



Minnesota AIDS Project



Overview of HIV Service Needs of Women and Children in Minnesota

Final Report

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EXECUTIVE SUMMARY

In response to the increasing numbers of women living with HIV, the Minnesota HIV Services Planning Council funded a systems advocacy position for women and families. The purpose for this service is to explore the care needs of HIV+ women and their families, examine the current Ryan White CARE Act service delivery system in light of those needs and to propose solutions to better fill gaps in services, including collaboration with non-HIV specific systems.

This report will focus on the needs HIV+ women and HIV+ children face in Minnesota. While there are relatively few HIV+ children in the State, where indicated observations and recommendations will be made. More often, children referenced will be the children being cared for by a mother who is HIV+. There are specific issues relative to HIV prevention and women, which will also be noted. These issues are often related to the need for HIV+ women to avoid reinfection as well as to avoid transmitting the virus to their sexual partners, drug sharing partners or their children. Finally, at the end of the report there will be some general comments, observations and recommendations regarding HIV prevention needs for the vast majority of Minnesota women who are not infected with HIV.

Epidemiological Observations about Women and HIV in Minnesota

Demographic and epidemiological data shows that women make up an increasing percentage of Minnesotans living with HIV and that HIV has substantially unequal impacts on women and children of color. Heterosexual contact is the most common risk factor for women and young women. Additionally, many HIV+ women are living in poverty while caring for themselves and raising their children.

Primary Factors Affecting Access to Care for Women and Families

The lives of women and children affected by HIV are complex. They access a wide variety of public systems just to meet both basic living and medical needs. As women comprise an increasing proportion of people living with HIV, it is important for HIV service systems to anticipate the needs of these women and their children.

The Ryan White CARE Act provides a federal grant to states and metropolitan areas to fund services for people living with HIV. The CARE Act provides a comprehensive set of services designed to allow access to medical care and improve quality of life for people across a continuum of HIV disease stages. However, facilitating access to quality medical care and HIV services for women can be easily overlooked in program designs, meaning that while high quality comprehensive services exist, they are in reality often unavailable to women living with HIV.

This report explores the major barriers to care for women and children as well as the service needs of various subgroups of at-risk or HIV+ women. Often, these barriers are not specific to HIV, but are co-factors of poverty, substance use and the traditional role women have as primary caregivers for children and other family members. Sadly, many of these barriers are the same as those that initially put women at increased risk of infection, making secondary prevention and

services inextricably linked. Following are key observations about a woman's ability to access HIV services and incorporate these secondary prevention messages into her life.

- ◆ **Poverty, substance abuse, mental illness, and domestic violence all impact how and if women will access services and incorporate secondary prevention messages into their lives.** For a long time, HIV professionals have been aware that women who live in poverty, suffer from mental illness, are chemically dependent or the victims of domestic violence are at increased risk of HIV infection. Often these conditions occur concurrently, which is a challenge for them, their family & friends as well as for the service providers.
- ◆ **Sociocultural roles of women affect access to HIV services.** Gender roles and assumptions about female sexuality hinder women from effective secondary HIV prevention methods. Additionally, women are still the primary caregivers for children and family members who may also be ill and as a result are more likely to subordinate their own health care needs to those of their families. Cultural norms also have a substantial impact on a woman's ability to access care.
- ◆ **Stigma and shame about HIV are substantial barriers both in access to testing and in living with HIV/AIDS.** Screening and testing are the key for women to access care early in disease progression. Multiple opportunities in health care settings exist to offer women testing, especially during annual exams or during pregnancy. However, significant barriers exist to testing including a general lack of awareness of risk behaviors, ineffective risk assessment by medical personnel, and lack of coordination between services targeting reproductive health, sexually transmitted diseases and HIV. Additionally, the stigma of HIV and corresponding fear of disclosure to neighbors, co-workers and classmates further complicates access to care and treatment.
- ◆ **High quality clinical care of women and children requires gender and age-specific treatment information.** To develop gender and age-specific treatment guidelines, research data obtained through clinical trials is of primary importance. Because women and children have been historically underrepresented in clinical trials gender-specific information is not plentiful.
- ◆ **Specific subpopulations of women have unique needs and face steep barriers to accessing care.** Women involved in prostitution and women in prison are two groups at disproportionate risk for contracting HIV and require targeted interventions and services especially tailored to meet their multiple needs. Women of color, young women, older women, women who have sex with women, and rural women and children all have unique care needs that may not be fully addressed by current HIV programs.

Continuum of Care

The HIV Services Planning Council has recently adopted a Continuum of Care as a model for services to people living with HIV/AIDS. This model represents a shift away from assessing impact and needs in specific populations and towards a view of impact at various disease stages.

This Continuum will inform prioritization and funding decisions of the Planning Council. Therefore, it is important to analyze needs, barriers and solutions so that the service gaps for women and children can be addressed within the context of the Continuum of Care.

Using the Planning Council's defined disease stages, single women appear to have greater service needs and barriers in the undiagnosed/at-risk/acute infection and recently diagnosed disease stages. The lives of these women can be improved by removing barriers to testing, providing increased access to safer sex information, including how to negotiate with their partner, and streamlining the connection to HIV programs. Families headed by women, on the other hand, show increased needs in the chronic, progressive and end of life disease stages. Once the disease is disclosed to the full family or the woman's health begins to decline, there is a greater need for both emotional support and practical daily living assistance than for men.

Recommendations

In general, actions outlined in this report call for improving access to HIV risk assessment and testing for women and for improving access to services for HIV + women and their children. These recommendations fall into one of the following five categories:

◆ Improve access to HIV testing for women

Improve access to HIV testing by integrating this testing into routine female reproductive health care. The stigma of testing can be lessened by more thorough and routine risk assessments that will identify women in earlier stages of HIV disease.

◆ Foster collaborative approaches and linkages between HIV and non-HIV specific systems and providers.

Non-HIV specific services play an important role in the lives of many HIV+ women. Collaboration between HIV-specific and non-HIV specific systems is essential for optimal care so as to lessen the duplication of services. Service networks providing care to high risk or HIV+ women who are unaware of their status include substance abuse treatment centers, correctional facilities, battered women's shelter and shelters for the homeless. Other providers include food shelf programs, crisis nurseries and welfare-to-work programs. All of these networks would benefit from training and assistance to help them identify and meet the needs of women living with HIV. Such training and technical assistance would also be valuable for schools and childcare centers working with HIV+ children and their families. Providers, who understand cultural values and the unique service needs of women, as well as gender-specific care guidelines, can best serve HIV+ women. Such approaches will lessen the unnecessary duplication of such services within the HIV continuum of programs. Given that many women present with a host of concurrent problems as described above, it is even more imperative for agencies to work together closely to best meet the needs of the client.

◆ Improve the quality of service delivered by HIV providers to respond to the needs of HIV+ women and families.

Examples would include expanding primary medical care to focus on the needs of both the HIV+ woman and her children. This can occur within a family-centered HIV service structure that is flexible enough to accommodate women with a variety of caregiver responsibilities. It also includes development of culturally competent provider networks. Emotional support services for all family members affected by HIV are another essential component of core HIV services. Access services such as childcare and interpretation/translation services are also important. Permanency planning and other legal service programs are crucial for HIV+ women who have families. Finally, programs which help HIV+ women and their children learn how to talk about HIV with others, how and when to disclose “mom’s status”, and allow the child(ren) a safe space in which to deal with the emotional difficulties of having a parent with a terminal illness are all important for maintaining a sound family structure. The Planning Council has a unique role in encouraging Ryan White funded services to evaluate their programs with the needs of women and families in mind.

◆ **Strengthen policies and programs that affect the economic needs of women and families.**

Publicly funded programs providing economic assistance, affordable housing and childcare (especially a state-sponsored childcare program not specifically tied to employment) help HIV+ women meet basic living needs and enable them to focus on the complicated medical care the management of this disease requires. There are multiple opportunities for HIV+ women to link with other service networks also dealing with poverty and lack of access to medical care. These include other disability groups serving low-income women. Many of the service barriers that HIV+ women face are not unique to HIV and are shared by parents with chronic or life-threatening diseases, families in poverty and others with disabilities.

◆ **Consumer empowerment**

We need to support the development of HIV primary and secondary prevention programs that foster women’s self-esteem and teach skills in negotiating safer sex. In addition, making HIV+ women aware of the medical treatment options, benefit programs and other services will provide them with the information they need to make informed decisions. Further, HIV+ women need to become more involved in planning and decision-making bodies, such as the Planning Council, to ensure that their voices are heard.

By developing a specific plan of action based on these solutions, MAP’s women and families systems advocate can work in partnership with other providers and networks to improve access for women to HIV risk assessment and testing, expanded medical treatment options, culturally competent programs for HIV+ women, children, youth and families. And just as importantly, all of this will help to prevent new infections in the future by expanding HIV+ women’s knowledge regarding transmission. This document can also serve to inform service providers and planning bodies when reviewing or designing programs for HIV+ women and families.

INTRODUCTION

It is the 20th year of the AIDS epidemic. Women comprise an increasing proportion of those becoming infected with HIV. Children who were HIV+ positive at birth are moving into adolescence. While death rates from AIDS have decreased dramatically, women have seen less dramatic declines than men. HIV disproportionately affects women of color. An overwhelming majority of children who are HIV+ are children of color. All of these facts are true both for the United States and for Minnesota. This expansion of HIV calls for an adaptation of the HIV service delivery system, often developed to meet the needs of men living with HIV, to ensure that it meets the needs of women and families.

The lives of women at risk for HIV, those living with HIV who are unaware of their status and those women who know that they are HIV+ are complex. In order to adequately meet the HIV needs of women and families, the complexities and multiple, interwoven relationships need examination. In looking at service needs, we find that women's care needs are often linked with children's needs and family responsibilities. It is common for HIV+ women and families to access a variety of public and private systems to meet their basic living needs. And, those basic needs generally take precedence over HIV care. In HIV prevention and services both, links to poverty, substance abuse and domestic violence are obvious.

HIV testing presents a tremendous opportunity for women to learn about prevention of HIV and other STD's as well as how to link to the HIV service network. Yet women are often unaware of their risk factors and reluctant to test due to the stigma. Service providers often don't consider women to be at risk for HIV and fail to adequately do, or even suggest, a risk assessment. As a result access to health care for HIV+ women is intertwined with gender bias.

This report provides an overview of epidemiological and demographic data and articulates key barriers faced by women living with HIV and their service needs. This is often done in comparison to men and is based on an environmental scan. It also discusses gender-specific needs as they fit into the HIV Services Planning Council's Continuum of Care. Further, this report makes recommendations for structural improvements to the existing HIV service delivery system and to non-HIV specific services that impact the lives of HIV+ women. Many of the recommendations can be achieved through systems advocacy and community partnerships. The ultimate goal of systems advocacy is to provide women, both infected and affected, with the resources to make positive, healthy life choices for themselves and their families.

Methodology

The first step toward improving services for HIV+ women and children is the identification of key systems used by women and children with HIV and a review of their capacities, gaps and barriers women face in trying to access these systems. These programs, include, but are not limited to, Ryan White CARE Act-funded services, primary health care, reproductive health

services, economic assistance programs, substance abuse and corrections programs and domestic violence shelters.

This report seeks to examine how HIV affects women, children and families from a wide variety of sources. Data for this report is drawn primarily from interviews with HIV service providers, reviews of state and national demographic and epidemiological data, including service use data, previously compiled needs assessments and a review of a variety of existing literature on the needs of women and families with HIV. Some of the providers interviewed are themselves HIV+ women, but all serve HIV+ women or women at high risk for HIV.

This report is not intended to provide a comprehensive review of the literature on women and HIV or to provide data drawn from a representative sample of HIV+ women and children, such as is done in a formal needs assessment. Rather, this report provides a snapshot of the epidemic and its affect on women and families in Minnesota and discusses some of the barriers that women encounter with systems designed to support and assist them in living with HIV. Further, it highlights gaps that need to be addressed and proposes areas for advocacy and further research with the goal of improving services and access to services. For additional information on the needs of HIV+ women in Minnesota as described in these women's own voice, please refer to CLEAR's analysis of the 1999 Comprehensive Needs Assessment by gender, available Fall 2000.¹

EPIDEMIOLOGICAL OBSERVATIONS ABOUT WOMEN AND HIV IN MINNESOTA

Demographic and epidemiological data provides some general information about HIV+ women and their service needs. Looking at emerging trends in HIV infection can highlight demographic expansion and as a result predictions can be made as to what services need to be added, modified or eliminated across the continuum

HIV infection is increasing among women in Minnesota.

- In 2000, 28% of new HIV infections were diagnosed in women.² This is up from 24% of new infections in 1999, 21% in 1998 and 17% in 1997.³
- Women comprise 18% of all the HIV cases and 10% of all AIDS cases ever diagnosed in Minnesota.⁴
- The number of women living with HIV/AIDS in Minnesota has more than tripled from 1990 to 1999.⁵

HIV/AIDS has a disproportionate impact on women and children of color.

- While people of color make up less than 5% of Minnesota's population, 62% of all women diagnosed with HIV in Minnesota were women of color.⁶
- African American women account for 51% of HIV infections diagnosed among women in 2000.⁷
- Correspondingly, 63% of HIV+ children in Minnesota are children of color.⁸ This is particularly troubling because mother-to-child transmission rates can be cut to 2% with appropriate prenatal and birthing care.
- The number of women of color in Minnesota living with HIV/AIDS has increased from 90 in 1990 to over 400 in 1999.⁹

Sexual contact is the most common risk factor for women.

- While heterosexual contact accounts for 6% of AIDS cases cumulatively, it accounts for 47% of cases in women and 55% of the new HIV infections diagnosed in 2000.¹⁰
- The second most common risk factor among women is "undetermined", suggesting that women do not have a good understanding of their sexual partner's behaviors and their own risk behavior.¹¹

Many HIV+ women are living and raising families in poverty.

