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FROM THE DIRECTOR

AIDS is increasingly a disease of women, particularly women of color. Each and every day, here in the United States, and across the globe, thousands of women are infected with HIV.

The impact reaches far beyond just these women, however. Children, families, communities, and even entire nations are being devastated by this epidemic.

Statistics alone cannot tell the whole story. While those in this country struggle to obtain state-of-the-art medications, most women with AIDS will be unable to afford even the most basic care.

And their children will fair no better. By the year 2010, there will be over 40 million AIDS orphans struggling to survive in a world that seems deaf to their cries.

My hope is that through today's meeting, we will identify ways to make AIDS more a part of the broader women's movement.

Those women who are at risk of infection, especially those that may not even know they are at risk, must be alerted. Those that are infected and affected must be given every opportunity to access those services that are available.

This terrible epidemic has cast a harsh light on the persistent inequities that you have fought with such dedication. Now we must ask you to see HIV is a reproductive rights issue, as a health care issue, as an issue of race, gender, and class disparities. You have all devoted much of your lives to these challenges, and we need your help once again.

Working together, we can truly make a difference in this epidemic. We can save lives. We can stop AIDS both here in the United States and across the globe.

I thank you for joining me today, and hope that this brief outline provides you with a better understanding of why the devastating impact of HIV/AIDS on women is an issue for us all.

Sandra L. Thurman
Director, White House Office of National AIDS Policy
June, 1998

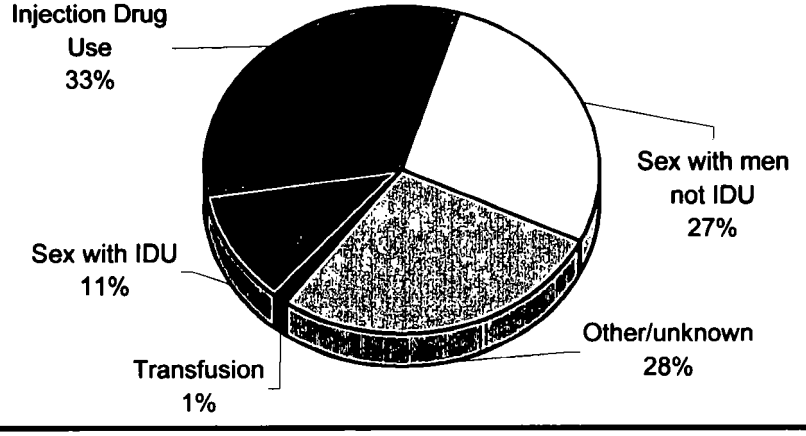
INTRODUCTION

Across the globe, an estimated 5.8 million people were infected with HIV in 1997, approximately 16,000 new cases every day. Of those, 14,000 are adults and 40% of them are women. In the United States, between 120,000 and 160,000 women are estimated to be infected with HIV, the virus that causes AIDS. Women are the most rapidly growing segment of the population at risk for AIDS in the United States. The proportion of female AIDS cases has nearly tripled, from 7% of the annual total in 1985 to 20% in 1996.[1]

Women are the most rapidly growing segment of the population at risk for AIDS in the United States

Heterosexual transmission is the most rapidly increasing means of transmission of HIV in women. Among women reported with AIDS in 1996, 40% acquired the disease through heterosexual intercourse. Increasing numbers of women are infected by partners who are bisexual or injecting drugs—without the women knowing it.[2]

New AIDS Cases in Women - 1997



INJECTION DRUG USE

The second most common means of exposure to HIV in women is through injection drug use (IDU). In 1996, among women reported with AIDS, 34% acquired HIV through IDU.

It is not only injection drugs that are the problem. In fact, data from a Centers for Disease Control and Prevention (CDC) study in 1996 showed a high prevalence of HIV among young women aged 18-29 years who had exchanged unprotected sex for crack, cocaine or money. These women were as likely to be HIV positive as men who had had sex with men.[3]

We also know that people are more likely to engage in risky behaviors when they are under the influence of drugs. For example, community prevention workers in San Francisco believe that the high rate of infection among young gay men is in part due to high rates of "recreational" drug abuse in that social group.

