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MINNESOTA AIDS PROJECT AIDSLINE BRIEF

A MAP journal providing you with information to strengthen your awareness in the fight against HIV.

BY THE NUMBERS

Since this issue is taking a look at ‘overlooked populations’ rather than providing known statistics, we are highlighting statistics we do not know. We don’t know these numbers because no one tracks them. In fact the data we do track often doesn’t help us understand much about those most at risk of infection. We may learn age, race, county of residence, history of injecting drugs and sexual orientation (male only), but other than that, little about the circumstances leading to new infections. There are no clear numbers on how many lesbians are infected with HIV. How many of the vastly growing heterosexual women who are becoming infected are married women who assumed they were in a monogamous situation? We don’t know how many transsexual individuals are HIV-positive. The current tracking system classifies all women as heterosexual if they had sex with a man even once and all men as “MSM” (men who have sex with men) if they ever have had sex with a man. Bisexual men and women who are HIV-infected are always classified as being infected through sex with a man, even if they may have been infected through sex with a woman.

So here are the numbers we do not know: Transgenders infected with HIV, Lesbians infected with HIV, Bisexual men or women infected through sexual contact with a woman



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MISSION

Minnesota AIDS Project envisions a world free of AIDS. Our mission is to lead Minnesota's fight to stop HIV and enhance the well being of those affected.

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Homophobia Causes HIV: It's Time We All Get It

Commentary by Bob Tracy, MAP director of community affairs

"So, how do you think you got it?" That's the unasked question on most people's minds when they learn someone has HIV. In most situations, it can be a judgment-laden thing to ask, so the curiosity is appropriately set aside. But there's also something to be learned from the answers.

I was diagnosed with HIV in 1986. People don't ask me "the question" so much anymore, and I don't see it going unasked in their eyes. I'm pretty much out there as a gay man, so there's probably enough of the answer in just knowing I'm gay. But I remember when I was first diagnosed and I was sitting around a boardroom conference table with my two-dozen or so co-workers telling then that I had HIV.

I calmly explained the disease to them, extending reassurances that I wasn't dead yet and had no intention of succumbing to the disease anytime soon. I like to think I was pretty cool, calm, collected and smart about what I had to say. That is, until I answered the question they all had on their mind but could not ask. When it came to explaining how I was infected, I could not control the emotions. I could not hide the anger.

I didn't say I went to bars, met men I didn't know, went home with them, and had unprotected anal sex. (Of course, except for concern about pregnancy, "unprotected" wasn't a term with much sexual relevance in the late 70s and early 80s.) I didn't explain to my co-workers how bath houses or certain parks could serve the same purpose without the fuss and muss of a lot of conversation, a relationship, or the inconvenience or risk of bringing a relative stranger back to my home and bed. I didn't go into the details of my secret life as a single gay man. After all, they knew and were most comfortable with me as a "married" gay man, or at least as someone who was in a committed relationship fairly similar to what was familiar to them. I didn't share the details, nor did they ask to understand why I would put myself at such emotional and physical risk or why I hid from others and myself when it came to sex, intimacy, love and friendship.

I just told them I blamed Ronald Reagan.

And you know something, it was not blame misplaced. Mr. Reagan spoke loud and clear when he refused to say the word AIDS. His inaction when the tragedy of HIV was becoming clear was a powerful social force. He took direction from one of the driving causes of the epidemic to define and shape his response – our nation's response. He accepted and endorsed homophobia as a social norm.

During the 1990s, researchers at the University of Minnesota confirmed this connection between homophobia and unsafe behaviors that put so many in harm's way for HIV. Apparently, we had done a pretty good job as a society to impress upon gay and bisexual men that they were without morals and social worth. These messages of homonegativity were received loud and clear and internalized. The research showed the internalized homonegativity was a factor in unsafe sexual behaviors, as well as other health risks that disproportionately affect gay and bisexual men, such as depression and substance abuse.

The research results rang true for me. I know what it's like to grow up understanding that it was okay for others to pick on me, hurt me, tell me I didn't belong or fire me because I was less than human or at least less than what a human should be. I know what it was like to be completely in the dark about who I was, or what I could be or have in sex or a relationship, because all the information I was given was about having babies, not having babies, abusing and objectifying women, and being married. Part of the reason "coming out" is so hard is because there is so much to be learned and unlearned in order to regain a sense of humanity that includes a clear sense of self.

I can look back on some wonderful things that have come into my life as a result of working at and growing beyond the homonegativity that was there. We all can, gay or straight, feel the impact of these changes. There have been some good moments. It was a huge thing when Minnesota added sexual orientation to the State's human rights protections. While no law can erase a long history of harmful and ingrained social attitudes, it at least declared the expectation that we would aspire to do better. We even made changes in our schools, churches, and families to ensure that young people understood the reality of being gay to better understand either themselves or others. We are even listing same sex unions on the society pages. While it wasn't always the stated reason for doing so, all of these have been important steps toward fighting at least one important aspect of the HIV epidemic.

Today, I have the opportunity, as MAP's director of community affairs and education, to talk to many people about HIV and my experiences with HIV. I can't say that I ever feel the inquiring, judging eyes upon me that are wondering, "how I got it." But people do ask me about how it is others are getting it. They want to know why it is these young kids are getting infected. "They know the facts, they know what can happen," I'm told.