- According to analysis by gender of a recent needs assessment of people in Minnesota living with HIV/AIDS, HIV+ women average \$789 in household cash income per month or less than \$10,000 per year.¹²
- The average rent for a two-bedroom apartment in the Twin Cities Metro area is \$684 or 87% of the mean survey income.¹³
- In the same needs assessment, HIV+ women were more likely to have children than men and also to have a child who is HIV+. In the analysis by gender, 88.5% of women surveyed had

children. 80% had 2 or more children and 33% had 4 or more children. 68% of women surveyed had children under age 20 and 48.4% had children under age 15.¹⁴

- The survey also reported that almost one-third of HIV+ people live with a spouse, other relative or a friend, meaning that more than one person is dependent on the below-poverty level income.¹⁵

Young women, who have grown up in a world with HIV/AIDS, comprise a growing number of those diagnosed with HIV.

- 52% of HIV infections among Minnesota women are diagnosed between the ages of 13 and 29. Men in that same age range comprise 41% of HIV infections among Minnesota men.¹⁶
- 63% of HIV+ women ages 13-29 are women of color and 51% of all HIV+ women in this age group are African American.¹⁷

PRIMARY FACTORS AFFECTING CARE FOR WOMEN LIVING WITH HIV AND THEIR FAMILIES

The lives of HIV+ women are very complex. A woman's ability to access HIV-related care often cannot be separated from the economic factors, proscribed behaviors and socially-influenced gender roles women play. Frequently these forces push women into the role as sole caregiver for her family. This section reviews these major factors affecting women's access to HIV care services. While these factors apply to HIV+ women in general, there are certain subgroups of women who face multiple or additional barriers. Unique barriers faced by these groups are also discussed in the following section.

- **Poverty, substance abuse, mental health needs, and domestic violence all impact if a woman with HIV will access services at all. If she does access services, all of these factors influence how and at what point in her disease progression she accesses these services.**

Poverty as a barrier to services

In all of the interviews with service providers, low-income and poverty issues, including access to affordable housing, transportation and childcare, were mentioned as having substantial impact on HIV+ women's ability to access services.¹⁸ Without the ability to provide shelter, food and other basic necessities for herself and her children, it is likely that an HIV+ woman will not receive care or that she will be forced to interrupt her treatment regime to deal with more basic living needs. And unfortunately, poverty is a fact of life for many people living with HIV in Minnesota, even more so for HIV+ women.

In 1999, the federal poverty level was \$8,240 for an individual and \$13,880 for a family of three.¹⁹ To be eligible for many federally funded HIV-related services, an individual's income cannot exceed \$24,720. However, in 1999, 53% of people who used such services in Minnesota had incomes of \$10,000 or less.²⁰ Of those people, 51% were caring for one or more other individuals, in most cases children, on that income. According to the Minnesota HIV Services Planning Council's 1999 "*Comprehensive Needs Assessment*", the average monthly income for men was \$915 per month (133% of poverty) whereas for women it was only \$789 (115% of poverty level).²¹ Women have less money to care for themselves and their dependents, making it more likely that they rely on other people or public programs to provide basic needs. Many of these women receive public assistance so as a result changes to the Minnesota Family Investment Program (MFIP), Minnesota's welfare program, have a direct affect on access to care. Similarly, publicly funded childcare and affordable housing programs also contribute substantially to access issues.

Minnesota Family Investment Program

The Minnesota Family Investment Program is Minnesota's welfare program for poor families and children. Women who are HIV+ but do not meet the criteria to receive Social Security disability payments often rely on MFIP as a source of monthly cash income. However, recent

changes to MFIP, including strict work requirements for almost all participants and a 60-month lifetime cap on cash assistance have made it difficult for families living with HIV to successfully use these MFIP benefits. Over the coming months, the State of Minnesota will make important decisions about changes to the MFIP program. For example, the state can exempt 20 percent of its welfare caseload from the 60-month lifetime cap. Even though that cap is less than 2 years away for some families, the state has still not decided if people with HIV will be included in that exemption. For women living with HIV who experience on-going bouts of severe and debilitating illness, serious and often life-threatening complications to medications and the additional stresses of being a primary parent, this safety net is a necessity.

Childcare

Childcare is key for parents of young children to ensure they are able to access health care and other HIV support services. Current childcare options are not meeting the needs of HIV+ families. State-funded programs are non-existent for parents not in the work force²². Public programs for working parents have long waiting lists, stringent requirements and restrictions. Because state-sponsored plans are tied to work, many parents living with HIV/AIDS are not eligible for these programs. On a related note, many childcare providers have concerns about transmission, liability and care issues when serving children with HIV and even when serving children who may have one or both parents living with HIV.

Childcare needs for HIV+ women become even more complex as women often experience episodic, complicated and often life-threatening disorders from this disease. There may be one, two or even many more episodes where she finds herself unable to care for her children due to her own illness. Traditional childcare systems are not equipped to deal with such problems.

In Minnesota, the only HIV-specific childcare dollars come from Every Penny Counts Emergency Assistance (EPCEA). This program combines federal CARE Act dollars with private funds²³. Funding HIV-specific childcare through emergency assistance forces parents to choose between other critical needs, such as medical co-pays, unexpected car repair bills or an extra-high heating bill, and the basic need for childcare. A previous attempt to develop one HIV-specific childcare center was not successful. One HIV-specific center was too difficult to access given the geographic scope of those living with HIV in Minnesota and parents were often not able to come up with money to pay for childcare in advance of a subsequent reimbursement.²⁴

There are also few options for parents who may need extended childcare. Such needs often arise when a woman is hospitalized or enters a substance abuse treatment program. Crisis nurseries are one option where parents can drop off children for up to 72 hours. However, there are limits on the number of times per year a parent can use this service and the 72 hour limit is not long enough for most of the situations mentioned above. Respite childcare, provided by licensed volunteers for high-needs children with disabilities, has not been incorporated into HIV services. This type of childcare would be appropriate for HIV+ children as well as HIV+ parents who may need some time without care responsibilities to meet their own health needs.

Affordable Housing

Affordable housing is a basic care need and consistently tops the list in all of the formal client needs assessments completed in Minnesota. It is directly related to improved health outcomes. Without an affordable and safe place to live, it is very difficult for people with HIV to meet their own health care needs. For women who have children, this need takes on a special importance and urgency. The Minnesota HIV Services Planning Council's report suggests that women are more likely to say they had difficulty finding housing; HIV has affected their housing situation; they need housing with more than one bedroom; and they feel their neighborhood is not a safe place for children.²⁵ This is consistent with a 1997 HIV housing needs assessment study completed in Minnesota. Major findings from that report included the lack of affordable housing units for families with children, a desire for safe neighborhoods, especially among parents with substance abuse histories, and dissatisfaction with current housing.²⁶ Another preference expressed in that survey was for housing options that allow parents to remain with their children, with a strong preference for in-home care over nursing facilities and adult foster homes, which don't allow children.²⁷

The difficulties faced by HIV+ women are exacerbated by a crisis in affordable housing throughout Minnesota, but particularly in the Twin Cities. In the Minneapolis-St. Paul metropolitan area, the current vacancy rate for rental housing is at 1%²⁸ and the average rent for a 2-bedroom apartment is \$684 per month.²⁹ Many families must pay a majority of their monthly income to rent, often for substandard units, or become homeless. The Wilder Research Center reports "women and children represent the fastest growing segment of the homeless population, with the largest increase occurring in the metropolitan area (881% increase between 1985 and 1997).³⁰ Homelessness among women is further complicated by a shortage of shelter beds for women and youth in the metropolitan area. Often, it is not safe for young people or women to stay in shelters or "safe waiting areas" with men due to assaults, including sexual assaults, drug use and dealing and prostitution.³¹ Shelter providers serve HIV+ women with a variety of needs and problems including substance abuse and mental health needs. Additionally, many of these women have a history of abusive relationships with these relationships directly affecting their ability to find and maintain housing or participate in substance abuse treatment programs.³²

Substance Abuse

For women in Minnesota, HIV infection through injecting drug use (IDU) is still lower than the national average; 5% of HIV+ women in Minnesota report IDU as their primary risk compared to 13% of women reported with AIDS nationally in 1999³³. The more likely risks for female infection in Minnesota come from heterosexual contact with injection drug users, heterosexual contact as a result of trading sex for drugs (especially crack cocaine) and high-risk sexual activities while under the influence of drugs or alcohol. For Minnesota women in 1999, heterosexual sex with an IDU accounted for 29% of newly reported HIV infections in women.³⁴ The Minnesota HIV Services Planning Council's 1999 "*Comprehensive Needs Assessment*" suggests that women

are more likely than men to report they have a partner who is using drugs or alcohol and that their partner's drug use is a problem.³⁵

Substance use and abuse as a barrier to secondary prevention

Substance use affects the way HIV+ women incorporate secondary prevention messages into their lives. Women who use alcohol before sexual encounters are less likely to use condoms during intercourse.³⁶ At least two studies, conducted in major metropolitan areas, suggest that there is a strong correlation between heavy crack cocaine use, unprotected oral sex and HIV infection among women.³⁷ In one study, among heavy crack cocaine users, the HIV seropositivity rate for men was 25.7% and for women it was 32.2%, a statistically significant difference.³⁸ Women were also more likely than men to exchange sex for crack and to do so with greater frequency. While injection drug use is lower for women than it is for men, women may be more likely to borrow a needle to shoot up "once or twice". In a survey of Twin Cities women involved in prostitution, IDU was rare but 72% of the women who had shot up did so with a borrowed, shared or rented needle.³⁹

If a woman successfully completes a treatment program, problems such as poverty, lack of job skills and lack of affordable housing may prevent her from remaining clean and sober. Also, returning to a partner who is still an active user increases the chances for relapse. Without adequate risk reduction information, including information on safer sex techniques and negotiation skills, women who successfully complete treatment may still be at risk for HIV and other sexually transmitted diseases (STDs) if they return to former sexual partners.

Barriers to substance use treatment

Access to substance abuse treatment programs may be more difficult for women who are HIV+, especially if they have children. Many women report being afraid to access health services for fear that their children will be taken away by child protection.⁴⁰ Additionally, the stigma of substance use keeps many women from disclosing to their health care providers. Many women have very poor experiences disclosing their HIV status to chemical dependency treatment staff, which further reinforces the lack of trust many of these women feel towards the entire health care community. Many women who are active users wait until there are no alternatives before accessing health care, including prenatal care.⁴¹ The double stigma and stress of being HIV+ and labeled as chemically dependent is often too overwhelming for women to cope with, out of fear they may avoid both pre-natal care and substance abuse treatment.

When women seek substance use treatment, they are often restricted to day treatment or outpatient programs due to lack of childcare alternatives. Women who know that they are HIV+ when they enter treatment are often encouraged by their counselor to not disclose that information. If disclosure happens involuntarily, the woman may be subject to harassment from other clients and even staff. Also, the lack of preparation of these treatment facilities to handle disclosure issues will cause an HIV+ woman to leave treatment prematurely. Overall, substance abuse treatment facilities are generally not meeting the needs of HIV+ women.⁴² For more information on how substance abuse treatment centers could better serve HIV+ clients, see

Fighting Twin Epidemics: Substance Abuse and HIV, the substance abuse systems advocacy report compiled by MAP staffer Bill Seed.

Mental Health

Unmet mental health needs prevent some HIV+ women from accessing services and being able to adhere to a treatment plan. Lack of mental health care can also interfere with basic care needs such as housing, employment and dealing with substance abuse issues. Early data from the Minnesota HIV Services Planning Council's 1999 *Comprehensive Needs Assessment Report* shows that 16.4% of women surveyed self-report a psychiatric disability.⁴³ This number is most likely an under-reporting of those who have mental health needs beyond solely emotional support. A *Mental Health Needs Assessment* also commissioned by the Minnesota HIV Services Planning Council and published in March of 1999 found that of the 25 people interviewed (10 women), only two had not used mental health services since they tested positive for HIV.⁴⁴

Providers consistently identified mental health problems as barriers to access and follow through for many clients. For women, mental health is repeatedly mentioned as an unmet health care need. According to Hennepin County Community Health, one third of the homeless population (men and women) have mental health problems⁴⁵ Again, concerns about child protective services and lack of childcare options create barriers to care for HIV+ women, particularly women with substance use issues.⁴⁶ Active substance users, who also have mental health problems, often will not disclose drug and alcohol abuse related problems to mental health professionals. And, fears about interactions with street drugs may lead to discontinuation of prescribed psychiatric medications.⁴⁷ The lack of comprehensive and HIV-sensitive mental health services for women, as well as men, throughout the State is an enormous problem. Providers face difficult decisions when working with a small number of HIV+ women who put themselves and others at risk for violence or abuse due to the lack of good mental health care.

Domestic violence

Literature examining the connection between domestic violence and HIV infection in women is scarce, but various studies suggest that women who are at highest risk for domestic violence are also at an increased risk for HIV infection⁴⁸, that violence is a significant cause of death for HIV+ women⁴⁹, that women who reveal their status to partners are at greater risk of abuse⁵⁰, and that childhood sexual abuse may put women at greater risk for HIV.⁵¹

Domestic violence as a barrier to secondary prevention

Interviews with local women's health clinics confirm that portions of their female clientele are in relationships where they are not in control of their sexuality. For example, some women who have medical procedures requiring them to abstain from vaginal intercourse for a period of time report that this is simply not possible with their partners.⁵² Women who are not able to control their sexual experiences by saying "no" to their partners, even after surgery, are also not able to insist on safer sex practices such as condom use. Also, women in physically abusive relationships are reluctant to ask partners to use condoms for fear of provoking a beating. A study recently reported by the Kaiser Family Foundation suggests that men who beat or sexually abuse their wives are also more likely to have extramarital affairs, thereby exposing their spouses to HIV and other STDs while denying them the means to protect themselves.⁵³ Based on all of

these data, it is clear that women who are HIV+ and in abusive relationships have little control over preventing secondary HIV infection.

Domestic violence as a barrier to HIV services

Women in abusive relationships generally have chaotic lives and little control over decisions such as when to see a health care provider. In addition, HIV+ women experiencing domestic violence may be seen as “noncompliant” with medical treatment plans. They may miss appointments, fail to follow-up on medical referrals or to adhere to complicated medication regimens. Based on that, providers may wrongly assume that these women are not interested in aggressive HIV therapy.⁵⁴ Service providers need to be aware of symptoms of domestic violence in the women that they serve and be able to offer resources and support. Similarly, domestic violence shelters and programs that work with women who have been abused need to understand the risks for HIV and STD transmission so that they can offer appropriate health and screening services.