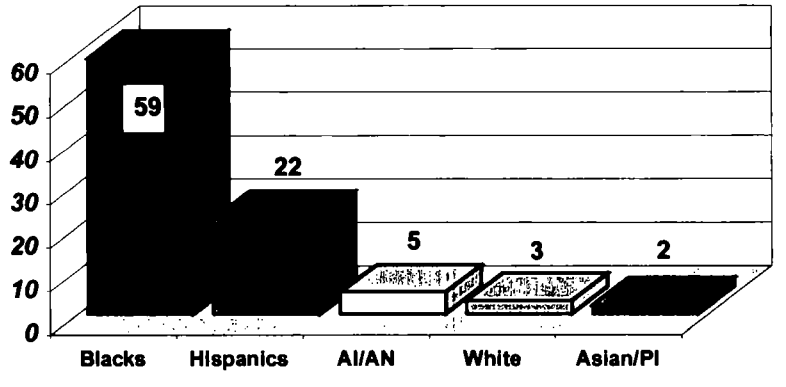
MINORITY WOMEN

Although black and Hispanic women comprise only 1/4 of the female population in the U.S., they make up 3/4 of all the AIDS cases in women.[4] The rate of AIDS was 7 times higher in Hispanic women and 20 times higher among black women than the rate among white women in 1997. The racial/ethnic distribution of women with AIDS corresponds to that of male injection drug users and heterosexual contacts with AIDS. Partner selection patterns resulting in an increased likelihood of contact with an infected sexual or needle-sharing partner may explain this correspondence.

The rate of AIDS was 7 times higher in Hispanic women and 20 times higher among black women than the rate among white women

There are consistently higher infection rates in black and Hispanic injection drug users which may be in part due to differences in high risk injection behaviors, but factors such as differences in HIV prevalence may be even more significant.[5]

New AIDS Cases per 100,000 in Women - 1997



YOUNG WOMEN

Women aged 15-24 years are at higher risk for HIV infection than older women. Young women may be more likely to have multiple partners, to engage in risky behavior, to have partners at higher risk for infection, and they may be more susceptible to cervical infections.[6] AIDS incidence rates have increased faster in young women infected through heterosexual contact than through IDU.[7]

Young women are at risk for HIV infection at an earlier age than young heterosexual men. This is demonstrated by the relatively high proportion of persons with HIV or AIDS that are women younger than 25 years infected through IDU or heterosexual contact. This finding suggests that young women are becoming infected by older sexual or needle-sharing partners and is similar to the documented age gap between teenaged mothers and their partners. Young women are less likely to use condoms with older heterosexual male partners than with same-age partners.[8]

GLOBAL EPIDEMIOLOGY

More than 30.6 million people are living with HIV or AIDS of whom 90% live in developing countries. The vulnerability of women to HIV infection is greater in the developing countries of the world compared to the industrialized countries of the world.[9]

The largest proportional growth of the HIV epidemic during the 1990s will be in Africa, Asia, and Latin America. In Africa, heterosexual contact is the predominant mode of HIV transmission. In Thailand and India, there have been increases of HIV among female prostitutes. In Latin America, heterosexual transmission has also increased and the rates of reported AIDS cases in women of Central America have increased 40-fold.[10]

Many socioeconomic factors influence the risk of HIV infection among women of developing countries. These include a large proportion of the population in sexually active age groups, urbanization, male migration, changing social structures, and poverty and gender inequality which foster prostitution. Women may not be able to choose safer sex practices because of their lower social position.[11]

CHILD BEARING WOMEN AND THEIR INFANTS

Approximately 14,920 HIV infected infants were born in the United States from 1978 through 1993. The risk of transmission of HIV from an untreated infected mother to her unborn child is approximately 25%. However, when an HIV infected mother takes zidovudine (AZT) during her pregnancy and labor, and her newborn receives AZT after delivery, the risk of transmission falls by two-thirds.[12]