Yes they do. Young or old, we know all too well the realities of living with over twenty years of HIV. We've heard it all. We get it. But apparently there are those who refuse to get it. We still hear loud and clear that protecting gays from discrimination is a "special privilege" that needs to be stopped. We also hear that no adolescent or young adult should know anything about sex except to be abstinent until they are married as husband and wife. We also hear that talking to gay men about sex and HIV prevention in a way that is effective is "obscene." And yet again, what we do not hear are the words from our leaders that affirm the lives of gay, lesbian, bisexual and transgender Americans as worthy of the dignity, rights or even the health services that are ascribed to our citizenship.

PAYING FOR MEDICATIONS

AIDS Drug Assistance Program (ADAP). Most Minnesotans living with HIV know that ADAP exists as a program that helps people living with HIV pay for HIV-related medications. They may have used it in the past or are currently using it – or, think of it as sort of an “unofficial insurance policy” – something that will be there for use if their current health insurance doesn’t provide adequate payment for a needed medication.

Every state has an ADAP program. It was conceived and designed for individuals with no or inadequate healthcare insurance so that the cost of medications would be covered. Funding for the ADAP program is part of each state’s federal award under Title II of the Ryan White Care Act. ADAP funding is “earmarked” by Congress, meaning it must be spent on the ADAP program, whereas the use of other Title II expenditures is decided locally. The ADAP “earmark” is the fastest growing area of the Ryan White Care Act. In 1996 \$52 million was spent on ADAP and by 2002 \$639 million was budgeted, an increase of 1000 percent.

States can and do add funding to federal ADAP dollars because they can greatly expand the types of activities that can be included under ADAP. In Minnesota for example, in addition to helping pay for actual prescriptions, the ADAP program assists eligible individuals in paying for health insurance premiums, which in turn can provide assistance for medications thus providing a more comprehensive approach to health care. In addition, the ADAP program in Minnesota allows for medication co-pays, dental insurance, and some nutritional needs. Each state also has a list of prescription drugs covered (called the drug formulary) under its’ ADAP program. The Minnesota program has one of the largest formularies in the country.

Increasingly states are running into a funding crisis with their ADAP programs. It is becoming almost routine to hear a news report that a state is taking emergency austerity measures to defuse their ADAP crisis, meaning that more and more people can’t get the meds they need when they need them. Most often states in ADAP crisis first try to restrict what drugs will be paid for, close the program to new participants, or create waiting lists to get into the program. States that have had the most stringent eligibility rules and put the least amount of extra money into the ADAP programs seem to be the ones that have been first to run into a crisis around funding. North Carolina for example, has always limited access to individuals with income at 125 percent of the Federal Poverty

Guidelines (in comparison, Minnesota’s is 300 percent) yet they were one of the first to create a waiting list to get into the program. In January 2002 they began their waiting list and by October more than 800 individuals were on it. To date, 12 states have enacted emergency measures. ADAP watchers are concerned that in 2003, states that have served the most people, including New York whose ADAP funding needs increase \$5 million every three months, are headed towards an ADAP funding crisis and are planning emergency measures.

Before protease inhibitors, there were no medications that significantly affected the course of HIV disease and ADAP was, from a budget standpoint, a small program. With the advent of protease inhibitors, costs of medications have increased enormously and because these drugs have been effective in extending lives, more people are accessing ADAP programs over a longer period of time.

The problem facing ADAP programs across the country is symptomatic of the problem facing the health care system as a whole. Drug prices rose 12 percent in 2001 – the biggest increase of any part of the health care system. And prescription drugs are one area that consumers increasingly have to pay for out of pocket. Employers add co-pays or place a cap on prescription drug coverage in order to offset the rising premiums they face. Medicare, the biggest federal health insurance program, doesn’t provide prescription drug coverage at all and Congress seems unable to find common ground that could provide this coverage. The lack of adequate coverage for prescription drugs increases the pressure on programs like ADAP. But the increased need for ADAP assistance comes as many states, including Minnesota, are facing large deficits. Whether needed for a short time until other health insurance kicks in, or for many years to assist with multiple co-pays, ADAP has greatly benefited the lives of thousands of people nationwide living with HIV. Until there is significant change in both public and private health insurance to make prescription drugs affordable, this program fills a critical need.

CORRECTION

In the last issue of AIDSLine Brief, Pillsbury United Communities was inadvertently omitted from the list of Minnesota Department of Health prevention programs. Pillsbury United Communities offers programs for men who have sex with men. For more information, please call 612-824-0708 or visit their Web site at www.puc-mn.org

Transgender and HIV: What Have We Learned From Prevention in Minnesota?

Walter Bockting & Jendeen Forberg, Program in Human Sexuality
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What is transgender?

Transgender refers to a diverse group of individuals—including transsexuals, crossdressers, transgenderists, bigender persons, drag queens and kings, and female and male impersonators—who cross or transcend culturally defined categories of gender. It is estimated that 1 per 11,900 males is male-to-female transsexual and that 1 per 30,400 females is female-to-male transsexual; transsexuals (who desire or have had hormone therapy or sex reassignment surgery to feminize or masculinize their body) are by far outnumbered by people with other identities under the transgender umbrella (who may not desire physical changes), but no reliable estimates for those are available. Transgender people may be attracted to men, women, or both, and therefore may identify as straight, lesbian, gay, or bisexual when it comes to their sexual orientation.