There is some evidence that partner notification programs may put women at additional risk of abuse.⁵⁵ Partner notification is a program run by state health departments and funded by the Centers for Disease Control. A disease intervention specialist contacts individuals who have recently tested positive for HIV and certain other STDs, providing safer sex and treatment information, assisting the individual in notifying all past sexual partners and encouraging partners to be tested. Various studies have shown that women are at greater risk for domestic violence, including beatings, shootings and even murder, after revealing their HIV status to a partner.⁵⁶ Should the abusive partner learn of their status from the disease investigator, even if the investigator doesn’t reveal the woman’s name, there remains a high probability that the woman will be at risk for physical abuse.

- **Sociocultural roles of women affect access to effective HIV services.**

Gender Roles

Debate about women and sexuality has been going on for hundreds, if not thousands, of years. It permeates all parts of society from legislative debates to personal relationships. Some social conventions call for women to be passive in sexual relations, deferring to their partners’ wishes. Accordingly, women are also expected not to express sexual feelings or engage in sexual relations outside of heterosexual marriage.

Clear delineations are made between “good girls” and “bad girls”. Women who know too much about sex or make sexual demands of their partners, such as condom use, are generally placed solidly in the “bad girl” camp. Women who carry condoms with them may be perceived as promiscuous. The notion still exists that in a committed relationship, the “one true love”, insistence on condom use is a sign of infidelity. While women are now more open about their sexuality, experiences outside the heterosexual norm, such as anal intercourse, may still bring about feelings of shame. And, anal intercourse carries with it a greater risk for HIV infection than does vaginal intercourse – a fact little understood in the heterosexual community.

Gender differences between men and women have substantial implications for prevention and service delivery. Many women are still reluctant to ask their steady partners to consistently use condoms, even if they know their partners to be engaging in risk behaviors outside of their relationship.

Women are primary caregivers

Women are generally still the primary care givers for children and sick family members. Minnesota's case management data from 1995 found that 71% of HIV+ parents living with children were female.⁵⁷ Women are likely to subordinate their own health care to the needs of their families. For HIV services to meet the needs of women, systems of care must acknowledge the multiple roles that women take, especially those of spouse, caregiver, parent and sexual partner.

It is not uncommon for a woman to find out that she is HIV+ during pregnancy or shortly after giving birth. While this allows opportunities to prevent transmission from mother to child (such as use of anti-retroviral medication by the mother), there is also a danger of focusing so heavily on delivering a healthy baby that the mother's care needs are overlooked. After a woman gives birth, the focus turns from her health to the health of her child. Even mothers with substantial problems, such as active substance abuse, try to meet check-up and immunization timetables for their children.⁵⁸ However, because these efforts are focused on the child, the mother's health needs may go unmet until she becomes too sick to ignore symptoms any longer.

Clinics that offer integrated health care and social services, or "one-stop shopping" where a mother can bring her children for well-child care, have her HIV and non-HIV medical needs met, and receive information about services can play an important role in ensuring that women access care for themselves. If a clinic offers a range of health care services aside from solely HIV care, it also reduces the stigma of going to an "AIDS clinic". Clinic staff and case managers also must be aware of the unique factors that affect a woman's ability to make appointments and follow through with treatment plans. Frequently, women miss appointments because of sick children or inability to arrange day care, time off work, or transportation. If a woman is not open to her family about her diagnosis, she may have difficulty adhering to a complex drug therapy regime. Missed appointments and non-adherence may be misinterpreted as a lack of interest in treatment rather than a problem with the service delivery system.⁵⁹

Because 79% of children in Minnesota living with HIV were infected perinatally, there is also a need for resources to help children understand their own HIV status.⁶⁰ As these children grow into adolescence, they need uniquely tailored prevention messages and treatment adherence strategies.⁶¹

- **Stigma and shame around HIV are substantial barriers both in access to HIV testing and in living with HIV/AIDS**

Stigma and shame about testing HIV positive still pose significant barriers to effective risk assessment and testing. Very real fears about disclosure of one's HIV status can be the most difficult issue for HIV+ people to address. This fear affects all family members, not just the HIV+ person. Stresses resulting from these fears have emotional impacts on couples and families.

Stigma as a barrier to testing

Women, on average, visit health care providers more frequently than men do. One reason for this is that women bear unique responsibilities when it comes to reproductive issues. Women are often responsible for contraception and many forms of birth control require annual pelvic exams. Women are also more likely to access care when pregnant or through services for their children than to seek out services on their own.

With all of these visits to health care providers, women should be receiving excellent health care, including regular screening for HIV and STDs and risk reduction information. Why is it then that women tend to present later in HIV disease progression, are less likely to test because of self-identified risk and are not offered HIV tests as a routine part of prenatal care? Some of the reasons include inaccurate risk assessments, provider and client discomfort, and lack of coordination of women's health services.

Risk assessments

Risk assessment is an important part of pre-test counseling. It allows the health professional to target risk reduction information, but on the whole, it does a poor job of identifying women who may be in need of HIV testing. A risk assessment is a series of questions asked prior to an HIV test to determine the client's potential exposure to HIV. Often, it is also used to determine whether or not a patient has had a risk exposure and therefore should be tested for HIV. While women's frequent contact with reproductive health care providers provides a wonderful opportunity for a risk assessment, they are often not done. And, inaccurate risk assessments result in women not being offered testing during routine reproductive health care.

One reason that risk assessments yield inaccurate results for women is that the woman herself may be unaware of the risk behaviors of their sexual partners. For example, a woman may believe that she is in a monogamous relationship, unaware that her partner has been having unprotected sex with other women or with men. Or a young woman may know that her boyfriend uses illegal drugs occasionally, but is unaware that he shoots up and shares needles from time to time. Even if women are aware that they have engaged in risky behaviors, they may be unwilling to admit that to health care providers. There is still a significant stigma for women in admitting that they have multiple sexual partners, engage in anal intercourse or use illegal drugs. Having to admit to these behaviors as a precursor to HIV testing presents a barrier to testing.

Provider discomfort

Women seeking health care are not the only ones who have difficulty talking about HIV risk behaviors. Health care providers also may be uncomfortable discussing sexual behavior or drug use with their patients. This presents a barrier to HIV testing, as these providers do not ask the questions necessary to accurately assess a women's HIV risk. For example, women who have sex with women often are not offered HIV tests even though they may have had risk exposures through sex with men or IV drug use.

For community clinics and managed care clinics, a sexual health history may not be a routine part of reproductive health care for women. Again, providers may feel uncomfortable discussing such subjects with female clients, may not believe that their clients are at risk or under the managed care system, do not have enough time or resources to provide a thorough risk assessment. Eliminating risk assessments and instead routinely offering voluntary testing as a part of women's reproductive health care can reduce the barrier of provider discomfort.

Lack of coordination of service

Another factor influencing HIV testing may lie in the lack of coordination between the systems that serve women's health needs. Often a woman is seen in a women's health clinic for annual exams, prescriptions for birth control or pregnancy testing. At this time she may also be asked to complete a sexual health history and risk assessment for STDs and HIV. Depending on the results of the risk assessment, she may or may not be screened for STDs or HIV. Many women who specifically request STD screening do not realize that they must ask for and consent separately for an HIV test. Some women assume that exams include STD and HIV tests both.

If a woman receives a positive pregnancy test result from a reproductive health clinic, a referral is made for prenatal care from an OB/GYN provider, generally at a different facility. Women's health clinics do not routinely offer women HIV or STD testing when they deliver positive pregnancy results, assuming that this will be incorporated into prenatal care at a later date, but such is not always the case. In addition, family planning services, HIV testing and STD testing are all funded separately, creating additional barriers to access.⁶²

Minnesota Department of Health Perinatal Prevention Pilot Project

Prenatal care offers an ideal opportunity for HIV counseling and testing. Routine risk assessment and offers of testing to all pregnant women have been recommended by the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists as the best way to prevent perinatal transmission.⁶³ Transmission rates from mother to child are normally about 25% without any pre-delivery medication therapy but can be reduced possibly as low as 2% with therapy for both mother and baby. This is in addition to preventative measures, which can be taken during delivery.⁶⁴

In 1998 the Minnesota Department of Health undertook a Perinatal Prevention Pilot Project, designed to increase HIV testing rates among prenatal care providers. The MDH found initial testing rates ranged from 36% to 78% of women seen at various clinics.⁶⁵ Even when clinics

demonstrated substantial interest in increasing prenatal HIV testing, barriers remained. Poor risk assessment, provider discomfort and lack of coordination of care posed some of the most substantial barriers to increased testing rates. Some providers felt uncomfortable discussing risk behavior with their female patients, believed that their patients were not at risk or thought that it would be insulting to offer HIV testing.⁶⁶ On the other hand, at one clinic, providers simply tested pregnant women without their knowledge, eliminating the need for what were perceived to be uncomfortable discussions. Such actions deprive women of their right to informed consent. Administrative issues, such as difficulty remembering to order HIV testing with routine lab work or lack of time for pre-test counseling were also barriers.⁶⁷

Results from the Pilot Project suggest that a change from offering HIV testing based on risk assessment to universal voluntary testing for all patients was key in increasing testing rates. Universal voluntary testing means offering testing to all women as a routine part of prenatal care rather than just selected women based on a risk assessment. During the course of the Pilot Project, two women tested HIV + positive who did not have known risk factors. One more case was reported after the completion of the Project.⁶⁸ Offering testing to all women seeking routine reproductive health care eliminates the stigma associated with admitting risk behaviors and also offers testing to women who may not know that they are at risk. The Pilot Project also showed that voluntary testing rates would be dramatically improved when administrative barriers were reduced. In less than 6 months HIV testing rates were increased to between 80% and 97% of women receiving care.⁶⁹

Stigma as a Barrier to HIV Care

Disclosure

If a woman tests positive for HIV, one of the most difficult issues she faces is disclosure to family, friends and children. Dr. Laura Hoyt, pediatrician at the Delaware Street Family Clinic, estimates that two-thirds of her female patients do not disclose to anyone. They struggle to hide the medications and doctor appointments from family and co-workers and cope with the emotional impacts of HIV in isolation. Many women are afraid that such disclosure will be too much of a burden for their children. They fear that knowing their parent is HIV+ will be too much for a child to handle or that the child will not be able to keep “the secret” and will disclose to neighbors or schools.

Even parents who are open about their illness have extra concerns when it comes to dealing with their children. One support group participant said, “You know I’ve really come out about this. I’ve told my boss, both our families know ... but when it comes to our neighbors and our church, I just can’t do it because it will label my son. I just can’t do it to him.”⁷⁰ Similar feelings were expressed in interviews with HIV service providers who were HIV positive themselves, suggesting that stigma presents a significant barrier to care even among well-informed women.⁷¹

Mothers often struggle with how to teach their children when and how to disclose a parent(s) HIV status. There are obvious differences based on the age of the child, however this is often a

very difficult and emotional challenge. Depending upon the child's age, their fear of illness, doctors and death differs. Once a mother discloses her HIV-status to her child(ren), she must continue to work with them over time as their level of understanding and emotional status regarding her situation changes.

Emotional impacts on couples and families

The stress of living with HIV is felt by all family members to some degree and is often made worse by stigma and fear of planning for the future. Therefore, HIV service providers must acknowledge the impact of HIV on sero-discordant couples when HIV-negative women are partners of HIV+ men. A study of heterosexual sero-discordant couples found that while there are similarities between the stress HIV and other chronic diseases have on relationships, the stigma that still surrounds HIV presents unique issues. In addition to stigma and disclosure issues, HIV places a burden on relationships in the areas of choices about sexual intimacy and childbearing.⁷²

Problems due to stress were the most frequently mentioned unmet need for these couples. All couples reported that HIV had seriously impacted their interpersonal relationships.⁷³ Fears about the reactions of family members and friends often silence the caregiver and deprive them of traditional forms of support. Groups that provide emotional support, discuss medication adherence and treatment side effects are rightly focused on HIV+ people but this results in fewer and less well publicized support services for affected caregivers. As a person progresses to later disease states, more of the responsibility for medical appointments, dosing schedules, nutritional requirements and side effect management falls to partners acting as caregivers. In some cases, partners may experience even greater distress in dealing with the illness because of their role as caregivers.⁷⁴

Discussions about sex and reproductive decision-making are particularly difficult for sero-discordant couples. At the 1999 Women and HIV conference, HIV+ women talked about changes in their sex lives including diminished sexual desire, concerns about transmission, changes in body image as a result of HIV treatments and difficulties in negotiating consistent condom use.⁷⁵ In the sero-discordant couple study, a lack of communication about HIV and its impact on sexual relationships led to risky sexual behavior. "Couples may cope using denial and avoidance strategies leading to unprotected sex. Many couples in this group discussed episodes of unprotected sex at various times since learning of the HIV infection", researchers found.⁷⁶ Couples also mentioned engaging in unprotected sex because of the desire to have children, underscoring the need for information and resources to help couples with reproductive decision-making.

There are also very difficult issues for couples who are both HIV+. In this case, the issue of secondary infection of each partner must be understood. Even if one partner infected the other, the need to not re-infect is of paramount importance. As HIV mutates over time, especially given various drug treatments, it is critical that the partners discuss and understand the importance of safer sex. This can be very challenging for women if their male partner doesn't

understand, doesn't want to understand or frankly doesn't believe there is a risk and insists on unprotected sex.

- **Lack of specific research and access to clinical trials for women and children make it difficult to develop gender and age-specific treatment guidelines.**

Quality medical care for women begins with an accurate diagnosis. As a result, medical staff who routinely provide services for women - family practice physicians, OB/GYNs and women's health clinic staff - need to be aware of the unique ways HIV presents in women. Infectious disease physicians who specialize in HIV care must stay current on treatment recommendations for women, such as PAP smears every six months due to the greater risk of cervical cancer they face. And given that the majority of those living with HIV both in Minnesota as well as throughout the United States are men, there are many HIV specialists who see few, if any, female patients.

