A Look Through The Gender Lens

2006 Summary Report from Roundtable on HIV/AIDS Among Women and Girls in Santa Clara County

March 2006

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April 10, 2005

Dear Friends:

This past March 10, 2006 marked the nation's first annual National Women and Girls HIV/AIDS Awareness Day. In recognition of this day, the Office of Women's Policy, the Commission on the Status of Women and the Health Trust AIDS Services sponsored a gathering of advocates and service providers working on the HIV/AIDS issue. Our goal was to learn more about the increasing impact of HIV/AIDS transmission among women and girls in Santa Clara County, challenges confronting our community, and developing recommendations to more effectively respond to this issue in our community.

Recently, U.S. Surgeon General David Satcher noted that while many people see AIDS as a disease that affects only gay men, women now make up 24 percent of new AIDS cases, up from 6.7 percent nearly two decades ago. Satcher further pointed out that 81 percent of the AIDS cases among women between June 1999 and June 2000 were among African-American and Hispanic women.

The event was an important opportunity to hear from some of the groups working day to day on this issue. We extend our deepest thanks to them for their participation and commend them for their tireless efforts to move our community from dialogue to action that will improve the health and well-being of all women and girls in Santa Clara County.

Sincerely,

Esther Peralez-Dieckmann, Director
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Emily Thurber, Chair
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Introduction

Despite increased international attention over the last decade, the HIV/AIDS crisis continues to be one of the most devastating and deadly threats to public health in the last century. Early in the HIV/AIDS epidemic, diagnosis and prevention was focused on men. Today, the HIV/AIDS epidemic represents a growing and persistent threat to women in the United States, particularly for young women and women of color. According to the Centers for Disease Control, in 1992 women accounted for an estimated 14% of adults and adolescents living with AIDS in the United States. By 2003, this percentage had increased to 22%.[i]

Human Immunodeficiency Virus (HIV) is the virus that causes Acquired Immune Deficiency Syndrome (AIDS). People can live for many years with HIV without developing AIDS with treatment. A person is considered to develop AIDS once their t-cell count drops below 200.

HIV/AIDS is increasingly affecting women in Santa Clara County. The gender distribution of HIV/AIDS cases in the county is consistent with national data that demonstrates females are becoming increasingly affected by HIV/AIDS. The proportion of females among recently reported HIV cases is slightly higher than proportion of females among existing AIDS cases. Further, AIDS incidence rates have been declining steadily among males since 1993 yet rates among females have not.[ii]

Recent trends indicate a change in the mode of transmission most commonly reported by female cases. A higher percentage of female HIV cases reported heterosexual contact as their mode of exposure (65.9%) compared with female AIDS cases (54.2%), revealing a shift toward a more heterosexual epidemic among women.[iii]

The landscape of women living with HIV/AIDS is changing. With these changes in mind, the Office of Women's Policy collaborated with the Health Trust, and the Commission on the Status of Women on March 10th to hold the first annual National Women and Girls HIV/AIDS Awareness Day. Key stakeholders came together to discuss these issues and their impact on women and girls in Santa Clara County. The following report is a synopsis of that event and summarizes the discussion heard from various participants.

HIV/AIDS: Every Woman's Issue

There are unique challenges for women living with HIV/AIDS. Many women have trust or betrayal issues because they contracted the disease from a partner with whom they believed they had a monogamous relationship. Issues also arise because women are frequently the caregivers of these partners. Many times as a result of these circumstances, women tend to be more isolated and hesitate to reach out for support.

Women frequently deny their risk of becoming infected with HIV. This presents a barrier, as they are less likely to get tested and receive treatment after a diagnosis. Developments in medicine have allowed people living with HIV/AIDS to live longer and more healthy lives with little or no obvious signs of disease; the old stereotypical image of people living with HIV/AIDS as weak and rapidly deteriorating is no longer accurate for the majority of the population. This is one reason why testing is imperative. Stakeholders all reported difficulties in getting women to

come in for testing, and one reason cited is that testing sites are all government based. Stakeholders suggested a more community-based site as a more welcoming, comfortable, and less intimidating venue for women to get tested.