HIV prevalence and risks

Although no national surveillance data are available due to the lack of a transgender-specific reporting category, several studies have found alarmingly high rates of HIV risk and infection among subgroups of the transgender population (Bockting & Kirk, 2001). Recent needs assessments in several U.S. cities revealed HIV prevalence rates ranging from 14-35 percent (see Table 1). HIV risks included multiple partners, frequent receptive anal sex, irregular condom use, and injecting drug and hormone use.

chronic lack of HIV prevention targeting the transgender community was seen as supporting a denial of risk already widespread in the community. Participants expressed concern about the belief among their peers that a change from male to female, or a change from a gay or lesbian to a heterosexual role, provided protection without any accompanying behavior change. Community involvement, peer education, and affirmation of identity were stressed as integral components of a successful intervention.

How have transgender people been neglected in HIV prevention?

Most HIV prevention services are structured based on conventional categories of sex, gender, and sexual orientation, such as men who have sex with men (MSM) or heterosexual women. No category exists for transgender individuals who might share characteristics with both or neither of these two groups. For example, female-to-male transsexuals who identify as gay may engage in receptive vaginal penetration with their male partners. In what risk group do these individuals belong? Can services designed for MSM effectively address their HIV risks? In the absence of a transgender HIV surveillance category, how should an HIV-positive female-to-male transsexual attracted to men be classified? Similarly, many male-to-female transgender individuals identify as lesbian and may engage in insertive vaginal or anal penetration with their female partners. Classifying

TABLE 1. RESULTS OF RECENT U.S. TRANSGENDER HIV PREVENTION NEEDS ASSESSMENTS

City	Reference	N	n(%) HIV+	Sexual Risks	Needle Risks
Los Angeles	Simon, Reback, Gatson, & Bemis, 1999	244	33 (14%)	Unprotected anal sex (39%)	Injecting drug (8%) and hormone (39%) use; sharing needles (1%)
New York City	McGowan, 1999	83	21 (25%)	Unprotected anal (21%) and vaginal (10%) sex	Injecting drug (16%) and hormone (39%) use; sharing needles (25%)
San Francisco	Clements, Katz, & Marx, 1999	392 male-to-females	137 (35%)	Unprotected anal (34%) and vaginal (26%) sex	Injecting drug (18%) and hormone (31%) use; sharing needles (8%)
		123 female-to-males	2 (2%)	Unprotected anal (4%) and vaginal (13%) sex	Injecting drug (18%) and hormone (51%) use; sharing needles (16%)
Washington, DC	Xavier, 2000	252	63 (25%)	Unprotected anal sex (25%)	Sharing needles (4%)

In Minnesota, we used focus groups to assess the impact of HIV, HIV risks, and prevention needs of the local transgender community. Findings indicated that HIV compounded the social stigma attached to being transgender. HIV risk cofactors included gender identity conflict, shame and isolation, loneliness, search for affirmation, prostitution, substance abuse, and injecting hormone and silicone use. Participants explained that the rejection they experienced because of their gender nonconformity created a void that they may try to fill through sexual intimacy. Some saw acceptance, even for one night, as worth the risk of HIV infection. For transsexuals, discomfort with one's own anatomy and fear of rejection complicated disclosure and sexual negotiation. Negotiating condom use would require acknowledgment of body parts that they rejected or disowned. Risks associated with injecting hormone use included needle sharing, effects on mood and impulse control, and erectile difficulties leading some to choose not to use a condom during sexual activity. The

and targeting these women as either heterosexual or lesbian women is not likely to adequately account for the reality of their experiences. HIV prevention structured along conventional categories of sex, gender, and sexual orientation therefore perpetuates the marginalization of transgender people and those with whom they interact.

All Gender Health: seminars for Minnesota's transgender community

To respond to the specific needs of the transgender community, the Program in Human Sexuality partnered with local transgender organizations to develop an intervention (named All Gender Health) funded by the Minnesota Department of Health. The intervention consisted of a two-day sexual health seminar combining large group lectures, panels, videos, music, and exercises with small group discussions. The curriculum explored transgender sexuality as distinct from male and female sexuality.

continued on next page

Highlights of the seminar include a sexual words exercise facilitated by a drag performer to help participants find language affirmative of their bodies and experiences; transgender-identified physicians discussing transgender-specific medical needs; and a panel of couples modeling how participants, despite the challenges associated with being transgender, could develop healthy and satisfying relationships. Trained peer educators facilitated the small group discussions.

Data on relevant health issues showed that 42 percent used feminizing or masculinizing hormones; 8 percent injected, and one participant reported having shared needles. Fifty-seven percent had been tested for HIV, one was HIV-positive. Forty-eight percent had not told their health provider of being transgender. Twenty-two percent abused alcohol and 15 percent used other drugs. Forty-seven percent attempted or considered suicide within the last 3 years, indicative of the hardship and mental health needs among this population. Sexual risks included unprotected anal or vaginal sex (15 percent) and unprotected oral sex (33 percent), including with men who have sex with men (40 percent), injecting drug users (11 percent), and exchange partners (sex work 10 percent). Closer examination of our data showed that participants who experienced higher levels of transgender-related discrimination and lower levels of social support were 1.4 times more likely to have had unsafe sex.

Seminar attendees that also participated in focus groups reported that the intervention gave them a boost in self-confidence to come out of isolation. They explained that the seminar increased ownership of their sexuality. They felt the seminar gave them permission to explore sex safely with their existing anatomy. Participants reported discarding needles more safely, getting an HIV test, and intending to use condoms. Some reported having decreased their number of sexual partners, in particular those met over the Internet. For many, the seminar introduced them to the female condom and the use of adequate lubricant, important especially for postoperative male-to-female transsexuals whose surgically constructed vaginas do not self-lubricate. Participants suggested that future interventions increase the focus on confronting internalized transphobia and promote relationship skills (e.g., how to come out to potential partners, how to cope with rejection). As one participant stated: "I was fitting a stereotyped notion of a role rather than being myself. Rather than worry about my gender presentation, I need to learn how to present myself as transgender and come out as such to potential partners." Finally, participants suggested we use the Internet to confidentially reach the more isolated members of their community.