Providing these medical care practitioners with information about the way in which HIV manifests in women and gender-specific care guidelines is difficult due to lack of women-focused HIV clinical research. Currently, there is no formal standard of HIV care set forth for women. As more information becomes available from research and women's treatment advocacy groups, HIV specialists may be able to determine a set of primary medical services that would be standard practice in women's HIV care. While clinical care guidelines exist for children, more information is needed as new treatment options become available. However, gender and age-specific treatment guidelines begin with data collected in clinical trials.

Many women with HIV do not seek care from infectious disease practitioners, but rather continue to see their primary care physician or family practice provider. It is important for these physicians to also understand how HIV disease manifests in women and to provide resources for these doctors, for example information on how to connect for consultation purposes with HIV specialists.

HIV treatment guidelines for women

Until a lawsuit in 1993, women were essentially not allowed to participate in clinical trials by the Food and Drug Administration (FDA). While the number of women participating in HIV clinical trials has increased in recent years, women, and especially women of color, are still under-represented. This means that treatment guidelines are most often based on studies of men only and then extrapolated to assume that women and men respond similarly both to the virus and to antiretroviral medications. Various studies suggest that women metabolize HIV drugs differently than men, that differences in body mass may require different doses and that hormonal changes in women affect the rates at which drugs metabolize.⁷⁷ But because women have not been present in great numbers in clinical trials, it is not possible to say with authority how treatment regimes should be altered. And, to exacerbate this situation, recent reports indicate that individual response to various medications differs based on race. This also complicates treatment for HIV+ women who disproportionately in Minnesota, as elsewhere, are women of color.

Recently, new research has suggested that women and men may have vastly different viral loads while having the same CD4+ cell count. Specifically, “the studies suggest that women have progression of HIV disease (at least as measured by CD4+ counts) at lower levels than men.”⁷⁸ According to one study, the A.L.I.V.E. study, presented in 1998, “women appear to progress to AIDS with approximately half of the viral load as men.”⁷⁹ Because decisions about when to begin antiretroviral therapy and when to switch from a “failing” regime are based on combinations of viral load counts and CD4+ counts, these findings could have major impacts on women’s treatment decisions. Again, not enough is known about this gender difference to provide clear guidance to patients and physicians.

Certain AIDS-defining illnesses are also more commonly seen in women, leading to an expansion of AIDS case definitions to recurring yeast infections, cervical cancer and bacterial pneumonia.⁸⁰ In fact, recurring yeast infections are the most common reason that HIV-infected women first seek medical attention.⁸¹ Additionally, STDs in HIV + women may be more difficult to treat and Pelvic Inflammatory Disease (PID), a major cause of infertility in women, is “more prevalent, severe and resistant to treatment among women with HIV.”⁸² Cervical cancer also appears to be more common in women with low CD4+ counts requiring HIV+ women to have more frequent PAP smears and follow-up testing to detect any abnormal cells as early as possible.

Clinical Trials

Currently, although various Minnesota hospitals participate in clinical trials, none are women-specific. There is interest at the AIDS Clinical Trials Unit (ACTU) at the University of Minnesota to both design women-specific trials and increase the number of women participating in ongoing trials. Currently, women make up approximately 14% of trial participants at the University of Minnesota.⁸³ However, before trial participation can be increased, the issues unique to women’s participation must be addressed. According to a San Francisco study, women not currently participating in trials listed lack of information about clinical trials, lack of interest and fear of side effects as major reasons for not participating. For women already enrolled in trials, a recommendation by their primary care provider and support of the care provider and research staff were major facilitators to participation. However, while “48% of the providers surveyed considered their patient to be a good candidate for a clinical trial, only 14% had discussed the option of participation in a clinical trial with that patient.”⁸⁴

Most participants at the ACTU are referred by their physician or case manager. Common problems noted to increased women’s participation include schedules, responsibilities of caring for children and arranging childcare, transportation and disclosure to family members. An ACTU outreach worker also cited lack of knowledge about clinical trials as an issue for women. In communities of color, historical mistrust of the medical community and medical experiments in particular is a major reason for low participation.

Treatment issues for children

If a substantive criticism of HIV care for women is that it is based on studies of men, that is even more applicable to treatment guidelines for children. Due to the lack of pediatric clinical trial data, recommended treatments until recently could be characterized as conservative versions of adult regimes. While clinical research into pediatric AIDS treatments still lags behind adult trials, treatment guidelines have become more aggressive, especially in recent years. Expert opinions on pediatric care favor beginning anti-retroviral therapy as soon as HIV infection is documented.⁸⁵ Further, current treatment guidelines suggest that all anti-HIV drugs approved for adult use may also be used with children, even if they haven't specifically been approved for pediatric use.⁸⁶ Immature immune systems in children are less able to fight off infections and even if children have high CD4+ cell counts, they may be susceptible to opportunistic infections.⁸⁷ Getting infants through their first year becomes vitally important.

However, because children are dependent on adults for their medication, any therapy regime must take in to account the caregiver's ability to consistently administer medications. Also, with children receiving the same medicines as adults, they often develop the same side effects and have similar difficulties in adherence. In the latest guidelines, the National Pediatric and Family HIV Resource Center notes that "coordinated, comprehensive, family-centered systems of care can often address many of the day-to-day problems facing children, adolescents, and families that may affect their adherence to complex medical regimes."⁸⁸

Minnesota has very low numbers of HIV-infected children, making it extremely difficult to conduct treatment studies here. Primary care for HIV+ children is most often provided through the University of Minnesota's Delaware Street Family Clinic, Children's Hospital St. Paul and Park Nicollet Clinic. The guidelines stress the importance of pediatric specialty care for HIV+ children and adolescents saying, "Management of infants, children and adolescents with HIV/AIDS is rapidly evolving and increasingly complex and therefore, wherever possible, management of HIV-infected children and adolescents should be directed by a specialist in the treatment of pediatric and adolescent HIV infection."⁸⁹

Therefore, even though numbers of children needing care in Minnesota are very low, it is important that those children who are infected have access to high-quality pediatric HIV/AIDS care. Additionally, caregivers for these children need resources and support to manage complex treatment and emotional issues.

- **Uncertainty regarding the course of HIV disease progression and its impact on her children often inhibits women from seeking care.**

As stated throughout this report, many women living with HIV in Minnesota are primary caregivers for minor children. The treatment of HIV disease has an uncertain future. This is an extremely frightening situation for women who have little outside family support, are fearful of an abusive partner who is father to their child(ren), or do not know what their options are for childcare should they become too ill to care for their children. And, for many women this will be a reality during the course of their illness. They may at times be too ill to care for their children,

only to recover and be well enough again to be a primary caregiver. Or, they may reach end of life and have no plans for what will happen to their children. As such, it is of critical importance that women with HIV disease begin permanency planning early in their HIV disease management. This includes plans for stand-by guardianship should they need to assign temporary guardianship for their minor children as well as longer-term planning should they reach end of life.

For many women this is an enormous step to take as by doing so they are acknowledging that they may not be present to assume the primary role in their child's upbringing. Just coming to the point of being able to discuss this can be overwhelming for many women, particularly those who are feeling isolated and have no outside support. HIV caregivers must approach this carefully, be prepared to provide resources such as the Minnesota Family Legacy Project at MAP which can aid women in taking the legal steps necessary for future planning. Too often in the past women have not had these resources and at end-of-life decisions that were made were made in a hasty and ill-prepared fashion. Once a woman is aware of her options for permanency planning, she often feels more prepared to address the issues facing her regarding medical treatment, potential hospitalizations and so forth.

SUBPOPULATIONS WITH MULTIPLE OR ADDITIONAL BARRIERS TO HIV CARE

For certain subpopulations of women, there are multiple factors affecting HIV care. In addition to being impacted by the concerns discussed in the previous section, additional factors often make access to HIV services even more difficult. The following section addresses these factors.

Women in Prison

In Minnesota, official number of HIV+ women in the state-run correctional system is very low – only 5 known cases currently at the Minnesota Correctional Facility – Shakopee. However, some professionals who have worked with women at MCF - Shakopee believe that this is an undercount of HIV+ incarcerated women. Possible explanations for such low numbers include reluctance to disclose HIV status to prison staff and significant barriers to HIV testing after entering the facility.⁹⁰ For women entering the prison system, HIV tests are offered free of charge during the intake process but if testing is desired later, there is a cost of \$3.00 for the woman. For many of these women who are very low-income, \$3.00 is a large sum compared to prison wages of \$.25 to \$1.00 an hour.

Once a woman has been in-processed, she will receive approximately one hour of HIV/STD education during her stay. Women who are incarcerated for long periods of time may have opportunities to repeat this education program. If an incarcerated woman would like to have an HIV test after intake, she must send a request to the medical staff. Staff will then ask why it is that she would like an HIV test at this time and what her perceived risk factors are now as compared to at intake. While this is a standard part of comprehensive pretest counseling, it is a problem for incarcerated women. If they admit to injection drug use or sexual activity, for example with a male correctional officer, while incarcerated, they are at risk for disciplinary action or retaliation from the staff.

Another barrier to HIV testing or disclosure is the serious concern regarding confidentiality of test results and treatment plans. Anecdotal evidence suggests that there are serious problems with staff confidentiality. And, the structure of prison life does not afford women a great deal of privacy. For example, if an HIV+ woman is on antiretroviral therapy, her meds will often be dispensed with meals, allowing other inmates to see the drugs. Even if meds are dispensed privately in a health care setting, both the health services staff and the guards must be aware that an inmate needs regular trips to health services. Because prison life is highly regulated, any deviation from the set schedule is noticed and questioned by the other inmates.

Quality of medical care for inmates has always been a controversial subject with advocates claiming that prisoners don't have access to HIV medications, prophylaxis treatments and routine screenings while prison officials claim that they offer high quality medical care, albeit with limited resources. Because health care for prisoners is funded through Corrections rather than Human Services, prisoners are not eligible for state-sponsored health insurance programs or the federally funded AIDS Drug Assistance Program (ADAP).

Currently in Minnesota, there is no specific process to connect HIV+ women prisoners with community-based services such as primary health care, case management, substance abuse treatment or housing. However, a pilot project is being developed by the Minnesota Department of Corrections to implement a system whereby women are connected to community resources prior to their release.

Women of Color

The historical and on-going issue of racism in the United States impacts a woman's ability to access care. Some of the solutions might be obvious, such as the need for high-quality, professional translation/interpretation services or targeted messages for the African-American or Latino communities. However, women of color are impacted in unique ways by cultural norms and gender roles in both accessing secondary prevention messages and meeting their health care needs. Studies have documented disparate levels of care, most especially for women of color. Practitioners have historically spent less time, offered fewer referrals and often neglected to provide as comprehensive of an examination as is done for white women. Obviously for HIV+ women of color this presents an enormous problem as they have also historically presented later in disease progression and with a greater number of symptoms.

African-American women

There has historically been a substantial cultural divide between African American clients and service providers who are most often white. Provider mistrust is a significant barrier for African Americans seeking care and for participation in clinical trials.⁹¹ In the Black Needs Assessment completed in Minnesota, negative perceptions of doctors and lack of understanding of what doctors were doing and why were listed as major barriers to primary health care⁹². Perhaps because of this, only 53% of those interviewed in the Black Needs Assessment had primary care physicians.

The connection between racism and poverty also impacts African American women's ability to access secondary prevention messages and HIV-related services. "Priorities of survival take precedence over healthy behaviors," the Department of Health reports in their Comprehensive HIV/STD Prevention Plan.

Hispanic/Latina women

Cultural norms dictate what kinds of safer sex behaviors are open to women and how receptive they will be to offers of HIV testing. For example, at Westside Community Health Service, Hispanic women were likely to decline an HIV test because it might signal that they thought their partner was unfaithful.⁹³ In cultures where women are seen as being passive in sexual relations, it is often difficult if not impossible for a woman to ask her partner to use a condom. In fact, condoms for many cultures are tied with prostitution or at the least, unfaithfulness, and therefore "good" women would not need or want to use them.⁹⁴

Asian-American women

Cultural norms regarding disease and death also affect a woman's willingness to seek health care services, especially for such severe medical conditions as HIV. In Hmong culture there is a belief that discussing a disease may bring it on; therefore talking about HIV and risk reduction with Hmong women may be more difficult.⁹⁵ It is important to note that even though it may be difficult for a provider to discuss sexual behavior with certain patients and to obtain their consent for HIV or STD testing, the provider cannot skip over these issues and test without the patient's consent. Westside Community Health was able to increase HIV testing among their Hmong female patients by assuring patients that the HIV test does not require an additional blood draw, something at odds with Hmong cultural norms.⁹⁶ These unique cultural matters do underscore the need for provider training in cultural competency issues and specific training to meet the service needs of individual populations. Using a "cultural broker" to interpret social norms and ideas between provider and patient is also an option.⁹⁷

Indigenous women

Again, issues of poverty, racism and substance use affect Indigenous women's access to HIV prevention and services. Many Indigenous women have had poor experiences with white health care providers and so are reluctant to return. There are also issues of shame and stigma surrounding HIV as with all women, however often basic living needs take precedence over HIV care. In the Department of Health's Comprehensive HIV/STD Prevention Plan, Indigenous people also mention the culture gap between Anglo medical care and native treatments including various ways of providing care.⁹⁸

Language and immigration barriers

Language barriers for women also differ from the barriers that men face. Often immigrant women, more often than men, rely on family members, including children, to provide interpretation services for them. This presents a substantial problem when discussing matters of sexuality. Even if the interpreter is an adult, there may be concerns about personal information getting back to others in the community. Often women will be accompanied by male relatives but do not feel comfortable discussing sexual issues in front of a male interpreter, especially a relative. Gender bias may also affect how a translator recounts information to the provider, with a male interpreter playing down the seriousness of a female patient's complaints and not providing accurate translation services. Also, very real fears about deportation and citizenship status keep women from accessing health care and social services.⁹⁹

Rural women

Women in rural communities face many of the same problems in accessing HIV prevention information and care that urban women do. Poverty, domestic violence and substance use are all shared between urban and rural women. However, women in rural communities face even greater ignorance of risk factors, concerns about confidentiality in testing and isolation if they test positive.¹⁰⁰

Many individuals in greater Minnesota do not believe that they are at risk for HIV or STDs. Consequently, many do not practice safe sex even when they engage in high-risk behaviors. The

lack of comprehensive sexual health education in many greater Minnesota schools puts young people at risk because they are unaware of risks associated with heterosexual transmission. Many people, including health care providers, still believe that HIV is a “gay disease”.¹⁰¹ There are important concerns around confidentiality of HIV/STD testing in local communities. People who are able often travel to larger cities or the Twin Cities for testing.¹⁰²

For HIV positive women living in greater Minnesota, the greatest problems faced are poverty and isolation. HIV services are concentrated in the Minneapolis/St. Paul area. This means long travel times, overnight stays and missed work for women who want to take advantage of these services. Even if women are able to access health care closer to home, there is still a significant stigma attached to HIV in rural Minnesota and so voluntary disclosure to neighbors and the community is almost unheard of. Unfortunately, this perpetuates the myth that HIV does not affect greater Minnesota.