Lack of knowledge and information contributes to the denial of risk and growing numbers of infected women, and presents a great challenge in combating this epidemic. According to a recent survey of adult women in Santa Clara County, ninety percent (90%) of women interviewed believed that they had little or no risk of becoming infected with HIV.[iv] Many think they only have to worry if they are promiscuous. One myth that prevents women from realizing their risk is the notion that marriage is as safe as abstinence. Many women assume they have no risk if they are married or in a committed relationship. Too often, however, a partner is dishonest and unfaithful and thereby introduces an increased risk for both partners. Women from higher social economic levels tend to also live with a false sense of security and believe “it can’t happen to me”.

One of the most difficult challenges for women living with HIV/AIDS is caring for children. Stakeholders reported that mothers with HIV/AIDS face a heavy burden and are deeply concerned with who will care for their children when they become too ill to do so, and once they are gone.

HIV/AIDS also has psychological impacts that are specific to women. In a focus group of women living with HIV/AIDS, one of the main concerns that differed from the male focus group was the impact the disease had on their romantic relationships. Many HIV-positive women feel emotionally frozen in the moment of diagnosis and are unable to move forward with healthy relationships, and fulfilling sexual lives.

One Woman’s Story

Julia is a local resident living with AIDS who joined the meeting to share her story. She is an attractive, well-dressed, and articulate woman; she is representative an emerging trend in the HIV/AIDS epidemic. She is someone who could be a family member or someone we live or work with whom you would never suspect was living with such a devastating disease.

Julia was deeply in love with her boyfriend. Soon they decided to move in together and got engaged. He became ill with cancer and she cared for him until his death eight months later. After he died, seeking some sense of connection, she found herself going through his wallet and discovered a hand written personal ad he had placed in the paper seeking sexual encounters with other men, emphasizing discretion. She found out that the cancer he died of was related to AIDS. It took her a year to work up the courage to get tested.

Julia was 24 years old when they tested her blood not once, not twice, but four times. Each time the results came up positive for HIV. She says the hardest part was telling her family. She shared that her father and mother held her and cried. She noted, “my father never cries.” Julia stayed healthy for a long time, until she came down with AIDS-related pneumonia. Additionally, she contracted a virus in her eye. She had to be hooked up to an IV via a catheter that went into her chest. Doctors invented an eye implant that must be replaced every few months to help her from getting infections. Due to complications with an implant, she became blind in her right eye. She says she has a strong strain of HIV/AIDS and has had pneumonia ten (10) times. She also has endured numerous surgeries on her sinuses and lungs.

Julia stresses that there is life after HIV: She enjoys being a speaker, especially with kids. She has been married for 5 years to an HIV-negative man. Julia has lived 18 years since the diagnosis of HIV and 13 with the diagnosis of AIDS.

Many facets of Julia's story reflect the changing face of people living with HIV/AIDS. Rates of infection continue to rise among women, and the most commonly reported mode of transmission is heterosexual contact. Just as Julia had no suspicion of becoming infected, many women perceive themselves as not at risk. Once faced with the possibility of infection, many women are afraid to get tested as it may confirm their fears. They may have not been educated to recognize their actual risk, and are forced to break through a general feeling of exemption from HIV/AIDS because they are not the stereotypical at risk population.

Intravenous Drug Usage

Although the principle mode of transmission for women is heterosexual contact, intravenous drug use is still a problem. In 2004, 26.1% of AIDS cases and 16.3% of HIV cases amongst women in Santa Clara County were transmitted via intravenous drug use. [v] This makes intravenous drug use the second highest mode of transmission reported among women.