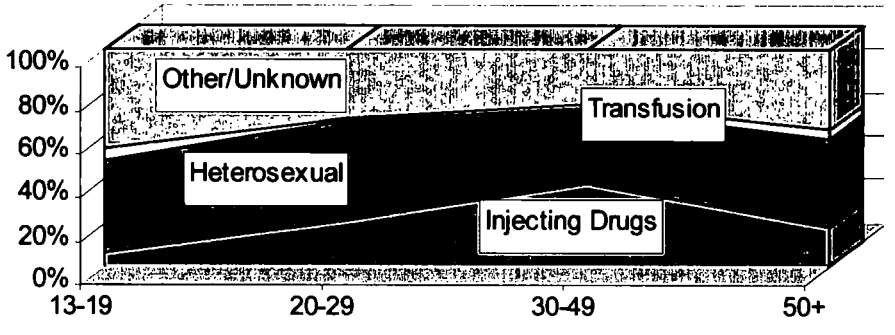
Through an increase in voluntary testing of pregnant women for HIV and the use of AZT as recommended, fewer than 500 babies could be born each year infected with HIV, a significant reduction from the more than 1,500 per year born in the early 1990s.[13]

The problem of transmission of HIV from mother to baby in developing countries is a far greater one. Nearly 90% of HIV infected newborns come from sub-Saharan Africa. In Haiti, over 8% of pregnant women in 1993 were HIV infected.[14]

A trial completed by the Ministry of Public Health of Thailand and CDC in 1997 is the first to describe the efficacy of a short-term regimen of an antiretroviral drug for preventing HIV transmission from mother to child. The preliminary results indicate that a short-term antiretroviral regimen of AZT reduced the risk for mother to child HIV transmission by approximately half.

The regimen studied in this trial is more feasible for implementation in Thailand and other developing countries than the regimen now used in the United States because it is less expensive and logistically simpler. Widespread AZT use among infected pregnant women would prevent thousands of mother to child HIV infections annually in Thailand, where an estimated 20,000 HIV infected women deliver infants each year.[15]

New AIDS Cases in Women - 1997



THE ROLE OF SEXUALLY TRANSMITTED DISEASES

Sexually transmitted diseases (STDs) facilitate the transmission of HIV. Studies from four continents, including North America, have linked STDs with a three to five-fold increased risk for transmission of HIV. This is true for STDs that cause genital ulcers such as herpes, syphilis and chancroid and non-ulcerative STDs such as chlamydia, gonorrhea and trichomoniasis.

Infection with another STD can significantly increase a woman's risk of acquiring HIV if exposed to the virus through sexual intercourse. An HIV positive person who is co-infected with an STD is more likely to transmit HIV to an uninfected partner because of a greater HIV viral load and increased shedding of the virus.[16]

Women with a STD have a three to five-fold increased risk for becoming infected with HIV upon exposure to the virus

PREVENTION

Prevention efforts remain critical. Although the current rate of HIV infection in women is not known, available information points to ongoing transmission. Efforts to prevent HIV infection in women may be complex for several reasons:

1. women who are financially dependent on male partners are at a disadvantage in negotiating condom use
2. women who are sex partners of HIV-infected men, bisexual men, and injection drug users are difficult to identify and target, and
3. women at highest risk may face a multitude of other problems, including poverty, substance abuse, alcoholism, violence, unemployment, and unplanned pregnancies.

Prevention counseling for risk reduction, prevention and treatment of STDs, unimpeded access to health care, and substance abuse treatment for women are critical factors in prevention and intervention.