Conclusion

Transgender people's HIV risks call for targeted interventions to respond to their specific prevention needs. All Gender Health is an example of such an intervention that will continue to be available for the local transgender community. We urgently need a transgender-specific HIV surveillance category to make the epidemic among this population visible and to prioritize resources to develop innovative interventions for those among this population most at risk.

For more information about All Gender Health or transgender and HIV, contact Jendeen Forberg, 612-626-0812.

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GLBT Community and the Abstinence-Only-Until-Marriage Conversation

Rachel Wolk, MAP community health education manager

What's missing in the following picture?

Boy meets girl. Boy marries girl. Boy and girl have sex. Boy meets boy, or girl meets girl. Boy, or girl cannot marry other boy, or girl because the State of Minnesota does not legally recognize same sex marriages. Boy and boy, or girl and girl do not have sex, ever. This is not a realistic option. What's missing from the above example is the acknowledgement of gay, lesbian, bisexual and transgender (GLBT) individuals in a committed relationship context and, an accurate, healthy representation of the GLBT community and life. Sometimes gay men and lesbians are not always in a committed relationship or may experience what has been termed "serial monogamy" – just like their heterosexual counterparts. Regardless, the GLBT community includes long term stable couples deeply committed to each other and the family they formed.

Historically, the topic of abstinence as it relates to sexuality education has not always been viewed as a traditional, community-wide GLBT issue to rally around. It has often-times been left to GLBT parents of school-age children to speak up against programs such as these, that either do not include mention or discussion of GLBT families in the context of normal, healthy relationships. Even worse are those abstinence-only programs that routinely give misinformation about the GLBT community and portray these families as sinful, harmful and damaging to the overall well-being of society. This trend must stop. The fight against adopting an "abstinence-only-until-marriage" approach in sexuality education must become everyone's issue—gay or straight; for this approach is one of exclusion by design, and will carry us back to a place and time some of our political leaders would like to visit, but which in itself could prove to be detrimental to whatever small amount of progress had been made in the civil and human rights movements since 1964.

Beyond the deliberate exclusion or misrepresentation of GLBT life, the abstinence-only-until-marriage approach to sex education also generally spreads inaccurate information about sexually transmitted infections (STIs), contraceptives, and HIV, including the promotion of the theory of STIs and HIV as "nature's retribution, or a natural consequence" for having sex outside of marriage; misinformation we are continuously striving to overcome even today. Even more damaging is the misinformation young people are taught about the effectiveness of condoms. We know that when properly and consistently used, condoms offer great protection against HIV, STIs and unplanned pregnancy. Of course human error or human choice enters this equation and condoms may not always be used. However, that fact is used by the abstinence-only crowd as evidence of "condom failure".

Like many of the topics we face on a daily basis here at the Minnesota AIDS Project, abstinence-only-until-marriage stirs people's passions. I strongly encourage all readers, be they part of the GLBT community or not, to examine this issue closely and with a discriminating eye and not be afraid to speak up—against the misinformation, misrepresentation, and misunderstanding. We are, and need to be, a part of the conversation.

Are *Lesbians* Really at Risk for HIV?



This is a frustrating topic to discuss. The Center for Disease Control and Prevention (CDC) acknowledges “vaginal secretions and menstrual blood (from a woman living with HIV) are potentially infectious.” The CDC also states “female to female transmission of HIV is a rare occurrence.” Any article written about lesbians and HIV will clearly state that there is a risk. In most cases though, the emphasis is primarily on the simple fact that there is a risk and neglects to talk about exactly what the risks are – making it difficult for lesbians to make informed decisions.

HIV is transmitted through some body fluids – blood, semen, vaginal fluids and breast milk. It is through individual behaviors – not the color of one’s skin, one’s age, economic status, country of birth or identity with a certain community that puts a person at risk. Anyone who engages in sexual activity that would allow for the transmission to occur is at risk - that includes lesbians.

Research on lesbian risk of HIV is scarce. Two cases from early in the epidemic were reported among women who have sex with women (WSW) – in both cases the assumption was made that transmission occurred during oral sex. It is questionable whether there are other documented cases of transmission between WSW – some statistics show there are less than 15 cases. Other factors play into the discussions and research regarding lesbian risk. Since lesbians account for the smallest group of infected individuals – the ‘pool’ of HIV infected lesbians that are able to infect other lesbians is certainly small.

Similar to others in the gay, bisexual and transgender community, many lesbians are uncomfortable dealing with health care systems and providers. Historically, health care providers are not adequately educated on how to communicate with this population. “Do you use condoms?” for instance is not a sufficient question to ask a lesbian and in many situations will set the tone for how comfortable a lesbian is in answering further questions. The trust level, inappropriate safer sex questions and discussions, and the high chance that a woman would choose not to disclose her sexual identity all contribute to insufficient data being collected.

The tracking system for women who are HIV-positive does not take into account the WSW population. There are no WSW options to check on risk assessment forms. WSW are usually placed in another category or in the “other” section. If a woman is HIV infected and has had any IV drug use – she is classified as an intravenous drug user. If a woman is HIV-positive and has ever had even one sexual encounter with a male – her risk is categorized as heterosexual contact. This makes it impossible to narrow down whether the transmission occurred during sex with a male, during IV drug use – or –from sex with a woman.