Intravenous drug use is not only affecting transmission rates directly, but it is also linked with the high rates of transmission through heterosexual contact. The three primary risk factors among women who acquired HIV through heterosexual contact are: sex with an intravenous drug user (41%), sex with an HIV-positive partner (30%), and sex with a bisexual partner (24%).[vi] As the developing trend of increased transmission through heterosexual contact is addressed it is important to addresses intravenous drug usage as well.

What Is Happening With Girls?

The wave of new infections is particularly hard-hitting among young women. The Santa Clara County Public Health Department has reported decreases in condom and birth control usage among girls.[vii] A study on the east coast reported that girls are not being educated about a sexually transmitted disease (STD) until they contract one. Once diagnosed, girls become well informed about that particular disease, yet are not educated on other STDs.

Nationally we are failing to provide adequate education on HIV/AIDS and STD prevention to our children due to a preference of federal funding for "abstinence only" programming. Funding for safe-sex programs, which talk about practices such as condom use, continues to decrease. Consequently, there has been an increase in the number of girls infected with STDs. This trend is mirrored locally. Rising STD rates have been associated with increases in HIV infection, and may indicate a higher risk for HIV/AIDS among girls.

Specific Needs: There appears to be a strong correlation between the budget cuts affecting programming that provides education on HIV/AIDS and STD prevention, and the current rates of HIV infections among women and girls, which are at the highest ever seen in Santa Clara County. Education efforts must go beyond abstinence only programming as that fails to teach youth how to be responsible with sexual behavior. Girls need information not only on how to use condoms, but also how to talk to their partners about condom use if they are going to engage in sexual activity.

What Is The Role Of Culture?

Santa Clara County is rich with a variety of cultures; Sixty percent of the county is immigrant and first generation, with one-third (1/3) of the county population born outside the United States.[viii] HIV/AIDS is perceived differently in each of these cultures, and without culture-specific programming it is difficult to reach these populations.

In the Asian/Pacific Islander community, there is little acceptance and few safe places to talk about HIV/AIDS. This lack of education extends beyond HIV/AIDS education and overlaps into LGBT (Lesbian, Gay, Bisexual and Transgender) issues as well. The risk of infection is not recognized as a high priority threat. High school Vietnamese girls, for example, report being more afraid of getting pregnant than contracting a STD. Without specific education and culturally sensitive programming, populations face greater risk for infection. Between 1996 and early 2003, the proportion of new AIDS cases among Asian/Pacific Islanders in Santa Clara County more than doubled from 4.5% to 9.8%.[ix]

Similarly, there is a strong link and stigma within the Latino community about HIV/AIDS and LGBT issues, as well as a stigma around sex education in general. Stakeholders working with the Latino community report a lack of knowledge about basic safe-sex practices, such as condom and birth control use. Educational classes and workshops on HIV/AIDS should include the basics of safe sex practices. There is a need for programming to serve the specific needs of the Latino population on HIV/AIDS: Between 1994 and 2004, the proportion of new AIDS cases among Latinos increased from 26.6% to 57.4%, with a corresponding decrease in the proportion of cases among whites.[x]

Rates of infection continue to increase among African American women as well. African Americans are disproportionately affected considering the size of their population in Santa Clara County. While African-Americans represent approximately 2% of the population, they represent 10.7% of all the AIDS cases and 10.9% of all HIV cases reported.[xi]

The Ethiopian community is extremely closeted about the issue; there are no words in the language to even talk about HIV/AIDS. Women will often not even come near an HIV/AIDS shelter because they are afraid someone will see them. Stakeholders working with African immigrant women suggest that these stigmas should not be approached directly. Educational programs must be family-oriented and information about high-risk behavior, such as extramarital affairs, must be included. When presented with condoms, the response from women of this community is often, "What is this for?" Education efforts must also include basic information on safe sexual practices.

Specific needs: Cultural taboos can prevent education and programming from being successful. In order to decrease the rampant and shocking rates of infection, programs need to be created that approach the issue from within the community and from a position of deep understanding of the complex issues that continue to keep populations at a greater risk. Many programs currently in progress offer multi-lingual services, but this is not sufficient to make an impact. The problems are more complex than accessibility to language.