Additional factors critical to successful prevention include reaching young women before they initiate sexual activity, continuing to develop interventions targeting women to increase condom use, and developing female controlled barrier methods such as microbicides which are safe, effective, affordable and confidential, to prevent HIV transmission.[17]

HEALTH CARE

Along with prevention efforts, adequate resources for care are critical. Based on national HIV prevalence estimates, a minimum of 60,000 to 115,000 HIV infected women not yet diagnosed as having AIDS by the end of 1995 will be requiring care for HIV infection in years to come, twice as many as have been diagnosed as having AIDS since 1981.[18] There may be disparities in the care of women with HIV compared to men with HIV. Women may be less likely to be tested for viral load and less likely to have protease inhibitors as a part of their combination antiretroviral therapy.[19]

Supportive services for women with HIV is an important component of a comprehensive and effective health care system. Women with children, for example, may neglect their own care in order to meet parenting demands. Adequate childcare, transportation, and "one-stop-shopping" service delivery models are essential to getting these women into care, and supporting them in maintaining that care.

For women of color, services offered by providers—doctors, nurses, case managers, even receptionists—that are from their own communities are more effective. Similarly, for those women that are struggling with both HIV and addiction, services that are designed to meet both these complex demands can make the difference between accepting or rejecting life-saving care.

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Facing Delicate Issues Of Life, Love and HIV

Black Women Cope With Rise in AIDS

By Lisa Frazier
Washington Post Staff Writer

The first time Nikiya saw the gold diamond cluster and matching wedding band displayed in a Georgetown jewelry store, she told herself she had to have them.

She bought the rings right then, slid them on her left finger and promised to wear them forever. But Nikiya wasn't married, engaged or even dating.

She wanted the rings to ward off potential suitors. Maybe then, she figured, she would never have to face telling a lover her most painful secret: She is among the thousands of black women infected with HIV, the virus that causes AIDS, which is spreading at an alarming rate among young women of color.

"When I saw the ring, I thought, 'Oh, this is so pretty,' " said Nikiya, 25. "Then I thought, a wedding ring—that should do the trick."

Seven years ago, Nikiya—who asked to be identified only by her middle name—was a high school senior planning her future when she learned that her boyfriend had infected her with HIV.

She felt she was the only young woman on earth experiencing such horror. The reality is much grimmer.

In just over a decade, the number of women with AIDS has increased dramatically—from 7 percent of the total number of AIDS cases in 1985 to 22 percent in 1997, according to the federal Centers for Disease Control and Prevention.

African American women have been especially hard hit, accounting for 60 percent of the AIDS cases reported among women in 1997. In recent years, sex has replaced intravenous drug use as the main source of exposure for women, the CDC data indicate.

Federal health officials say the trend shows no signs of abating. A CDC analysis of HIV and AIDS data collected in 25 states over three years shows that women make up a greater proportion of

See WOMEN, *A8, Col. 1*

BY DUDLEY M. BROOKS—THE WASHINGTON POST

Nikiya, 25, learned when she was in high school that she had the AIDS virus.

Post 6/22

ISSUES- Groups - Women

1

Facing Life and Love Amid HIV

WOMEN, *From A1*

newly diagnosed HIV infections than AIDS cases. Between January 1994 and June 1997, women in those states represented 17 percent of the total AIDS cases but 28 percent of HIV infections.

That means that women probably will make up a larger proportion of future AIDS cases. In the District and its suburbs, the situation is even more severe, with African American women accounting for 86 percent of the AIDS cases among women.

"That is why we are focusing more of our prevention initiatives on women," said Ronald Lewis, administrator for the D.C. Department of Health's Administration for HIV/AIDS. "There is still a lot of denial in the community from people who think [women] don't have anything to worry about."

With the increased availability of powerful new drugs, the AIDS death rate nationally has declined across the board. But for African American women, as well as African American men, ages 25 to 44, AIDS still is the leading cause of death.

After her diagnosis, Nikiya prayed for a quick death. But her life began to change when she sought counseling at Family And Medical Counseling Service Inc. in Anacostia, one of the few black-owned clinics that provides a full range of medical and mental health services.

The clinic excludes no one, but its patient population is about 99 percent black. Nikiya said she felt less alone when she saw the black, brown and beige faces of other HIV-positive women at the clinic. With their support, she is learning to live with HIV.