Determining what is safer sex for WSW is another issue to consider. Of all the sexual behaviors that have been studied – unprotected anal and vaginal sex are clearly the highest risk behaviors. In studies on oral sex, the risk is acknowledged and in some cases has been proven as a route of transmission. Oral sex however is clearly indicated as less

risky than other behaviors. So one of the lowest risk factors in general – oral sex – is the highest risk for WSW. Oral sex would be a risk for the woman performing oral sex. This is particularly true if the woman who is receiving the oral sex is HIV-positive and is menstruating, or has another STI. Another possible risk behavior is women sharing sex toys without proper cleansing or use of condoms/latex barriers on the toys between one woman’s use and the others. This would raise the possibility of exchange of fluids inside the vagina or anus.

The incidences of transmission in the above mentioned sexual activities identify the largest risks, but to assume that all lesbians are performing oral sex and/or playing with toys would be a huge mistake. Most other sexual activities that WSW engage in would not put them at risk unless there was a large open wound on a body part where the infected woman’s fluids could enter.

So are lesbians at risk for HIV transmission? Yes, of course they are. Nobody can negate this possibility.

Until heterosexism, or the assumption that everyone is heterosexual or should be, is eradicated amongst health care professionals, and they are trained in how to ask appropriate questions regarding safer sex practices, and until lesbians feel more secure in honestly discussing sexual activities, and further research is completed, lesbian HIV risk will remain unclear.

It is key to remember that behavior is what puts someone at risk – not the person’s sexual identity. Health care professionals and HIV/STI testing counselors should not make assumptions about what lesbians do or don’t do that might put them at risk. Lesbians too should not take this risk or make assumptions in new dating situations.

To be ‘safer’, lesbians need to talk about their risks with one another – just like anyone else. They should ask questions of potential sexual partners and assess their ability to trust the women they are considering getting involved with. They need to ask whether the other person has ever been tested for HIV, whether the person has used IV drugs, what their sexual risks have been, if they have had HIV-positive partners and if they have had other STI’s. Some people may choose to use protection every time with every partner.

It appears that for lesbians, the risk of becoming HIV infected has been and remains a small one. At the same time it doesn’t seem like it is a risk worth taking until we know more.

Importance of Including HIV-positive Women in Clinical Trials

Debra Smith, MN AIDS Clinical Trials Unit community program associate

Despite many advances in HIV science, information on the natural history of HIV disease in women is still limited. In addition to having many of the opportunistic infections seen in men, women have gender-specific symptoms that are often hormone-related or gynecological. Recent information suggests that while women may have lower viral loads than men, HIV seems to progress at the same rate for both. Women most likely differ from men in absorbing, metabolizing and experiencing side effects of certain medications. Most medications have never been tested specifically in women.

In 1985 only 7 percent of newly reported AIDS cases in the U.S. were in women. That percentage grew to 14 percent in 1992 and 23 percent in 1999. Today, in 2002, women comprise 26 percent of new cases of AIDS in the U.S. while it's 47 percent worldwide and 55 percent in sub-Saharan Africa. Despite the increasing numbers of women becoming infected yearly, women are continually underrepresented in clinical trials.

Before 1993, women were, for the most part, excluded from participating in clinical trials. Researchers feared women might become pregnant and they didn't want to risk harming the unborn child with experimental drugs. Treatments, toxicity and medication safety information were studied in men and assumed to be the same in women. Because of strong activist pressure and the fact that women living with HIV were not responding well at all to many of the approved medications in 1993 the Food and Drug Administration (FDA) said that women could no longer be kept out of clinical trials. The argument that they may become pregnant no longer stood as a barrier. Unfortunately, women still make up only 12-23 percent of total participants in clinical trials.

The federal government spent about \$2 billion on HIV research through various programs in 2002. In addition, non-profit foundations, colleges and universities and pharmaceutical companies also sponsor clinical trials. Some of the federal dollars have gone to fund two major research projects for women: The Women's Interagency HIV Study, which investigates the nature and rate of disease progression in women, and the Women and Infants Transmission Study to investigate factors associated with perinatal HIV transmission. This is a start, but it's not enough. Women need to have a larger presence in most all of the HIV clinical trials being conducted in the U.S., whether specifically designed for women or not.

There are many clinical trial options for women and men with HIV in the Twin Cities. Most of these studies want to enroll large numbers of women so that gender-specific data can be gathered. The questions we have surrounding women and HIV can only be answered when more women become involved in clinical trials. Until then, women will continue to be treated based on information gotten from men. Become involved! Look for a trial that interests you or refer someone you know to join a clinical trial.

To learn more about HIV research, science and clinical trial opportunities, join the MN AIDS Clinical Trials Unit (ACTU) Community Advisory Board (CAB). This group welcomes your involvement to learn new information and to make research recommendations to the clinic staff. It meets every 2nd Thursday from 12-1:30 (lunch is provided) at the Minneapolis Urban League (2100 Plymouth Avenue North). To learn more about the CAB or to register for the next meeting, call Debra at 612-625-3205. To hear more about opportunities to participate in a clinical trial, please call an ACTU study nurse at 612-625-1462. Transportation assistance is available and many studies pay you to participate. Give them a call and they will help you determine if there's a clinical trial that's right for you. Be a part of the solution!

Have You Heard About the WOMEN & FAMILIES NETWORK

The Women and Families Network (WFN) is a collaboration of HIV service providers and consumers. We have been meeting since March 2002 to brainstorm how we can use this network to improve the quality of medical care and social services for women and families affected by HIV. This work expands on the good work of the Women and Families Workgroup, W.O.M.A.N. and the other Minnesota organizations, which have existed in many forms during the past decade.