Often individuals living with HIV are in conflict as to where they would prefer to receive care. While long and expensive trips to Minneapolis/St. Paul are often difficult, many women have expressed concern about receiving such specialized care too close to home for fear that someone in the clinic or pharmacy may discover their HIV status. And, given the relatively small number of HIV+ women living outside of the Twin Cities and the fact that they are scattered throughout the State, the HIV service delivery system becomes strained as it determines if and where to locate specialized services.

Young Women

Youth who are already HIV positive have a variety of issues to deal with. Most of the young women case managed at the Youth and AIDS Project have children. They may also be confronting substance abuse problems, be victims of domestic violence or have engaged in survival sex. Resources are often limited for youth under the age of 18 and systems that are adult-focused often do not make youth feel safe or welcome.¹⁰³ Even if positive youth do not face any of these additional barriers, there are concerns about medication adherence, disclosure to peers and the normal adolescent questions about how to negotiate social, romantic and sexual relationships.¹⁰⁴

Older women

Similar to youth, older women may feel that HIV services are not set up to meet their needs. Not only is there a lack of prevention messages targeted at older women, there is a lack of information about how HIV and the aging process intersect for those who are HIV+ and in their later years. This lack of information includes how HIV drug therapy affects treatment for health disease, arthritis, osteoporosis and menopause.¹⁰⁵ Many HIV+ people in this age group do not feel comfortable in support groups that seem to target younger people. They experience a lack of peer relationships, concerns about decreasing work options due to age and a lack of resources to help older people deal with intimacy issues.¹⁰⁶

Women who have sex with women

Given that the Centers for Disease Control and the State of Minnesota do not track the sexual orientation of women infected with HIV it is impossible to determine the number of Lesbian women living with HIV. Given that Lesbians are at greater risk of HIV infection due to occasional sexual contact with bisexual men and greater rates of drug and alcohol abuse, this is a serious issue. Services for women generally assume that the women served will be heterosexual and as such may be perceived to be unwelcoming and insensitive to Lesbians.

Refugee Women

Recently the United States Department of State reversed their long-held stance against allowing HIV+ refugee's entrance to the United States. In fact, the Twin Cities is one of five sites chosen throughout the Country to accept HIV+ women who may have been living for some time in refugee sites around the world. In order to come here these women must have a family connection, that is to say someone from their family who is willing to house them and to help acclimate them to American society. However, these women face enormous hurdles as the stigma of HIV in refugee and immigrant communities is quite intense. And, it is difficult to not have that status known. Breaches of confidentiality lack of trust in interpreters who often come from the same small community, and language barriers all contribute to the problems these women face. In addition, HIV services in the United States with all of the paperwork, eligibility requirements, complicated medical terms and so forth place a further challenge for these women.

CONTINUUM OF CARE

The Minnesota HIV Services Planning Council has adopted a Continuum of Care as a model for HIV services. This Continuum will inform the Planning Council's prioritization process and CARE Act (Titles I & II) allocation decisions in Minnesota. This model represents a shift away from assessing impact and needs in specific populations and towards a view of impact at various disease states. This report analyzes the needs, barriers and solutions for women and children within the context of the Continuum of Care.

The five HIV disease states outlined in the Continuum are: 1) undiagnosed/at-risk/acute infection, 2) recently diagnosed, 3) chronic illness, 4) progressive illness, and 5) end-of-life. Additionally, services are divided into access services, core services and HIV plus services with the goal of providing services appropriate to each unique disease state. Service goals are also articulated for each disease state. For a more detailed look at the Continuum of Care, see additional materials provided in Appendix B.

Single women's greatest service needs and barriers to services appear to be experienced in the undiagnosed/at-risk/acute infection and the recently diagnosed disease states. Because of this there is a need to focus on removing these barriers to testing, provide access to safer sex information and negotiation skills and streamline connections to HIV services. Families, on the other hand, have increased needs in the chronic, progressive and end of life disease states. Once the disease is disclosed to family members or the primary caregiver's health begins to decline, there is a greater need for both emotional support and practical daily living assistance. The following is a more complete analysis of needs, barriers and solutions to service gaps for women and children within the context of the Continuum of Care.

Undiagnosed/At-Risk/Acute Infection

This is the disease state where HIV prevention and services meet. People in this disease state may be uninfected but at risk or HIV+ and unaware of their status. Many of these women repeatedly engage in behaviors that put them at risk for infection. Women in this disease state come from a wide range of subpopulations, including:

- Women of Color
- Young women
- Pregnant women
- Women living with domestic violence
- Women in prison or in relationships with men who have been incarcerated
- Women with substance abuse and/or mental health problems
- Women involved in sex work
- Women who are homeless
- Immigrant women whose sex partners may be traveling to parts of the world with very high rates of HIV infection

Needs/barriers/solutions

Because early diagnosis is linked to improved health outcomes, the focus in this disease state is on making testing available to at-risk women, providing appropriate pre- and post-test counseling, and making training about HIV testing available for providers so that they can incorporate testing into routine women's health care. Training for providers will also help medical personnel be able to recognize the signs of HIV in women.

At-risk women, defined as those engaging in high-risk behaviors, need targeted HIV prevention. Long-term prevention solutions - the most important is development of female-controlled protection methods, such as microbicides - remain only in the research stage. Microbicides will offer women protection choices that are not dependent on partner cooperation. Until the development of a woman-controlled means of HIV prevention, at-risk women need education and practical risk reduction information and resources. Programs that emphasize self-esteem and a woman's ability to control her own sexual health are particularly appropriate at this stage. In particular programs that encourage role-playing regarding such difficult topics as negotiating condom usage, practical lessons focusing on correct condom use, and how to avoid high risk situations should be encouraged. Woman-specific prevention messages that offer a range of options across the harm reduction continuum will benefit women who are not able to insist on consistent condom use.

When it comes to health care services, perhaps the most important need of women in this disease state is to provide them with a reason to test for HIV. Many women are unaware or in denial about their risk behaviors. Traditional risk assessments may yield inaccurate results due to the stigma surrounding sexual and drug using behaviors. Women need opportunities for voluntary testing, including pre- and post-test counseling, in a non-judgmental setting where they can speak openly about the realities of their lives. Providers working with women at highest risk would benefit from the lessons learned by harm reduction workers who work with female intravenous drug users (IDUs). For example, these women, many of whom are involved in sex work, need safer sex information and resources, easy access to sterile syringes, lessons about how to "shoot safe", information on HIV testing and other health services. And they may also benefit from receiving information on resources for women who want to leave prostitution.

Additionally, providers must be knowledgeable about the interplay between HIV, substance use, domestic violence, adolescent development, and sex work as well as referral sources for their patients dealing with these. Domestic violence shelters, substance abuse treatment centers and homeless shelters all are potential entry points that can encourage testing and connection to services. For example, HIV counseling can be incorporated into a care plan developed in a domestic violence shelter. Due to these linkages, service providers would benefit from opportunities to come together for training and collaboration. HIV service providers also must be aware of signs and symptoms of non-HIV-related problems and referral resources for their clients dealing with one or more of these issues.

To insure that women with risk factors have opportunities to test, providers must routinely and consistently offer HIV testing as a part of women's health care, even for those women presumed

to be at low risk. To integrate HIV testing into a routine part of women's health care will require systems change, provider training and consumer empowerment. A helpful step would be the removal of funding barriers separating family planning programs and HIV testing. Provider training is necessary, beginning with prenatal care providers and women's health clinics to encourage testing as routine part of gynecological care. This will also ensure that HIV tests are offered to all pregnant women. Ideally, HIV testing would be offered to all women who test positive for STDs as well as pregnancy. This removes the stigma associated with HIV risk assessments as well as the chance that some groups of women, such as bisexual women, are overlooked in the assessment process. With increased testing comes the need for linkages between non-MDH testing sites and HIV specialists and services, especially with regards to up-to-date HIV screening tools and pre- and post-test counseling. In rural areas, existing networks of family planning clinics are starting points for increased access to testing.

Because of the multiple needs of certain groups of at-risk women, a network of core providers who have expertise in culturally competent care with specific populations is necessary. Women need to feel that there is safe space to discuss with their health care providers issues such as substance abuse or sex work, or just to have a provider who is sensitive to African-American cultural issues or is experienced working with youth. In addition, there is a need for linkages between HIV specialists and providers who routinely serve these populations to ensure quality health care. A starting point would be outreach to all health clinics serving minority at-risk populations to develop competency on HIV prevention, testing and care with a specific focus on clinics that provide prenatal care.

In addition, improving or creating linkages between health clinics, peer education programs, teen pregnancy programs and other STD prevention efforts to incorporate HIV information into programs that incorporate discussion on sexual behavior will help reach young women at risk. Similarly, outreach to organizations and groups that work with youth at risk for homelessness, substance abuse and prostitution will improve access to testing for an extremely high-risk group of young women.

Non-HIV specific programs also play an important role in prevention and early services. If women are able to meet basic living needs for themselves and their families, they are less likely to remain in risky situations or engage in high-risk behaviors such as survival sex. Economic support programs must be maintained and must also take into account the unique needs of families living with HIV. Where programs are non-existent or long waiting lists render them inaccessible, system capacity must be developed or increased. Affordable housing development, shelter space for women and youth, and substance use treatment programs are HIV prevention programs in the sense that they give women and youth alternatives to high-risk behaviors. Additionally, women need health insurance, either through their employer or a state-sponsored program as the crucial first step to accessing health care. Simplified and accessible applications for state-sponsored health insurance programs will help women to obtain coverage.

Recently diagnosed

People in the second disease state are newly diagnosed HIV+ and are most likely struggling to understand what this diagnosis means as well as to make beginning care decisions. Pregnant women or new mothers who were diagnosed through prenatal care often fall into this category. Other groups of women include women in prison or substance abuse treatment centers where they were tested upon intake or women in homeless shelters.

Women in this disease state often have other issues that take precedence over HIV care, including care of children. They may also have substance abuse and/or mental health issues. Often these women experience feelings of isolation and denial and may not be emotionally able to access resources even when they are aware of their availability.

Needs/Barriers/Solutions

The most basic needs of women in the recently diagnosed disease state are resources to help in understanding and coping with the HIV diagnosis. At this stage, women have many questions about treatment options, side effects and information to prevent transmission. This information can best be obtained, at least in this disease state, from HIV specialty care providers who can explain their care and treatment options. Ideally, providers will have an understanding of women-specific care needs and treatment standards and culturally competent providers will be available as well. Case managers or other advocates can also play important roles in helping women connect with health care services, obtain health insurance, and be aware of additional HIV-related support services. Early intervention services can help connect women diagnosed during pregnancy to support and services.

Resources to help with disclosure to family, friends and especially children need to be available beginning in this disease state even though women may not be emotionally ready to deal with issues of disclosure. Disclosure often begins with sexual partners and disease intervention specialists need also to be aware of the potential implications of partner notification on domestic violence, even when notification is done anonymously, and be able to offer resources and support. Any proposed changes to partner notification services must keep in mind that women are at increased risk of battering when they reveal their status to a male partner. Women in this disease state need information about HIV transmission and prevention, especially if the woman is continuing to engage in high-risk behaviors as she comes to terms with her diagnosis.

Development of support systems for parents of HIV+ children and child and youth-specific support systems will help to meet emotional needs of families living with HIV. This includes the development and promotion of self-care and advocacy programs, emotional support groups, and other peer-based models. Often women feel much more at ease discussing HIV, its manifestations, disclosure issues, planning needs and so forth with other women in similar circumstances. Also needed is increased support for partners and caregivers, including information about treatments and medications, reproductive health information and options, and information on disclosure to family, children and work/school.

Again, it is important that providers have experience working with women who have multiple needs and that women can feel comfortable discussing issues that affect HIV care with their provider, including substance use, sex work and domestic violence. Providers that understand the care needs and barriers to care for HIV+ youth are also needed. Provider training is important for both HIV and non-HIV specific providers on women's care needs. General practitioners and ob/gyn doctors need training about HIV and woman-specific care needs and woman-specific standard of care guidelines should be developed as part of overall care guidelines for HIV specialists. However, these guidelines cannot be developed without gender and age-specific clinical trials. As mentioned earlier this will only occur through increased participation by women in current clinical trials.

Additionally, health insurers must recognize the need for gender-specific testing and treatment and the need for continued work on uncompensated or under-compensated care issues so health care providers can be reimbursed for time spent with patients explaining safer sex techniques and complex treatment regimes.

Also through provider training, increased capacity of substance use treatment centers, domestic violence and homeless shelters to respond to the needs of women with HIV can be developed. This provider training would also benefit those who work with at-risk youth, especially in the identification of mental health providers who have expertise and willingness to work with HIV+ adolescents.

Women in this disease state also need assistance in meeting basic living needs, including food, housing, childcare and transportation. Some women may also need access to mental health, substance abuse and domestic violence resources. Family-friendly HIV care services that are flexible enough to accommodate women with a variety of care responsibilities are needed at this stage and this need continues through all remaining disease states. This includes transportation and increased availability of childcare, especially "social service" childcare that is not tied to work. "One-stop shopping" service centers where women can receive HIV specialty care, non-HIV medical care for themselves and their families and connect to service and support programs are one option for women who often have to balance work and other family obligations with clinic visits.