Intimate Partner Violence

An abusive relationship can limit one's ability to address safe sex practices. Partner cooperation is necessary in safe sex practices such as condom use. With the unequal power dynamic in an abusive relationship, women are at a disadvantage in initiating discussion about sex practices or negotiating condom use. Many times women avoid discussing or requesting the use of condoms out of fear of violence or rejection from their partners. In a study done about safe sex and intimate partner violence one woman said, "once you raise the issue of your husband using a condom, there no longer will be peace in the house."[xii]

Specific Needs: Safe sex and STD education needs to be added to domestic violence prevention programming and batterer intervention programs. Because of the hostile environment domestic violence creates these women have specific issues that increase their risk of STD infection.

Transgender Women: A community at risk

The transgender community faces specific challenges and prejudices that leave them ignored and underserved. There is very little data in regard to the needs in this community and as a result there are very few services offered specifically for the transgender community. Most individuals are afraid to identify in public as transgender, much less get tested for HIV. Most Latina and Asian/Pacific Islander HIV-positive transgender women are unemployed, not legal citizens/residents, and cannot apply for services offered.

Some of these individuals have substance abuse issues and are using "crystal meth" among other dangerous substances. Furthermore, there is a huge population of sex-workers as a result of discrimination and low self-esteem. The lack of mental health, medical and community services dramatically impacts this historically underserved and marginalized community. The knowledge of being HIV-positive often leads to an increase in drug usage. Many decide that they would rather not know. Unfortunately these women also practice unsafe injections of silicone and hormones in order to match their bodies with their gender identity, therefore creating major health problems, fatalities and spread of HIV/AIDS and other STDs.

Stakeholders affirmed that there is too little data on the transgender community. It is estimated that forty-five percent (45%) of the male- to-female transgender population in San Francisco live with HIV/AIDS, and half of that transgender population is closeted. Because data on transgender people is not collected consistently in Santa Clara County, it is difficult to say with certainty what percentage of people living with HIV/AIDS is transgender.

Specific needs: Stakeholders identified a great need for data collection and services for the transgender community. Currently, transgender identity is not part of the gender breakdown in any of the HIV/AIDS reports done in the County. This creates an obstacle in developing programs that target this community, and results in an absolute void of programming to serve the needs of this population. Issues around HIV/AIDS, mental health service, primary medical care, and substance abuse in this community overlap, and effective programming should overlap as well. Just as with culturally specific programming, the transgender community needs programming designed from within the community in order to be successful. Overwhelming HIV/AIDS infection rates in this community are associated with the extremely complex issues that transgender people face.

Successful programming should provide services that address other challenges specific to this community along with HIV/AIDS.

Non-homosexually Identified Men Who Have Sex With Men

There is a specific group of men that engage in sexual activity with men, but that do not identify as homosexual. In a study done by the Centers for Disease Control, they found that 29% of heterosexually identified men had engaged in unprotected anal sex with men, and that 58% of those men had primary female partners. The study also noted that few men in the study had ties to gay communities.[xiii] Men may engage in sexual activities with other men, but do not identify as homosexual or bisexual because they are married or have relationships with women. Since HIV/AIDS is stereotyped as a disease only affecting homosexual men, men who identify as heterosexual do not consider themselves at risk. Because these men are not active in the gay community, they do not receive education or programming about HIV/AIDS targeting that community. They are less likely to take precautions to prevent STDs.

Sexual identity is a complicated issue, and those complexities need to be taken into account when designing programming targeting women and the gay community.

Serious Funding Gaps

There is a great lack of funding for education and prevention programs overall. All stakeholders reported they do not have enough funding to provide the services needed to make a community-wide difference. Most funds serve programs targeted toward the homosexual male population or programs that provide medical services. This is likely due to the fact that homosexual men represent the first population in which the HIV/AIDS epidemic was seen, and that men, overall, are disproportionately affected. More funds are required in order to fully serve the needs of the male population. Education and program efforts have made a difference in this population and male rates of infection are decreasing.