We have over 30 active members in the WFN. Network members contribute a wide range of experience and expertise that guides Network activities. Membership consists of both service providers and consumers. Service providers in our Network represent the following disciplines: case management, clinical trials, social work, medical care and HIV specialty care (including nurses, nurse practitioners, and physicians), psychology, health education, outreach, housing, legislative advocacy, research and evaluation, substance abuse and public health.

How can you get involved?

The WFN has not been in existence for very long but we already have a lot to offer. We encourage participation in the network by consumers, providers and anyone else who is concerned with the needs of women and families affected by HIV. You can get involved in the network in a number of ways:

- Become a member of the Network. By being a member you commit to working on one of the two committees:
- Forums and Training Committee: This workgroup plans educational and social events for people living with HIV.
- Seamless Services Committee: This group works to create coordinated, comprehensive services across agencies and disciplines for people living with HIV.
- Sign up to receive our quarterly newsletter filled with news, articles and resources for both service providers and people affected by HIV.
- Come to one of our networking events! These networking events take place twice a year and are geared to service providers who want to share resources, discuss available programs and help improve services for those affected by HIV.

For more information on the network and to find out how to get involved contact Ribka Berhanu, MAP women and families systems advocate at 612-373-9175 or by email at rberhanu@mnaidproject.org

A stylized illustration of a house in shades of blue. The house has a gabled roof, a balcony with a white railing on the upper floor, and a window with a white frame. The lower floor also has a window and a balcony with a white railing. The background is a light blue gradient.

HOUSING HAPPENINGS

The Invisible Homeless

Homelessness remains a persistent, complex and difficult problem. Some aspects of homelessness are very visible to all of us. But for every homeless person we see on the street, there are hundreds more who are invisible to us. They may be “couch-hopping”, doubled up with extended family, or living in their cars. Others with nowhere to go create makeshift shelters in camps, under bridges or wherever they can find a “safe” space. Minnesota shelters serve approximately 7,000 people every night, about half of those are children or unaccompanied youth. Another 1,000 or so are turned away each night. We have no accurate way to count the true number of people who are homeless or at risk of homelessness.

The invisible homeless – living outside

For many people living outdoors, the key to their survival is invisibility. However, this same invisibility makes it difficult to be aware of the problem. Patrick Wood, Homeless Outreach Project outreach coordinator spends a lot of his time going to the camps and other places where people are living outside. The majority of the people he sees living outside are Caucasian men. He estimates the population to be 70 percent Caucasian and 30 percent Native American, with some Latinos in the summer. Men outnumber women eight to one. The people he meets are generally independent and self reliant, almost half of them are working. Many also have mental health or chemical dependency issues. However, Wood emphasizes, it is a myth that they are homeless due to the closing of mental institutions. The reality is that there is simply a lack of affordable housing for low wage earners, particularly the old “flop houses” or hotels with cheap rooms that used to be around, but have since been torn down. Others can’t find a place because of low incomes, poor rental history and criminal backgrounds.

Homeless youth

Youth face different challenges than homeless adults. Because of their age, homeless youth have few legal means to earn enough money to meet basic needs. Many homeless adolescents find that exchanging sex for food, clothing, and shelter is their only chance of survival on the streets. Studies indicate that a disproportionate number of homeless youth have attempted to commit suicide or have been victims of sexual abuse or domestic violence.

In October 2000, the Wilder Research Center conducted a survey of homeless youth that found that on any given night, 660 youth are homeless and without shelter in Minnesota. It is not uncommon for this population to slip through the cracks. StreetWorks, a collaboration

continued on next page

HOUSING HAPPENINGS

The Invisible Homeless

of Twin Cities agencies that work with youth reported that in 2001, their outreach workers had contact with 32,000 youth.

An increasing number of gay, lesbian, bisexual, transgender (GLBT) young people experience alienation by peers, rejection from family and friends, and derision by society at large. Home and school often lack the necessary resources to help GLBT youth with the fear and isolation they may face. Without support from their peers or allies, many are likely to find themselves confronted with HIV disease, depression, drug and alcohol abuse, homelessness, and suicide. Recent research shows that GLBT adolescents leave home more frequently, are victimized more often, use highly addictive substances more frequently and have more sexual partners than heterosexual adolescents.

Multiple Stigmas

Among the most marginalized of people experiencing homelessness are those whose gender identity transgresses cultural norms. Transgender individuals experience homelessness for all the same reasons that other people do – lack of affordable housing, mental health and addiction problems, physical abuse and estrangement from families. But their social isolation and stigmatization are disproportionately high. People who are homeless are marginalized by our society, which is compounded by stigma because of sexual orientation or gender identity. Shelters and other agencies that serve people experiencing homelessness need to create safe and respectful environments for GLBT individuals and others at risk for stigma and discrimination.

HIV

Not only are those who are homeless at greater risk for HIV, but for those already living with HIV, the disease is exacerbated by homelessness. The prevalence of HIV is dramatically higher among homeless people than in the general population, between 3 and 20 percent, with some subgroups having much higher rates of the disease. Conditions associated with homelessness make HIV prevention and control especially difficult. In addition to barriers to health care, homeless people living with HIV are often unable to adhere to the complex medical regimes required. Homeless subpopulations for whom HIV prevention and care are known to be especially problematic are rural populations, homeless women and transgender individuals.