Two specific subgroups with unique needs in this disease state are incarcerated women and rural women. For incarcerated women, systems changes in partnership with the Department of Corrections, to improve prison culture regarding HIV including staff training on issues of transmission, treatment and inmate confidentiality are needed. In addition work must be continued to ensure that women receive high quality medical care while incarcerated and that women know where and how to access HIV services when they are released. This will require comprehensive pre-release planning on the part of prison staff to work with community-based HIV resources. For rural women, investments in technology can link HIV+ women in rural areas with care resources including medical information and support resources. Also, translation and

interpretation services need to be available to serve growing immigrant, refugee and migrant worker populations outside the Twin Cities

Chronic illness

In this disease state, the HIV+ woman has generally been able to access health care and support services as needed and has developed a care strategy. They are able to manage their day-to-day living needs and while they may experience some common illnesses, overall their health is good and HIV disease is manageable. However, it is important not to lose sight of the fact that many HIV+ women in this disease state still do not know they are infected.

For women who do know their status, in this stage they may begin to address issues that were too difficult to address earlier, such as disclosure to family, friends and children. However, many women have concerns about the stigma of HIV and therefore do not disclose even in this disease state. They also struggle with feelings of isolation and difficulty with medication adherence, especially if they have not told family members about their status.

Needs/Barriers/Solutions

Women in the chronic illness state have a need to balance personal HIV care needs with other family responsibilities and if their health is good, learn how HIV care can be integrated with other family needs. Women may have other issues that interfere with access to care such as substance abuse, mental health problems, homelessness and domestic violence. Because HIV affects families and not just individuals, support resources for affected partners, family members and caregivers are also important.

Many of the needs, barriers to care and solutions are the same as those introduced in previous disease states. However, there are some needs that take on added importance in this state. These include support for medication adherence and support and resources around disclosure issues. Women whose health is good and who feel that their illness is under control may begin to explore returning to work. For women receiving MFIP, employment is mandatory. The job training and return-to-work issues, including balancing work, family responsibilities and HIV care, need a more thorough examination so that state-sponsored programs are responsive to the needs of families with HIV. To help women achieve or maintain economic independence, links with job training and job counseling programs are needed to make existing work-readiness programs aware of training and employment needs of HIV+ women. Assistance with workplace disclosure issues, benefits counseling and job retention will also help women retain employment. Because some women in this disease state are not able to hold full-time employment, further examination of other economic assistance programs (MFIP/SSI/SSDI) for explanations of the gender income gap between HIV+ women and men is warranted.

Some HIV+ women have little or no prior work experience, thus the issue becomes not one of re-entry to work, but one of learning workplace skills. There are many programs designed to work with women in this position, however, most of these programs have little or no experience working with women who also suffer from a chronic and often debilitating disease. For many

women newly entering the workforce, use of sick time, needing time on the job to take meds, follow dietary regimes and so forth can lead to early termination from the job. It is important for women to explore their options regarding disclosure of these needs to the workplace prior to taking the job. Such discussions work best when held with a trained professional, such as an attorney who specializes in workplace discrimination or ADA (Americans with Disabilities Act) so that her rights are fully explained.

In this stage, couples may also consider starting a family or having more children. It is crucial that couples find support for family planning decisions and providers willing to help them explore their options. With medical advances rendering mother-to-child transmission rates as low as 2%, the decision to have children after HIV diagnosis is a legitimate, valid and responsible one. Even without therapy, chances of mother-to-child transmission are less than those of certain genetic diseases. Parents also need resources and guidance in working with school districts and childcare providers about policies that are supportive of infected and affected students. These problems often raise ethical questions such as access to fertility treatments for HIV+ women or couples and as such, professionals experienced in these matters should be sought out.

Progressive Illness

In this disease state, health begins to decline and individuals may no longer be able to care for themselves without assistance. However, it is common for people to move back and forth between disease states, especially from progressive illness back to chronic illness. Service needs begin to emphasize support for family members and caregivers in this state. The needs of women who are partners of HIV+ men or who care for other family members with HIV are extremely important and need to be included in this disease state.

For women in this state, concerns about care of children and other family responsibilities are prominent. Fears increase about how to provide economically both in the short and long-term for the family and who will care for children if the illness worsens. Self-advocacy becomes more difficult also as health declines and women may no longer be able to access support services outside the home such as support groups or on-site meals. As is true for all disease states, other issues such as poverty, substance use, domestic violence, and mental health issues may continue during this state. In some cases, women may also be in the “recently diagnosed” stage at this time, having just tested positive during hospitalization for an opportunistic infection.

Needs/Barriers/Solutions

Women dealing with progressive HIV illness need access to services that help people remain in their homes, such as home care nursing and chore services. Should a woman need in-patient or hospice care, programs should recognize the needs of parents and develop family specific resources. There is a lack of hospice programs where children can also live with HIV+ parents. This is also the stage where permanency planning for children must play a prominent role if it hasn't been addressed previously. With changes in health status can come a wide range of emotional needs both for the HIV+ individual, caregivers and family members. Counseling and support services for other family members affected by the client's declining health are vital.

Solutions unique to this disease state are increased options to help parents remain in their homes and assistance with permanency planning and respite childcare.

End-of-life

In the final disease state, end-of-life, health declines significantly and individuals can no longer care for themselves. AIDS-defining illnesses are common and changes to therapy regimes do not bring about improvement. For women in this disease state, their needs are very similar to those in the progressive illness state. Again, the needs of non-infected women, especially in caregiver roles, and the emotional needs of other family members must be taken into account. Important needs such as for palliative care may arise at this time; often women with children do not seek pain relief out of fear that it will so dull their senses that they will be unable to interact with their children. It is important that professionals skilled in hospice or end-of-life care are available and able to act as advocates for the woman.

Needs/Barriers/Solutions

Barriers to high quality care for women in this stage include lack of awareness or options in making custody arrangements and lack of support resources that address the needs of the whole family, especially children. There are no previously identified solutions, other than that mentioned above for palliative care, that are unique to the end-of-life stage but the solutions identified in the progressive illness state are particularly important also to women at the end of their battle with HIV.

RECOMMENDATIONS

In general, all of the proposed solutions to improve access to prevention, testing and services for at-risk and HIV + women and children fall into one of the following five categories:

- 1) Improving access to testing for women.
- 2) Fostering collaborative approaches and linkages between HIV and non-HIV specific systems and providers.
- 3) Developing and maintaining a core set of HIV service providers able to meet the needs of women and families.
- 4) Strengthening policies and programs that affect the economic needs of women and families.
- 5) Working to empower consumers.

◆ **Improve access to testing for women**

Improved access to HIV testing will identify women in earlier stages of HIV disease. By integrating testing into routine reproductive health care and removing the stigma of only offering HIV testing based on risk assessment, women will be more likely to test. However, in order to increase access to testing, funding barriers that separate family planning programs and HIV testing services must be removed. Because the opportunity to reduce perinatal transmission is so great, it is especially imperative that HIV testing is offered to all pregnant women, regardless of perceived risk factors. An effort needs to be made to streamline service connections with delivery of positive results, especially for clinics outside of the Department of Health testing network. Often clinics that are not MDH testing sites feel “out of the loop” as far as HIV services updates.

GOAL: Work with providers currently serving women through prenatal care and STD testing to increase HIV testing rates among at-risk women.

Specific actions to implement this recommendation are as follows:

- First, MAP’s systems advocate will work with MDH to identify non-MDH testing sites that return positive HIV test results and insure that these sites have up-to-date information and training on pre- and post- test counseling as well as resources for HIV care.
- Second, MAP’s systems advocate will work with women and family clinics as well as substance abuse treatment providers, homeless shelters, domestic violence shelters and correctional institutions to provide expanded access to information and screening/testing resources by increasing knowledge and ability to link screening and testing.
- Third, MAP’s systems advocate will work with a core group of women’s health clinics and the Minnesota Department of Health, to evaluate the potential for a pilot program, modeled

after the Perinatal Prevention Pilot Program, to offer HIV screening and voluntary testing as a routine part of sexual health care.

- Fourth, MAP will support efforts by MDH and health care systems to continue to train providers about the importance of universal screening for pregnant women. This support will include seeking ways to create awareness and increase resources for universal screening and perinatal prevention efforts.
- Fifth, MAP's systems advocate will work with policy makers at the Minnesota Department of Health and Department of Human Services to explore opportunities for collaboration as well as barriers that separate HIV, STD, family planning and maternal and child health.

◆ **Foster collaborative approaches and linkages between HIV and non-HIV specific systems and providers**

Collaboration between HIV-specific and non-HIV specific systems is essential for optimal care without duplication of services. Non-HIV specific services play an important role in the lives of many HIV+ women.

GOAL: Provide resources and training to service providers to enable them to better serve HIV+ women and children.

Specific actions to implement this recommendation are as follows:

- First, through the Midwest AIDS Training and Education Center (MATEC), MDH, Hennepin County Community Health (CHD) and MAP's systems advocate, provide training, technical assistance and resources to non-HIV specific medical providers serving women and families. Additional training to HIV specialists on the resources available to help meet the needs of women can also be provided. HIV specialists need to understand the linkages between HIV, substance use, mental health, sex work and domestic violence so that they can provide appropriate referral resources for their patients.
- Second, provide training, technical assistance and resources to non-HIV specific systems including women and family health service providers, as well as corrections, substance abuse treatment centers, domestic violence shelters, child care facilities and homeless shelters that serve women and youth to create environments that are supportive of HIV+ clients and responsive to their needs.

MAP's systems advocate could do this through a series of workshops and development of communication tools. The goal will be to develop infrastructure within these sectors so that they learn to integrate HIV information into their own program curricula. Without doing so, these training efforts are short-lived and only last as long as the staffs that have received the training remain at that site. Given the mobile nature of employees in the social services and

health care sectors, the main emphasis needs to be on how to incorporate HIV prevention and service information on an ongoing basis. Also, these providers need to know where to access current HIV information in the future, therefore, marketing the Minnesota AIDS Project AIDSLine Program will be an important component of these training efforts.

- Third, work with HIV service providers to ensure that they are also aware of these resources.
- ◆ **Developing and maintaining a core set of HIV service providers able to meet the needs of women and families.**

Woman-specific provider training and network development are critical in a service delivery system that responds to the needs of women and families. The creation of provider networks with expertise in serving women and subpopulations of at-risk and HIV+ women is recommended to ease access and improve overall health outcomes.

GOAL: Support development of women and family or HIV specialty clinics willing to explore the creation of family-friendly HIV health care settings.

Specific actions to implement this recommendation are as follows:

- First, MAP's systems advocate will work with existing women and family or HIV specialty clinics to help develop family friendly policies that best serve their clients and to address barriers to HIV care for women and families. This could include such services as flexibility in appointment scheduling, on site childcare, improved access to transportation programs and resources for emotional support. Activities might include:
 - Cultivating support for on-site child care at clinics or support groups.
 - Education about how to use existing social service child care options
 - Expand child care options for parents with disabilities that are not tied to work.
- Second, MAP's systems advocate will work in collaboration with culturally specific service providers to expand alternatives for culturally competent care by identifying providers willing to serve specific subpopulations of women and development of networks for referral. The first step is creating dialogue with consumers to identify what are critical components of culturally competent care.
- Third, MAP will encourage family or HIV service providers to develop programs to provide emotional support for children and youth, support for parents, and for family members impacted by HIV. This involves identifying what resources are currently available, ensuring that HIV providers such as case managers, MAP AIDSLine and HIV specialists know about these, and finally building support through increased funding for programs.

- Fourth, MAP will encourage the stakeholder group of HIV specialists to develop woman-specific standard of care guidelines as part of overall HIV treatment guidelines.
- Fifth, MAP will work to improve awareness of and access to the permanency planning services available through its Legal Program. Financial support for these services needs to be secured as the program was established on a two-year trial basis through pro-bono support from a local law firm.

◆ **Strengthen policies and programs that affect the economic needs of women and families**

Because of the importance of meeting basic needs, economic programs that are not HIV-specific are a key component of HIV care.

GOAL: Provide policymakers with information about current gaps in economic support services for HIV+ women and propose solutions to better serve these women.

Specific actions to implement this recommendation are as follows:

- MAP’s systems advocate will work in coalition with other affected groups to support the development of economic programs that meet needs of families impacted by HIV. These include:
 - Welfare (MFIP) reform
 - Increased funding for services that meet basic needs for groups at the highest risk, including homeless women and youth.

◆ **Consumer empowerment**

A key component of systems advocacy is encouraging infected and affected women to give voice to their needs, demand changes and improvements in systems not currently meeting their needs, and to be aware of the resources currently available in both prevention and services.

GOAL: Increase consumer empowerment in both HIV prevention and services.

Specific actions to implement this recommendation are as follows:

- First, MAP will support the development of workshops targeting “at risk women” to teach risk reduction, self-esteem, self-advocacy and access to services.
- Second, MAP will encourage development of workshops in collaboration with existing programs that serve HIV positive women to educate them about treatment options, benefits programs and services available to them.

- Third, MAP's systems advocate will work to identify HIV+ women to serve on the HIV Services Planning Council and its committees to better articulate the needs of women and families.
- Fourth, access needs to be expanded to self-care and advocacy programs which work with consumers to empower them regarding disease management.

CONCLUSION

While comprehensive health care and support services exist for people in all stages of HIV disease, it is apparent through this report that women have specific barriers to accessing care for themselves and their families. Systems currently in place have the capacity to meet women's care needs but may not understand the unique needs and barriers that women and families face.

This report highlights the barriers to care that women face. In addition, it develops a plan of action to address these barriers through MAP's systems advocacy work. But like all systems change, these barriers will be removed only through partnership with the community. This report offers suggestions for consideration by those making decisions within various communities, including formal planning, service providers, individuals and caregivers and those outside the HIV prevention and service system. The Ryan White CARE Act plays a crucial role in funding services that help women and families. It is hoped that the information and recommendations contained in this report will help these communities better understand the needs of women and families as they make program and funding decisions.