Programming for men does not include the particular group mentioned above of non-homosexually identified men who have sex with men because they do not consider themselves part of or participate in the gay community. This specific group of men needs programming and services designed to fit their specific issues.

Female infection rates are increasing and there is an immediate need for funding to provide services for women and the populations that contribute to these rising rates. Gender responsive programming is crucial in the success of programs targeted toward women.

Specific needs: More funding is needed across the board. It would be irresponsible to decrease funding for programs targeting and serving the homosexual male population in order to provide funds targeting women. Both are equally important and supplemental funding is needed to provide programs specifically targeting women and men who have sex with men and women.

Recommendations

The following recommendations emerged from the discussion:

- The County needs to gather data on all groups with higher risk of infection (youth, lesbian, gay, transgender, male, female, cultural/ethnic groups) to know the full impact of HIV/AIDS
- Programming is needed that takes into account the complexities of and is sensitive to sexual identity
- STD education should be given via Batterer Intervention Programs
- Get political representatives involved—invite them to meetings, and AIDS day functions
- Engage the Domestic Violence community, LGBT organizations, and other advocates in HIV/AIDS prevention and education (don't rely only on health organizations)
- Get youth involved with HIV/AIDS awareness through school programs (need to move beyond abstinence only)
- Need to find a way to reduce the stigma associated with people getting tested—maybe hold women's testing day
- Publicize testing sites (some are free)
- Look at gender programming for the prevention and treatment of HIV/AIDS
- Raise awareness about candidates' views on HIV/AIDS for elections (elect officials who demonstrate a commitment to addressing HIV/AIDS and finding support and funding for education and programming)

Final Thoughts

America's politically conservative environment is a hindrance to successful preventative and educational programming. Policies are being created by politicians who do not understand the issues of the community or how funding effects these programs.

There is a need for the HIV/AIDS education and prevention efforts to extend to people of every gender and sexual identity. Both men and women must be actively engaged in efforts to increase the level of advocacy for the vast needs that exist in our county.

People with HIV/AIDS are living longer, healthier lives. Since the advent of protease inhibitors during the 1990's, there has been a steady decline in AIDS mortality with a corresponding increase in the number of people living with AIDS. Yet rates of infection in certain populations are on the rise, particularly for women and minorities. Additionally, we do not fully know the impact of the disease among other groups, such as the transgender community.

We would like to acknowledge and thank the men and women who were part of this important gathering. Through dialogue with these individuals, we have greater information about the reality, needs, gaps, and services for women and girls with HIV/AIDS. Their work and our support are essential to ensuring a healthy, safe community for everyone.

[i] Centers for Disease Control & Prevention, HIV Prevention Strategic Plan Through 2005.
[ii] Santa Clara County Public Health Department, Annual AIDS Surveillance Report, 2003.
[iii] Santa Clara County Public Health Department, AIDS Case Registry, 2005.
[iv] Santa Clara County Public Health Department, Behavioral Risk Factor Survey, 2004.
[v] Santa Clara County Public Health Department, AIDS Case Registry, 2005.
[vi] Ibid.
[vii] Santa Clara County Public Health Department, Children and Youth: Key Indicators of Well-being, 2003.
[viii] 2000 US Census
[ix] Santa Clara County Public Health Department, AIDS Case Registry, 2005.
[x] Ibid
[xi] Ibid
[xii] *Reviewing the Links Between HIV/AIDS and Violence*, Asian Americans for Community Involvement, 2006.
[xiii] Doll, Lynda S. and Lyle R. Petersen. 1992. Homosexually and Nonhomosexually Identified Men Who Have Sex With Men: A Behavioral Comparison. *The Journal of Sex Research* 29 (1): 1-14.