if they were a tax write-off. (She laughs.)

This looks really good. It looks like people are starting to get more information about women. The thing I saw on the news last night, there was a woman in New York City and they had a women's AIDS center there.

(Looking at the AA, etc. listings) There is also a Nar Anon, but they are harder to get a hold of. You have Al Anon listed here. There's also one for families of addicts which is Nar Anon. The Al Anon main office is in Braintree. The Nar Anon office is a bit harder to track down, but if you call the NA hotline they could probably tell you.

Women, Inc, yes. That's another thing, too, when you get to treatment facilities or half-way houses, dealing with young women who are addicted. When I speak from the podium at AA meetings I get a lot of people asking me, "Should I get tested?" It's tricky because for somebody who is newly sober it could be devastating. They could use it as a great excuse to just run with it and never come back. I think counseling on that level is really important for young addicted women, or any addicted women. In the old days when people used to ask me that — I don't give advice because people have to make their own decisions — I used to lean towards putting sobriety first and remembering what your first disease is, the one that will kill you faster than anything else. That is your addiction. That was before they had the conclusive evidence on AZT and how it helps. They didn't have aerosolized pentamidine available. There wasn't a whole lot you could
do. Now there is a lot you can do. It's really to a person's advantage, the sooner they find out the quicker they can take action. Like the way my immune system has disintegrated, I don't really have a lot left. I have some left, so everything I am doing is making the most of what I have left. So the sooner someone finds out, the more they can make with what they have left. There are people coming in with T4 counts of like 500 and 400. And that's alright, they have something to work with. The sooner they do something about it the more chance they have of keeping ahead of the virus. That kind of counseling is important.

This looks really good.

Do you have the Living Center in here?

k- No.

It's new. It's the Boston Living Center. It's right across the street from AIDS Action and the YMCA on Clarendon Street. It's a drop in place for PWAs and ARC's. It's on the 7th floor. Again, I don't know.... There are women who feel overwhelmed in a room full of men. I was the only woman when I got involved in these workshops or whatever. It was a bunch of guys and then me. It was okay. "You're special," and all of that. They were always really nice to me, but some women have a hard time with that, being around all men. So I think that's another issue. I went to this women's support group for a while that was from AIDS Action Committee before my schedule changed. It's no longer convenient for me to go anymore. There was just a handful of women and I was surprised that there weren't more. It was like, "Where are all these people. Don't they want to get some help?" I don't understand why more people don't get involved. It's the same thing with the client advisory board from AIDS Action. It seems that the meetings aren't very well attended. And again there are only one or two women that go. That disturbs me. It seems that in a situation like this a person would want to get involved. Then again, I look back on my evolution with this thing and it took me a while. When I was ready I took the next step. It's weird that more women aren't involved with these things. Or maybe they are and they just don't know where the resources are. Maybe that's part of the problem.

This is good.

I wish the insurance companies would.... Anyone with this virus who is working their butt off to stay healthy and spending a lot of their own money on vitamins and acupuncture and nutrition and holistic medicine and traditional medical care, we're just trying to stay healthy so that we can save the insurance companies a lot of money. (She laughs.) I've had to pay out of pocket for a lot of stuff that I'm hoping
will keep me off the insurance companies list of expenses. And so far I haven't cost them a whole lot of money, nothing like some people. You would think they would want to encourage people to get involved in this stuff. I'm really glad some of these insurance companies have picked up chiropractic, because that's something a lot of HIV people use to help their whole system, whole body.

k- Insurance companies tend not to cover much preventive.

No. It's all once something has happened to you. Preventive is critical for HIV. A person who works hard at doing something can avoid a lot of things if they are a little educated and know what to be careful of.

Looks good.

[end interview]
Bibliography