But some of the scariest parts of her new life, she said, are the delicate issues she never imagined facing again—like dating, sexual intimacy, falling in love.

Two months before high school graduation, Nikiya was awaiting the results of an Air Force medical exam when a recruiter called and asked, urgently, that she report back to the military doctor.

Her body trembled when the doctor told her she was HIV-positive.

"I was thinking, God, I'm just graduating and my life is over," Nikiya recalled.

She had been infected at 15 by her boyfriend, Steven, who was 21 and her first love. He was a hemophiliac who had regular blood transfusions. But she had been naive about how HIV is spread and had not insisted that he use condoms.

In Nikiya's mind, AIDS was a disease of white gay men—a fairly common notion among African Americans at that time, even as the disease claimed a disproportionate share of African American lives.

Part of the problem, black AIDS activists say, is that influential African American institutions, such as churches and civil rights organizations, have been slow to address AIDS prevention and education.

When Nikiya heard her diagnosis, she rushed home and swallowed 20 of her mother's painkillers. Two years later, her brother stopped her as she crawled out a third-floor town house window planning to jump.

Through it all, Nikiya and Steven clung to each other. Then, just months after her diagnosis, Nikiya made a decision that health professionals say is fairly common among young HIV-positive women who suddenly face their mortality. She began trying to get pregnant.

"It was a conscious decision," Nikiya said. "I figured I may as well do everything I can now."

Despite the virus lurking in her blood, she still felt healthy. There was about a 15 percent chance her baby would be born HIV-positive.

"I figured I'd leave it in God's hands and take my chances," she said.

Six years later, in 1998, researchers would discover that treating a pregnant HIV-positive woman with the drug AZT significantly lowers her chances of passing HIV on to her child.

But Nikiya had no such proof. Fearful of AZT's side effects, she refused the therapy. She would have to wait 18 months after her daughter's birth—the time it takes for a newborn's immune system to develop fully—to learn that the infant was healthy.

Nikiya, Steven and their daughter lived together in the District, but in January 1994—when their baby was 1 year old—Steven got sick again. He died eight months later.

A case worker at Georgetown University Medical Center, where Nikiya has received medical treatment since she was 17, referred her to Family And Medical in Anacostia for counseling.

Depressed and isolated, Nikiya needed to know that she was not the only young African American woman living with HIV. She needed to see others, to hear their stories. And she needed a tough-talking counselor who could push her without the question of race clouding the approach.

Diane Jones, then 29, fit the mold. She recalls her first meeting with Nikiya: "She was very young, and very angry and feeling very sorry for herself," said Jones, the mental health coordinator at Family And Medical. "She had no concept of life with HIV or beyond HIV."

In an early session, Jones confronted Nikiya in that girlfriend, sisterly language that bonds black women—even those who don't know one another's names: "Girl, you need to get your life together. If you keep on thinking you're going to die, you are."

In that moment, the counselor connected to the part of the patient that wanted to fight.

Picture Nikiya today: the color of rich tea, about 120 pounds, with a slim body that sometimes draws double-takes from men. For the moment, her hair is strawberry blond, shoulder length with long bangs. But her styles change on a whim.

She has won battles with pneumonia, stomach viruses and a skin rash that left faint blotches on her face. Nothing about her appearance says she is sick. Her energy fluctuates, but since 1997 she has suffered little more than a cold.

She sinks into the cream-colored sofa in her stylish Prince George's County apartment and reflects on her love life. The sun burns fiercely outside, but the air indoors is cool and sweet with the scent of burning candles.

She hadn't expected to date again. After watching Steven suffer, she vowed never to let anyone see her that weak. She bought the wedding ring set. She developed a hostile demeanor. And she could burn a hole in a man's intentions with one hot glare.

But in a vulnerable moment, she lifted the steel around her heart, and a new guy slipped in.

They met at an auto parts store. He told her he was a mechanic and offered to install her car alarm. She flashed her wedding ring and said her husband wouldn't like that. He said her husband didn't have to know and slipped her his card.

She called.

