

SPECIAL REPORT: HIV & WOMEN

Minnesota has the resources to meet many of the health care needs of women. However, a challenge facing us is to create a system that meets the basic care needs of HIV+ women. In an attempt to address the challenges of HIV infected and affected women and children, the Minnesota Department of Health funded a program to discover what those needs are and to recommend strategies to meet them. This women and families systems advocacy contact was awarded to the Minnesota AIDS Project. For the past six months, Kerri Pearce Ruch has been conducting an environmental scan of needs and barriers to services common to HIV+ women and families in Minnesota. A full report will be presented at a community forum this summer. While there are certainly similarities in care needs among men, women and children living with HIV, several key differences stand out. Following is a summary of our findings.

• **Clinically, much less is known about how HIV affects women, as compared to how it affects men.** Even less is known about effective medication and treatment for HIV+ children.

Until recently, women were not recruited or included in many clinical trials due to the unknown effects of new and powerful drug therapies on women who could become pregnant. As a result, we know much less about the effects of protease inhibitors and other HIV-related drugs on women. For example, we do not know how drug therapy is affected by menopause or the normal hormonal changes that women experience monthly.

We know that many women who didn't know they were HIV+ may seek care for chronic vaginal yeast infections or cervical cancer. Health care providers need information about how HIV affects women so that they are able to screen for HIV and accurately diagnose.

There is also some disagreement in the medical community about when to begin drug therapy for HIV+ children and questions about how these therapies may affect growth and development.

• **Poverty, substance abuse, mental health needs, and domestic violence all play a role in how and when a woman might access services.** Service providers in these areas need to include HIV-prevention messages in order to educate women about risk.

Often, HIV+ women experience barriers to accessing these services or continuing with program goals that are actually not HIV-related. Without adequate financial resources, women are often unwilling to become involved in these services due to the pressures of children and other family members. She might be fearful of a partner's reaction to her seeking help. Or, she may finally access services only to discover that the provider is afraid or unequipped to deal with the complications of HIV.

• **Women are still the primary caregivers for children and sick family members.** Therefore, HIV services must look at working with the family, not just the individual.

While we often just look at how many women there are with HIV or AIDS to determine demand for services, we must remember that there are female partners, mothers, and children of HIV+ men who need HIV-related services and support as well.

For example, a woman caring for her positive partner needs emotional support and prevention information, as well as nutrition and medication information. She will often be the one responsible for managing doctor visits, medication dosing and benefits paperwork, especially if her partner is not feeling well. Even if both partners are positive, studies suggest that women still do most of the treatment management.

• **Primary medical care sites need to improve HIV-screening for women.**

Improving HIV services for women begins with improved access to testing. By partnering with family planning clinics and women's health clinics, HIV service providers can insure that women receive the most up-to-date information about prevention, testing and self-care.

HIV testing should be offered to all women as a routine part of prenatal care. As one local pediatrician tells moms-to-be, "unless it was Immaculate Conception, you've been at risk!" Removing the stigma and shame around testing based on risk assessment will go a long way to improving care for women. Prenatal transmission rates can be reduced to a range of 2 percent to 8 percent, depending on the use of appropriate medications and the type of prenatal care provided.

• **Cultural norms have a large impact on a woman's ability to access care.**

Some cultural barriers to care are obvious. Top of the list is a lack of providers from the wide range of cultural backgrounds represented in Minnesota. Lack of confidential interpreter services and providers who might be unknowingly disrespectful of a client's cultural background are just two problems women frequently mention. Taboos against discussing sex and sexual norms which require women to be passive and not make demands of their partners, like condom use, also affect a woman's ability to make healthy decisions. Some communities have substantial mistrust of health care systems and therefore only seek treatment when it can't be delayed any longer and may terminate medical care once the patient "feels better." These barriers underscore the need for culturally competent

providers; providers who can not only speak the language of their patients but can deliver prevention messages and care in culturally appropriate ways as well.

To improve services to women and families in Minnesota who are living with HIV/AIDS, the following steps need to be taken to reduce barriers unique to women and children:

• **Increase access to clinical trials and additional funding for women and children-specific research;**

• **Develop standard of care guidelines for women's HIV care;**

• **Increase awareness among medical staff including general practitioners and OB/GYNs of how HIV presents in women;**

• **Increase capacity of organizations that serve high-risk women to meet the needs of their HIV+ clients.** This includes easy access to testing, streamlined connections to services, and targeted prevention messages. It also requires economic security programs and other support to ensure that women are able to meet basic needs without having to remain in abusive relationships or resorting to high-risk activities;

• **Shift health care and services from an individual level to a holistic family approach;**

• **Provide assistance and support for caregivers and family members who are affected as well as those that are infected;**

• **Offer HIV testing as a routine part of prenatal care and streamline health care services for women and families.** This "one-stop shopping" approach to health and support services works best when coupled with prevention and care that takes into account a woman's cultural background and identity.