Housing Happenings is a timely update of housing-related information for HIV service providers and consumers. For further information contact Kim Lieberman, MAP housing systems advocate, at 612-373-9166, 800-243-7321 or by email at klierman@mnaidproject.org



HIV DISCLOSURE

FOR FAMILIES

RISKS, BENEFITS AND TIMING

A 1994 study revealed that disclosure of one's positive status ranked very high in degree of stressfulness out of 14 HIV disease "crisis points" – second only, in fact, to the receipt of a positive test result. It is little wonder, then, that many individuals with HIV experience anxiety when confronted with the thought of disclosing, especially to family members. Depending on a family's dynamic, disclosure can inspire an outpouring of support – or isolation resulting from stigma and fear. Because one can never be sure of the outcome, it is necessary to weigh the potential risks and benefits, as well as timing issues, before disclosing an HIV diagnosis.

Disclosure is an important issue for all individuals with HIV. Health information must be shared with medical providers, for example, in order to receive proper care. Outside the clinical setting, however, disclosure is not always so clear. Because many people with HIV, either through first-hand experience or anecdotally, understand that disclosure can lead to rejection and abandonment by both family members and peers, there is a need to develop a personal strategy. Further, some of the behaviors associated with HIV transmission, including substance abuse, can trigger feelings of shame and guilt among diagnosed individuals. These feelings can create barriers to reaching out for support and assistance, further increasing an individual's isolation. All of these factors must be considered when deciding when and how to disclose HIV status.

Many commentators encourage individuals to take inventory of their social support network, including family members, and decide who should be considered for disclosure – and why. Ideally, these candidates should have stable, consistent relationships with the individual. They should be trustworthy, meaning they are willing and able to keep the disclosure confidential, if requested. The individual should consider the extent of the family member's knowledge of HIV, or their willingness to learn. By sorting out the facts related to potential recipients of a disclosure, an individual is able to determine who should be told now, who can wait, and who should be a "wait and see." Such a process of elimination should help avoid at least some of the negative consequences associated with HIV disclosure.

Despite one's best efforts, disclosure can lead to uncomfortable situations or even family crisis. For example, a parent might make an issue out of the other parent's HIV status in a custody battle, seeking to alienate the child from the positive parent or create the perception of danger to the child. Relatives might ostracize the HIV-positive individual, cutting off communication, denying access to family functions, disclosing to others who have no need to know or excluding from estate planning. Other times the alienation is less extreme but just as hurtful, as in the form of belittling comments. Such experiences can lead to negative emotional and physical effects on the individual with HIV.

There are, however, many encouraging aspects associated with disclosure. If an individual is fortunate enough to have a supportive family network, then disclosure can open the door to help, hope, and

even better health. Researchers have found that sharing one's HIV status can alleviate distress, rebuild or strengthen ties with family members, and relieve anxiety for the people who love and care for the individual with HIV.

As with all family members, disclosure between a parent and child can be very difficult, but also rewarding. Many parents do not want to face the possibility that they might not always be there for their children. One of the most important issues to reconcile for a parent is the need to protect the child from bad news. According to several researchers, lack of disclosure can actually increase a child's anxiety because he or she witnesses the parent's mental and/or physical deterioration, but does not know the reason why. Communication is therefore critical in the parent-child relationship. Disclosure should be age appropriate, gradually increasing in complexity with a child's years, and conducted on a continuum, meaning that discussion is not limited to the one-time event of disclosure. Successes and setbacks should be spoken about in an open and supportive manner. Social supports should also be made available to the child. Finally, communication will help the parent make plans for the child's future, in the event that the parent becomes too ill to provide care or dies. An older child, especially, will benefit from the opportunity to partner in this planning.

Finally, many families face the issue of when to disclose a child's HIV diagnosis to the child, not to mention the community-at-large. Again, age-appropriate tactics are recommended, and many parents grapple with the decision of whether to disclose to a child even if the child is not engaged in drug therapy. As a child grows older, however, and begins to question why he or she is receiving certain treatments, the need for open communication grows. Additionally, children with HIV confront stigma and misinformation as well, particularly in schools. It is often up to the parent to advocate on behalf of the child and educate the public. Again, the same criteria mentioned earlier will be helpful to the parent in weighing the risks and benefits of disclosing a child's status to family members and beyond.

There is no easy answer to the problem of disclosure. Every individual has different experiences, usually a mix of positive and negative outcomes. Ensuring that some level of social support exists, however, is absolutely critical to maintaining physical and emotional health. Disclosure, however daunting at times, serves a vital purpose for the individual living with HIV.

resources for women

Below are a few resources that have health care information or services specifically for women. If you would like to know about other health care, social service, chemical or mental health services available to women, contact MAP AIDSLine, 1-800-248-2437, 612-373-2437 or online at mapaidline@mnaidsproject.org and click on Resource Guide. You can also order a free copy of the HIV Resource Guide by contacting MAP AIDSLine.

Delaware St. Clinic – Fairview-University Medical Center

420 Delaware St., Minneapolis
612-625-4680 Toll Free 800-688-5252 ext. 54680

Infectious disease clinic providing HIV treatment and medical care, HIV testing, counseling and consultations. Affiliated with AIDS Clinical Trials Unit at the University of Minnesota. Clinic has a pediatric infectious disease physician who sees HIV-positive children or children of mothers who are HIV-positive. Also have physician who specializes in HIV-positive pregnant women. Clinic offers a free “orientation visit” so that potential clients can learn more about the clinic, the health care team and get answers to any questions about insurance, pharmacy, etc.