She kept her condition secret for months, even after they slept together for the first time in January. She made sure he used a condom. She liked him. Then, he started asking her to move in with him.

In her own place, she easily guarded her secret and followed the regimen that was keeping her alive: five pills in the morning on an empty stomach, three at mid-day and five more at night. It was time for him to know.

But, given the AIDS paranoia she sometimes witnessed among fellow African Americans, she wondered how he would react. Even her doting grandmother still boils the dishes after Nikiya eats a meal.

"I knew if I ever got in a relationship, I would tell," Nikiya said. "Once I got to the point where I felt like the relationship was going somewhere, I just knew I would tell."

So, as they were driving to dinner one spring afternoon, she blurted it out.

"I'm positive," she said from the passenger seat. "I'm HIV-positive."

He seemed more hurt than angry: "Why didn't you tell me?" he asked.

"Well, I'm telling you now," she retorted in her feisty mode.

Tension filled the car like gunpowder. But the mechanic moved quickly to defuse the moment.

"So, when are you moving in with me?" he asked.

They never discussed it again, Nikiya said. Instead, he began babying her, giving in to her every demand.

"I was like, yell at me or something," she said. "I'm not gonna break."

"He changed," Nikiya said. "He turned into such a sucker."

In May, Nikiya asked him to stop calling. She had been weak once, after Steven died, when she was so despondent she couldn't lift herself out of bed. But she is that woman no more.

With Social Security income and money Steven left, Nikiya and her daughter, now 6, live comfortably. She earned an education degree from the University of Maryland, and she expects to receive a master's in child psychology from Howard University next year.

It took years before Nikiya allowed herself to imagine a future. But she is trying hard to live up to the Swahili middle name that her mother chose with such care: Nikiya, "Little Warrior."

"I'm thinking of starting my own private practice counseling kids," she says with ease.

That is what motivated Nikiya to do the thing she never believed she would be able to do: Stand in front of a crowd and tell her story.

On a scorching recent Tuesday morning, she sat behind a desk in a stuffy classroom at Phelps Senior High School in Northeast Washington. The teenagers were wide-eyed as Nikiya rose to tell them how she got infected with the virus that causes AIDS.

She didn't tell them to avoid sex—convinced that that advice would fall on deaf ears. But she believes that she—someone who looks like them and is young enough to relate to them—has a better chance of planting information that could save lives.

"Half of y'all guys in here were trying to talk to me when I came in here," she said.

A few students giggled.

"What you don't know is I'm HIV-positive," she added. "And I have been positive for 10 years. You can't look at somebody and tell if they're positive.... Use a condom. Don't let decisions you make today ruin your life tomorrow."

When she was finished, the students applauded. Nikiya strolled out, climbed into her green Ford pickup truck and headed home. It was a long journey to get to that stage, she realized, and there are still miles to go.

Her small hands rested in her lap. And there, she saw the tool that she hopes will protect her from too much pain.

It is the wedding ring.

BY SUSAN BIDDLE—THE WASHINGTON POST

Barbara Dorman, who works for an Anacostia counseling service, hands condoms to a motorist.

Women's AIDS Fight Puts Condoms on the Streets

By LISA FRAZIER
Washington Post Staff Writer

Their first stop this sunny Saturday morning is a methadone clinic on Bladensburg Road NE. The women are working the block when Bessie Wilkes, a stout 45-year-old with warm brown skin, recognizes an old friend.

"Hey baby," Wilkes says, offering a warm embrace. Wilkes reaches into her canvas bag and pulls out a row of 10 latex condoms wrapped in shiny black paper.

"Take these condoms, baby," Wilkes says. "We're out here promoting safe sex."

For Wilkes, a recovering heroin addict who is HIV-positive, the streets are painfully familiar. But these days, when she returns, she is trying to save lives.

As an AIDS prevention education specialist for Family And Medical Counseling Service, an Anacostia health clinic, she heads a peer education program called "Healthy Choices, Healthy Sisters," aimed at training the clinic's female patients to educate other women about safe sex.