APPENDIX A – EPIDEMIOLOGICAL DATA

Following are charts that provide both a national and local picture of HIV/AIDS among women. This data was compiled from the Centers for Disease Control and Prevention’s HIV/AIDS Surveillance Report, Midyear edition Vol. 12, No. 1 and the Minnesota Department of Health Surveillance Reports dated January 1, 2001. The data is provided here as a reference point for discussion of profiles of the epidemic and to give a broad overview of how HIV/AIDS affects women and children in Minnesota and across the country.

The National Picture

Numbers in parenthesis are actual number of cases reported.

	HIV	AIDS
Women: Annual rate per 100,000	N/A	9.0
Women: exposure category IDU	11% (797) ‘99-‘00	27% (2795): ‘99-’00
	20% (7033) cumulative	41% (51,592): cumulative
Women: exposure category heterosexual contact	37% (2577) ‘99-‘00	39 % (4114) ‘99-’00
	41% (14,589) cumulative	40% (50,257) cumulative
Women as percent of total cases	32% (6984) ‘99-‘00	24% (10,469) ‘99-’00
	27.8% (35,775) cumulative	17% (124,911) cumulative
Women by race: White (not Hispanic)	19.7% (1377) ‘99-‘00	17.8% (1865) ‘99-’00
	23.4% (8404) cumulative	21.7% (27,215) cumulative
Women by race: Black (not Hispanic)	69% (4836) ‘99-‘00	63.2% (6625) ‘99-’00
	67.7% (24,229) cumulative	57.4% (71,741) cumulative
Women by race: Hispanic	8.5% (595) ‘99-‘00	17.3% (1814) ‘99-’00
	6.9% (2469) cumulative	19.8% (24,710) cumulative
Women by race: Asian/Pacific Islander	0% (36) ‘99-‘00	0% (83) ‘99-’00
	0% (127) cumulative	1% (670) cumulative
Women by race: American Indian	0% (50) ‘99-‘00	0% (60) ‘99-’00
	1% (210) cumulative	0% (339) cumulative

Women by age: 13 – 19	8% (2970) cumulative	1% (1601) cumulative
Women by age: 20 - 29	35% (13,202) cumulative	21% (26,901) cumulative
Women by age: 30 - 39	34% (12,572) cumulative	43% (55,981) cumulative
Women by age: 40-49	14% (5240) cumulative	22% (28,464) cumulative
Women by age: Over 49	5% (791) cumulative	9% (11,964) cumulative

	HIV	AIDS
Pediatric: Mother with/at risk for infection	82% (185) '99-'00	87% (195) '99-'00
	86% (1782) cumulative	91% (8027) cumulative
Pediatric: White, not Hispanic	13.3% (30) '99-'00	15.6% (35) '99-'00
	22.3% (461) cumulative	17.4% (1535) cumulative
Pediatric: Black, not Hispanic	70.2% (158) '99-'00	66.5% (149) '99-'00
	64% (1321) cumulative	58.5% (5158) cumulative
Pediatric: Hispanic	12.4% (28) '99-'00	15% (34) '99-'00
	11.3% (234) cumulative	22.8% (2016) cumulative
Pediatric: Asian/Pacific Islander	0% (2) '99-'00	1.3% (3) '99-'00
	0% (14) cumulative	0% (49) cumulative
Pediatric: American Indian/Alaska Native	1.3% (3) '99-'00	0% (2) '99-'00
	0% (13) cumulative	0% (31) cumulative

Deaths, Cumulative	
Under 15 years of age* <i>*Includes males and females as % of total AIDS deaths</i>	1.1% (5086)
Women, 15-24 as a percentage of female deaths	3.6% (2379)
Women, 25-34	32.4% (20,894)
Women, 35-44	38.3% (24,693)
Women, 45-54	14% (9014)
Women, 55 or older	7.6% (4893)
Women, White, non Hispanic	22% (14,263)
Women, Black, non Hispanic	56.8% (36,616)
Women, Hispanic	20% (12,965)
Women, Asian/Pacific Islander	0% (314)
Women, American Indian/Alaska Native	0% (187)

The Minnesota Picture

For the period January 2000 – December 2000 for women:

Category	HIV	AIDS
Women: as a % of cases	27.7% (56)	18% (25)
Women: Exposure Category IDU	11% (6)	12% (3)
Women: Exposure Category Heterosexual Contact (all categories)	55% (31)	40% (10)
Women: Exposed through heterosexual contact: Heterosexual contact with IDU	29% (9)	30% (3)
Women Exposed through heterosexual contact: heterosexual contact with HIV+ person/Risk not specified	58% (18)	40% (4)
Women: Exposure Category Other/Undetermined	34% (19)	48% (12)
<i>Cumulative Women by race: White (not Hispanic)</i>	38% (197)	44% (169)
<i>Cumulative Women by race: Black (not Hispanic)</i>	51% (266)	40% (153)
<i>Cumulative Women by race: Hispanic</i>	4% (23)	8% (29)
<i>Cumulative Women by race: Asian/Pacific Islander</i>	2% (11)	2% (7)
<i>Cumulative Women by race: American Indian</i>	5% (24)	7% (27)
<i>Cumulative Women by age: 13 - 19</i>	9% (45)	0% (2)
<i>Cumulative Women by age: 20 - 29</i>	43% (224)	23.6% (91)
<i>Cumulative Women by age: 30 - 39</i>	34% (176)	42% (162)
<i>Cumulative Women by age: 40-49</i>	8% (42)	21.5% (83)

<i>Cumulative Women by age: Over 49</i>	3% (18)	9.3% (36)
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	HIV	AIDS
<i>Cumulative Pediatric</i>	35	22
Mother w/or at Risk for HIV infection	80 % (28)	82% (18)
<i>Cumulative Age Under 13 by Race: White (Not Hispanic)</i>	37% (13)	41% (9)
<i>Cumulative Age Under 13 by Race: Black (Not Hispanic)</i>	45.7% (16)	41% (9)
<i>Cumulative Age Under 13 by Race: Hispanic</i>	11.4% (4)	9% (2)
<i>Cumulative Age Under 13 by Race: Asian/Pacific Islander</i>	5.7% (2)	5% (1)
<i>Cumulative Age Under 13 by Race: American Indian</i>	0% (0)	5% (1)

Some additional statistics about this population include:

- 12% of people with AIDS live in Greater Minnesota
- 10% of new positives in 1999 were reported in Greater Minnesota.

APPENDIX B – CONTINUUM OF CARE

For additional information on the HIV Services Planning Council's Continuum of Care, please contact Mary Doyle of the Planning Council at 612/ or mary.s.doyle@co.hennepin.mn.us.

The following documents provide detailed information about the development of the Continuum of Care and included services:

- Minnesota HIV Services Planning Council (October, 1999): *Continuum of Care (Draft)*
- Continuum of Care Graphic Chart
- Glossary of Services

APPENDIX C - HIV SERVICES PLANNING COUNCIL CHART:

Issues for HIV+ Women and Their Families: Barriers and Recommendations
**Issues for HIV+ Women and Their Families
 Barriers and Recommendations**

Issue	Previous Planning Council Service Category	Planning Council Service Category for 2001-2002	Women and Families Systems Advocacy
Affordable Housing	1. Housing: intensive housing intervention 2. Housing: permanent housing subsidy 3. Housing: permanent housing program 4. Housing: temporary shelter 5. Housing: emergency shelter 6. Housing: systems advocacy	1. Housing: emergency housing assistance, systems advocacy and adult foster care* 2. Home health care * Permanent housing subsidy and permanent housing program were removed from service categories because Ryan White funds can not be used to pay for these services.	<ul style="list-style-type: none"> • Women and Families systems advocate coordinates work with Housing systems advocate where appropriate. <p>Ex: on-going training on HIV transmission and services available for HIV+ individuals with shelter providers.</p>
Case Management	1. Case Management: comprehensive case management 2. Case Management: greater MN case management	1. Case Management: case management and care advocacy 2. Primary Care: early intervention insurance 3. Emotional Support: emotional support and culturally appropriate 4. Education/Self	<ul style="list-style-type: none"> • Work with DHS to incorporate women and families issues in HIV case management training curricula • Provide information and referral resources to all case management programs on women and families issues

Issue	Previous Planning Council Service Category	Planning Council Service Category for 2001-2002	Women and Families Systems Advocacy
		Advocacy: information access for health insurance counseling and assistance	<ul style="list-style-type: none"> • Increase capacity of case management programs to work with non-HIV service providers that serve HIV+ women and children, in part through information and training opportunities such as Lifeline Forums • Ensure that programs and services working with HIV+ women and families are included in the appropriate sections of the HIV resource guide
Chemical Dependency	1. Substance Use Services: demonstration projects 2. Substance Use Services: systems advocacy	1. Substance use services: substance use services and systems development 2. Primary care: early intervention insurance	<ul style="list-style-type: none"> • Women and Families systems advocate coordinates work with substance use systems advocate where appropriate. <p>For example, developing an on-going training for women's substance use providers on HIV transmission, confidentiality issues and services available to HIV+ women.</p>
Child Care	1. Emergency Financial* child care expenses can be reimbursed through emergency financial assistance; there is no specific funding dedicated to child care.	1. Emergency Financial* child care expenses can be reimbursed through emergency financial assistance; there is no specific funding dedicated to child care.	<ul style="list-style-type: none"> • Can assist planning council in child care needs assessment/ review of current programs and options
Clinical Trials	1. Drug Adherence Support	1. Primary Care: Med Adherence	<ul style="list-style-type: none"> • Work with Axis program to reach women with information about

Issue	Previous Planning Council Service Category	Planning Council Service Category for 2001-2002	Women and Families Systems Advocacy
	2. Transportation	2. Case management 3. Transportation	current clinical trials through support group networks <ul style="list-style-type: none"> • Can assist in developing plan to target outreach to women not in case management
Domestic Violence	N/A	1. Information and Referral: women and children* * no specific service area or activity for domestic violence	<ul style="list-style-type: none"> • Working to increase capacity of domestic violence shelters to serve HIV+ clients • Conducted interviews with metro area domestic violence shelters to assess number of HIV+ women served, need for staff and client trainings on HIV and current knowledge about available HIV resources • Will develop HIV training specifically targeting domestic violence shelters to improve capacity to serve HIV+ women • Will develop informational materials/training for HIV service providers regarding domestic violence • Share resource and referral information with AIDSLine, case management and other HIV service providers.
Emotional Support	1. Emotional support: individual and group support 2. Emotional support:	1. Emotional support: emotional support and culturally appropriate	<ul style="list-style-type: none"> • Work with support groups currently serving HIV+ women, including those targeting specific cultural groups, to ensure

Issue	Previous Planning Council Service Category	Planning Council Service Category for 2001-2002	Women and Families Systems Advocacy
	culturally appropriate		<p>that HIV+ women are aware of systems advocacy, Women and Families Workgroup and other educational opportunities and resources.</p> <ul style="list-style-type: none"> • Develop support program for HIV+ parents and other family members affected by HIV.
Incarcerated women/female partners of incarcerated men	* no services specifically targeting incarcerated individuals	* no services specifically targeting incarcerated individuals. Once a woman is released she is eligible for all Ryan White funded services	<ul style="list-style-type: none"> • Work with the MN Department of Corrections (DOC) to assess HIV services for women incarcerated in MCF Shakopee and to improve access to HIV testing and care • Work with DOC to develop a pre-release plan for HIV+ women being released from MCF Shakopee • Can assist in developing plan to work with county workhouses and jails.
Language and Literacy Skills	<ol style="list-style-type: none"> 1. Education/Self Advocacy: culturally appropriate 2. Education/Self Advocacy: information access 	<ol style="list-style-type: none"> 1. Interpretation/ Translation 2. Education/Self Advocacy: information access and culturally appropriate 	<ul style="list-style-type: none"> • Work with interpreters at the Hennepin Co. HAB clinic to understand services available to women and families living with HIV, communicate this information to their clients and understand confidentiality issues around HIV. • Could assist in developing outreach plan to health organizations and community groups serving immigrant women.