Family Planning Special Project for Cook County

Norshor Building
21 2nd St., Suite C, Grand Marais
218-387-2216

Offers family planning counseling, contraception, and related medical services to female residents of Cook County and their partners in conjunction with Sawtooth Mountain Clinic. Confidential HIV testing available.

Family Tree Clinic

1619 Dayton Ave. St. Paul
651-645-0478
www.familytreeclinic.org

Provides testing and treatment for sexually transmitted infections (STIs), including urine testing for chlamydia and gonorrhea. HIV testing can be done anonymously or confidentially. Appointments are required.

Health Care for the Homeless Project

Minneapolis Office	St. Paul Office
525 Portland Ave., Level 3 MC963	438 Main St.
Minneapolis	St. Paul
612-348-5553	651-290-6814

Provides health and wellness services to homeless adults, youth and children. Services include treatment of general illness (colds, flu, etc.) physicals, chronic disease management, pregnancy testing, prenatal care, HIV/STI testing, birth control, and immunizations. Also provides social services, case management and public health nursing services. Offers assistance in linking to mental health, chemical health and other community resources. Operates nine clinic sites at shelters and drop-in centers in Minneapolis and seven at shelters in St. Paul.

Minnesota Family Planning and STD Hotline

1619 Dayton Ave., St. Paul
651-645-9360 Toll Free 800-783-2287
www.stdhotline.state.mn.us

Free statewide telephone hotline offers confidential information about birth control, sexually transmitted infections and low cost clinic referrals throughout Minnesota. Provides accurate information on the reproductive system, specific birth control methods, pregnancy testing, sexually transmitted diseases and other family planning matters.

Model Cities of St. Paul, Inc.

839 University Ave., St. Paul
651-221-4442

Provides outpatient chemical health services for women, maternal/child health services and long term case management for women with chemical dependency issues. Will work with health care providers to address HIV needs of women, pregnant women, infants and children. Some housing is available for chemically dependent women with 90 days of sobriety. Provides transportation and childcare for those who qualify. In-home therapy and counseling is also available. Provides crisis intervention and support programs for survivors of sexual violence through the African American Sexual Violence Program.

Project Inform

205 13th St., San Francisco CA
Hotline 415-558-9051
Office 415-558-8669 Toll Free 800-822-7422
www.projectinform.org

Offers confidential treatment information by phone and on Web site. Includes Project WISE, a program focusing on HIV treatment information and advocacy for women. Information from Project Inform is available in English and Spanish.

Women's Health Center

32 1st St. E., Suite 300
Duluth
218-727-3352
www.whcduluth.org

Women's Health Center is a reproductive health care clinic located in Duluth. Provides HIV and STI testing and treatment, family planning and related health care.

Women Alive

1566 Burnside Ave., Los Angeles CA
Toll Free 800-554-4876
www.women-alive.org

National toll-free hotline staffed by HIV-positive women volunteers providing encouragement to other women with HIV and information about mediations, medical care and symptoms. Spanish-speaking volunteers are available on Wednesdays. HIV-positive lesbian counselors are also available. The Web site provides information on women and HIV, as well as links and resources.



Minnesota AIDS Project™

www.mnaidsproject.org



Answering a Need in the Community

A PROGRAM OF THE MINNESOTA AIDS PROJECT

PrideAlive, MAP's gay and bisexual men's community building and HIV prevention program regularly offers HIV testing from a mobile testing unit in the Twin Cities Metro area. We believe that people at risk of becoming infected with HIV are more likely to be tested for HIV if they can talk freely about their risk with a peer.

In the fall of 2001 PrideAlive explored the possibility of offering HIV testing in Greater Minnesota by examining communities based on the population at risk, ways to connect with the community, and HIV services available. After eliminating communities that had HIV testing for gay and bisexual men in place, we arrived at two potential choices: St. Cloud and Rochester. Although both have active gay, lesbian, bisexual, and transgender organizations, regular HIV testing and outreach prevention programs for gay, bisexual, and transgender men were absent. Also, both communities had organizations and events that attracted a large group of people from an extended geographical area.

Coming into a Community

In the spring of 2002 we met with St. Cloud's Gay and Bisexual Men's Group (GAB) to offer testing at their monthly community dance. GAB was very open to this and in May, a PrideAlive staff member attended the dance to better understand the community, the number of participants and to assess the physical space to determine if the location was adequate for testing, including offering private space.

Shortly before the dance, the bar that had held the dance for years was sold to new owners who informed GAB that a gay

dance was not part of the bar's business plan. Not only was HIV testing on hold, the group has been forced to relocate their monthly community event.

Being Invited to a Community

In June, a member of Rochester's Gay and Lesbian Community Services (GLCS) visiting the Twin Cities encountered the PrideAlive team offering testing at a Minneapolis bar. He asked when PrideAlive was going to bring the mobile testing unit to Rochester and he suggested that the annual Halloween dance would be the best community event to initiate an HIV testing program. In the months that followed, PrideAlive laid the groundwork in the community. Together with GLCS the details of testing were finalized, including logistics, how test results would be made available and how referrals for more information or services would occur.

The dance was held at a local hotel, and meeting rooms that offered privacy for testing were available on the same floor as the dance. The Halloween dance was well attended and five people chose to be tested that night...a great start for a new community initiative.

PrideAlive will continue to look at ways to offer testing in Greater Minnesota and hopes to have community-based HIV testing available in both communities in 2003.

For more information about HIV testing in Greater Minnesota or PrideAlive contact MAP AIDSLine, 612-373-2437, 1-800-248-2437 or visit www.mapaidline@mnaidsproject.org