HIV and AIDS are growing faster among African American women than any other group. The federal Centers for Disease Control and Prevention has encouraged agencies to target women in their education and prevention programs.

Family And Medical's 10-week training program takes Wilkes and other trainees to drug rehabilitation houses and community groups across the city to sponsor safe sex parties for women. The participants munch on snacks as Wilkes discusses issues such as how to negotiate condom use with a partner.

Wilkes also leads a Saturday caravan of women, all Family And Medical patients and program trainees, through some of the District's roughest streets to hand out condoms. Slipping condoms into the hands of strangers and old friends is sometimes uncomfortable, but the women, all HIV-positive, say it is worth it if they save just one life.

"I guess I go to a lot of places like that because those people generally don't come out of their environment," Wilkes said. "I guess I'm not afraid because I've been there. I tell them, 'I'm just like you. The only difference is I'm not using today.' "

Wilkes was 17 when she ran away from her grandmother's home in Baltimore, started smoking marijuana, shooting heroin, sniffing cocaine. She sold drugs to make enough money to use them and went to jail countless times on drug charges. Still, she was shocked in 1988 when an old boyfriend reached her in a federal prison in Lexington, Ky., to tell her to get tested for HIV, the virus that causes AIDS. He was HIV-positive.

"I was like, 'Yeah, okay.' I didn't think anything was wrong," Wilkes said. "I thought, aw, that's for gay people."

A prison doctor brought reality home. For five years, Wilkes told no one she was HIV-positive and avoided counseling or medical treatment. In 1993, she joined a support group in the D.C. jail; in 1995, she entered an 18-month drug rehabilitation program.

"I was just tired, and I realized I didn't want to die," Wilkes said. "In treatment, I realized I had nothing to show for my time here on earth. I never knew what my purpose was until I came here."

She is talking about Family And Medical Counseling in Anacostia, where she has been a consultant since last year. She was the clinic's paid community liaison until the grant that paid her salary ran out. Wilkes worked unpaid until the clinic could put her back on the payroll.

For the first time, Wilkes felt her life had meaning.

"So many of the women I knew," Wilkes said. "They were in the same environment I was in. They were in transition houses, shelters, and many of them were HIV-positive. But they acted like they didn't care."

So, Wilkes goes back to her old haunts to offer hugs, encouragement, condoms.

It's about 10:45 a.m., and the women are canvassing the area around Minnesota Avenue and 51st Street NE. A middle-aged woman wearing sunglasses and black stretch pants with huge neon flowers calls to them from a bus stop. "Hey, here come my girls," she says. "Come on and give me my issue."

A volunteer rushes over, opens the canvas bag, and the woman walks away with condom-filled hands.

At a grocery store counter, a young man, no older than 20, with drooping jeans and a baggy red T-shirt, slips up to Wilkes.

"Hey, y'all got some rubbers?" he says softly.

"Sure, baby," Wilkes responds, digging into her bag.

Outside, a police officer watches as they make exchanges with strangers. He moves his cruiser to a lane nearer the sidewalk and slowly keeps pace with the women.

Wilkes reaches into her bag and pulls out shiny black packages, then waves them into the air.

"Want some?" she asks. "Police officers need to practice safe sex, too."

Their mission ends on New York Avenue NW near Hanover Street, where people with glassy eyes hover, passing time. The women stop, join the talk, hand out condoms.

Before leaving, the volunteers huddle to discuss their day. One woman's eyes fill with tears.

"On the one hand, I feel like we did something good," says Wanda, wearing a blue baseball cap over her curly brown hair. "But on the other, I feel hurt because all we can do for them is give them a condom."

"Yea, but some people don't get that much," Wilkes says.

The women say goodbye. Their bags, stuffed with 2,000 condoms at the start of the day, are empty. Wilkes lingers a bit, pulling out a cigarette.

"A lot of times when we see people, we see ourselves," she says. "That's why I always say good morning and give them a hug. Giving them condoms might not seem like much, but a condom might have saved any one of our lives."