Issue	Previous Planning Council Service Category	Planning Council Service Category for 2001-2002	Women and Families Systems Advocacy
Medication adherence	<p>1. Education/ Self Advocacy: drug adherence support</p> <p>2. Primary Health Care: drug reimbursement</p>	<p>1. Primary Care: med adherence, early intervention insurance and drug program</p>	<ul style="list-style-type: none"> • Can assist in increasing capacity of med adherence programs to serve HIV+ women and in identifying barriers to compliance and adherence.
Permanency Planning	<p>1. Legal services: legal services</p>	<p>1. Legal services*</p> <p>* no specific service area or activity for permanency planning. Permanency planning is currently funded through the Minnesota Family Legacy Project.</p>	<ul style="list-style-type: none"> • Worked with the Minnesota Family Legacy Project to pass stand-by custody law in Minnesota • Disseminate information about permanency planning to HIV service organizations and non-HIV specific organizations that work with HIV+ women who may be in need of this service.
Transportation	<p>1. Transportation: transportation</p>	<p>1. Transportation</p>	<ul style="list-style-type: none"> • Can assist in review of barriers to accessing transportation with regard to gender

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- ¹ Swanson Kroll, PhD, B. & Jackson, J. (August, 2000) Gender Analysis of HIV Comprehensive Needs Assessment. Minneapolis: Minnesota HIV Services Planning Council.
- ² Minnesota Department of Health. (January, 2001) Reported non-AIDS cases of HIV infection: Surveillance Report. Minneapolis: Minnesota Department of Health.
- ³ Hanson, J. [Personal interview]. 5 May 2000.
- ⁴ Minnesota Department of Health. (January, 2001) Acquired immunodeficiency syndrome (AIDS): Surveillance Report. Minneapolis: Minnesota Department of Health.
- ⁵ Minnesota Department of Health. (November, 1999) Persons living with HIV and/or AIDS reported to the Minnesota Department of Health. Minneapolis: Minnesota Department of Health.
- ⁶ Minnesota Department of Health. (January, 2001) Reported non-AIDS cases of HIV infection: Surveillance Report. Minneapolis: Minnesota Department of Health.
- ⁷ Ibid.
- ⁸ Ibid.
- ⁹ Minnesota Department of Health. (November, 1999) Persons living with HIV and/or AIDS reported to the Minnesota Department of Health. Minneapolis: Minnesota Department of Health.
- ¹⁰ Minnesota Department of Health. (January, 2001) Reported non-AIDS cases of HIV infection: Surveillance Report. Minneapolis: Minnesota Department of Health. & Minnesota Department of Health. (January, 2001) Acquired immunodeficiency syndrome (AIDS): Surveillance Report. Minneapolis: Minnesota Department of Health.
- ¹¹ Ibid.
- ¹² Swanson Kroll, PhD, B. & Jackson, J. (August, 2000) Gender Analysis of HIV Comprehensive Needs Assessment. Minneapolis: Minnesota HIV Services Planning Council.
- ¹³ Walsh, J. (March 2000) "Why is affordable housing so important for welfare reform?" Minneapolis: Affirmative Options Coalition.
- ¹⁴ Swanson Kroll, PhD, B. & Jackson, J. (August, 2000) Gender Analysis of HIV Comprehensive Needs Assessment. Minneapolis: Minnesota HIV Services Planning Council.
- ¹⁵ Swanson Kroll, PhD, B. & Jackson, J. (1999). HIV Comprehensive Needs Assessment Report. Minneapolis: Minnesota HIV Services Planning Council.
- ¹⁶ Minnesota Department of Health. (January, 2001) Reported non-AIDS cases of HIV infection: Surveillance Report. Minneapolis: Minnesota Department of Health.
- ¹⁷ Ibid.
- ¹⁸ HIV Service Providers. [Personal Interviews] September 1999 – March 2000.
- ¹⁹ Department of Health and Human Services. (1999) 1999 HHS Poverty Guidelines. Federal Register, Vol. 64, No. 52, 12428-13430.
- ²⁰ Ashley, J. [Personal interview] 17 March 2000.
- ²¹ Swanson Kroll, PhD, B. & Jackson, J. (1999). HIV Comprehensive Needs Assessment Report. Minneapolis: Minnesota HIV Services Planning Council.
- ²² Clark, B. [Personal interview] 9 December 1999 & Minnesota Department of Children, Families and Learning. (1998) Do you need help paying for child care? St. Paul: Minnesota Department of Children, Families and Learning.
- ²³ Every Penny Counts volunteer [personal interview] 15 December 1999.
- ²⁴ Lucid, J. & Gnerer, M. [personal interview] 13 September 1999.
- ²⁵ Swanson Kroll, PhD, B. & Jackson, J. (August, 2000) Gender Analysis of HIV Comprehensive Needs Assessment. Minneapolis: Minnesota HIV Services Planning Council.
- ²⁶ Minnesota Department of Health. (1997). Housing Needs of HIV Positive Parents with Children. Minneapolis: Minnesota Department of Health Disease Prevention and Control AIDS/STD Prevention Services.
- ²⁷ Ibid, p.4
- ²⁸ Walsh, J. (March 2000) "Why is affordable housing so important for welfare reform?" Minneapolis: Affirmative Options Coalition.
- ²⁹ Ibid.
- ³⁰ Hennepin County Community Health Department. (1999) Supplemental Funding Request, Ryan White CARE Act Title I Emergency Relief Grant FY 2000 p. 28.
- ³¹ Shelter Providers Association - Women's issues meeting. [Personal interview] 25 February 2000.

³² Ibid.

³³ Minnesota Department of Health. (January, 2000) Reported non-AIDS cases of HIV infection: Surveillance Report. Minneapolis: Minnesota Department of Health. & Centers for Disease Control and Prevention, National Center for HIV, STD and TB Prevention. (2000) HIV/AIDS Surveillance Report. Vol. 12, No.1. Atlanta: Centers for Disease Control and Prevention, U.S. Department of Health and Human Services.

³⁴ Minnesota Department of Health. (January, 2001) Reported non-AIDS cases of HIV infection: Surveillance Report. Minneapolis: Minnesota Department of Health.

³⁵ Swanson Kroll, PhD, B. & Jackson, J. (August, 2000) Gender Analysis of HIV Comprehensive Needs Assessment. Minneapolis: Minnesota HIV Services Planning Council.

³⁶ AIDS Action. (1999) HIV/AIDS and Substance Abuse: Fighting Twin Epidemics. Washington DC: AIDS Action.

³⁷ Center for AIDS Prevention Studies, University of California San Francisco (1996) Are Substance Abusers Who Don't Inject At High Risk of Infection? & McCoy, H.V. and Miles, C. (1992): "A Gender Comparison of Health Status Among Users of Crack Cocaine." Journal of Psychoactive Drugs Vol. 24(4).

³⁸ McCoy, H.V. and Miles, C.: Ibid

³⁹ Parriott, Ruth. (1994) Health Experiences of Twin Cities Women Used in Prostitution. Minneapolis: Family and Children's Service PRIDE Program. p. 16

⁴⁰ Herrig, S. & Riste, D. (1999) [Focus group interview] Women with A Point active users group; conducted by Hennepin County Child and Teen Check-up.

⁴¹ Ibid.

⁴² Swanson Kroll, PhD, B. & Jackson, J. (August, 2000) Gender Analysis of HIV Comprehensive Needs Assessment. Minneapolis: Minnesota HIV Services Planning Council.

⁴³ Swanson Kroll, PhD, B. & Jackson, J. (1999). HIV Comprehensive Needs Assessment Report. Minneapolis: Minnesota HIV Services Planning Council.

⁴⁴ Jackson, J. & Swanson Kroll, B. (1999) HIV Mental Health Report.

⁴⁵ Hennepin County Community Health Department (1999): Supplemental Funding Request, Ryan White CARE Act Title I Emergency Relief Grant FY 2000 p. 28

⁴⁶ HIV Service Providers. [Personal Interviews] September 1999 – March 2000

⁴⁷ Herrig, S. & Riste, D. (1999) [Focus group interview] Women with A Point active users group; conducted by Hennepin County Child and Teen Check-up.

⁴⁸ Center for Women Policy Studies. (1996) "Women with HIV/AIDS Speak Out on Domestic Violence." Womancare News. December.

⁴⁹ Denenberg, R. (1997) "Childhood Sexual Abuse as an HIV Risk Factor in Women" Treatment Issues, Vol. 11 (7/8) New York: Gay Men's Health Crisis

⁵⁰ Center for Women Policy Studies. (1996) "Women with HIV/AIDS Speak Out on Domestic Violence." Womancare News. December.

⁵¹ Denenberg, R. (1997) "Childhood Sexual Abuse as an HIV Risk Factor in Women" Treatment Issues, Vol. 11 (7/8) New York: Gay Men's Health Crisis.

⁵² Sovern, A. (Midwest Health Center for Women)[Personal Interview] 7 December 1999 & Bedner, R. (Family Tree Clinic) [Personal Interview] January 2000.

⁵³ Kaiser Family Foundation: *Indian Domestic Violence Study*

⁵⁴ Denenberg, R. (1997) "Childhood Sexual Abuse as an HIV Risk Factor in Women" Treatment Issues, Vol. 11 (7/8) New York: Gay Men's Health Crisis

⁵⁵ Ibid.

⁵⁶ Ibid.

⁵⁷ Minnesota Department of Health. (1997). Housing Needs of HIV Positive Parents with Children. Minneapolis: Minnesota Department of Health Disease Prevention and Control AIDS/STD Prevention Services.

⁵⁸ Herrig, S. & Riste, D. (1999) [Focus group interview] Women with A Point active users group; conducted by Hennepin County Child and Teen Check-up.

⁵⁹ Hoyt, MD, L. [Personal Interview] 10 September 1999. & Tatro, A. [Personal Interview] 1 October 1999.

⁶⁰ Minnesota Department of Health. (January, 2001) Reported non-AIDS cases of HIV infection: Surveillance Report. Minneapolis: Minnesota Department of Health. & Minnesota Department of Health. (January, 2001) Acquired immunodeficiency syndrome (AIDS): Surveillance Report. Minneapolis: Minnesota Department of Health.

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- ⁶¹ For more information on the unique challenges facing HIV+ kids as they move into adolescence, see “Growing Up Positive” by Laura Engle, Body Positive, August 1999, Volume XII, Number 8.
- ⁶² Sovern, A. (Midwest Health Center for Women)[Personal Interview] 7 December 1999.
- ⁶³ American Academy of Pediatrics and American College of Obstetricians and Gynecologists. (1999) “Human Immunodeficiency Virus Screening (Joint Statement)” Pediatrics Vol. 104(1).
- ⁶⁴ Hoyt, MD, L. [Personal Interview] 10 September 1999
- ⁶⁵ Minnesota Department of Health. (1999) “Prenatal HIV Screening Practices in Minnesota.” Disease Control Newsletter Vol. 27(2) pp. 9-12.
- ⁶⁶ Minnesota Department of Health (1999): Results from the Perinatal HIV Prevention Projects: Successful Strategies to Integrate HIV Testing Into Routine Prenatal Care Minneapolis: Minnesota Department of Health.
- ⁶⁷ Ibid.
- ⁶⁸ Ibid.
- ⁶⁹ Ibid.
- ⁷⁰ VanDevanter, N., Thacker, A.S., Bass, G., and Arnold, M. (1999) “Heterosexual couples confronting the challenges of HIV infection.” AIDS Care, Vol. 11(2) p. 189
- ⁷¹ HIV Service Providers. [Personal Interviews] September 1999 – March 2000.
- ⁷² VanDevanter, N., Thacker, A.S., Bass, G., and Arnold, M. (1999) “Heterosexual couples confronting the challenges of HIV infection.” AIDS Care, Vol. 11(2) pp. 181-193. See also National Women’s Health Information Center Sociocultural Issues Related to HIV/AIDS and “Study: Women Give Dying Family Care.” (1999, September 22) New York Times.
- ⁷³ VanDevanter, Ibid.
- ⁷⁴ Ibid.
- ⁷⁵ 1999 National Conference on Women and HIV/AIDS “Navigating into the new millennium through collaboration” [website www.womenandhiv99.com] Los Angeles.
- ⁷⁶ VanDevanter, N., Thacker, A.S., Bass, G., and Arnold, M. (1999) “Heterosexual couples confronting the challenges of HIV infection.” AIDS Care, Vol. 11(2) p.189
- ⁷⁷ Lucey, M. & Zangeneh, T. (1999) “Gender Agenda.” Women Alive. Summer.
- ⁷⁸ Project Inform. (1999, March) “Gender Differences in Viral Load?” WISE Words, Issue 3.
- ⁷⁹ Ibid.
- ⁸⁰ Lucey, M. & Zangeneh, T. (1999, Summer) “Gender Agenda.” Women Alive.
- ⁸¹ Project Inform (1999, January) “GYN Conditions in Women Living with HIV/AIDS Fact Sheet”
- ⁸² Ibid
- ⁸³ Smith, D. [Personal Interview] 21 March 2000.
- ⁸⁴ Monroe, A. (1999-2000) “Women in Clinical Trials” Community Research Initiative on AIDS. Vol. 9(1)
- ⁸⁵ Project Inform (1998, September) “PI Perspective 25: Federal Guidelines for treatment of children with HIV”
- ⁸⁶ National Pediatric and Family HIV Resource Center (1999) Synopsis of ‘Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection’.
- ⁸⁷ “More Than a Spoonful of Sugar: Meds for Parents and Kids”, (1999, September) Special Report: Kids, Number Five HIV Plus.
- ⁸⁸ National Pediatric and Family HIV Resource Center (1999) Synopsis of ‘Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection’. p.3
- ⁸⁹ Ibid, p. 1
- ⁹⁰ HIV Corrections Community Advisory Group [Group discussion] 30 March 2000.
- ⁹¹ Smith, D. [Personal Interview] 21 March 2000.
- ⁹² Jackson, J. (1998) Black HIV/AIDS Services Needs Assessment. Minneapolis: Minnesota HIV Services Planning Council, p. 43.
- ⁹³ Minnesota Department of Health (1999): Results from the Perinatal HIV Prevention Projects: Successful Strategies to Integrate HIV Testing Into Routine Prenatal Care Minneapolis: Minnesota Department of Health.
- ⁹⁴ Women’s Policy Institute/notes
- ⁹⁵ Minnesota Department of Health (1999): Results from the Perinatal HIV Prevention Projects: Successful Strategies to Integrate HIV Testing Into Routine Prenatal Care Minneapolis: Minnesota Department of Health.
- ⁹⁶ Ibid.
- ⁹⁷ Mania, N. (1999) “The AIDS Epidemic in Africa and its implication in Minnesota.” Midwest AIDS Training and Education Consortium Conference Notes.

⁹⁸Minnesota Department of Health (1998) Minnesota Comprehensive HIV/STD Prevention Plan. Minneapolis: Minnesota Department of Health AIDS/STD Prevention Services Section.

⁹⁹ Arboldea, M. [Personal Interview] 8 November 1999 & Brehme, M. [Personal Interview] 8 February 2000.

¹⁰⁰ Rural AIDS Action Network and Clay County Public Health (1998) Women at Risk: Results of Regional HIV Prevention Needs Assessment Activities. Minneapolis: Minnesota Department of Health, AIDS/STD Prevention Services Section

¹⁰¹ Ibid.

¹⁰² Chamberlin, K. [Personal Interview] 10 September 1999.

¹⁰³ Gordon, S. and Smith, V. [Personal Interview] 16 November 1999., Velazquez, C. [Personal Interview] 20 September 1999., Nathe, M. [Personal Interview] 6 October 1999. & Prevention Task Force Youth Council [Personal Interview] 28 January 2000.

¹⁰⁴ Engle, L. (1999, August) "Growing Up Positive" Body Positive. Volume XII(8), No. 8. The Body: An AIDS and HIV Information Resource (www.thebody.com)

¹⁰⁵ Williams, D. A. (1999, October 12) *Older Women With HIV Face Stereotypes About Their Age, Sexual Activity*. Boston Globe Online.

¹⁰⁶ Ibid.