

INSIDE

STIGMA AND HOMOPHOBIA 5

Addressing homophobia and HIV stigma is critical to decreasing the spread of HIV in communities of color.



FIGHTING HIV IN COMMUNITIES OF COLOR 8

Experts from four communities weigh in on the HIV prevention issues that need to be addressed.

Personal Perspective: THE TIGERS OUTSIDE MY WINDOW 14

There is a need to have providers who not only speak your language but who also are sensitive to your customs and culture.



A LEGACY OF MISTRUST: RESEARCH AND

PEOPLE OF COLOR 16

Personal Perspective:

"COME BACK WHEN YOU'RE DRESSED LIKE A MAN" 18

CARING FOR CULTURE 20

Race and culture can affect health outcomes.



EDITORIAL 23

*Achieve is a joint publication of
ACRIA and GMHC.*



Since I began working as an HIV treatment educator in New York City, I've seen the faces of those I served change. As those faces grew to include primarily African-Americans and Latinos, I found myself both inspired and moved by my clients.

Race Troubles

Why do African-Americans with HIV fare worse?

by Donna M. Kaminski

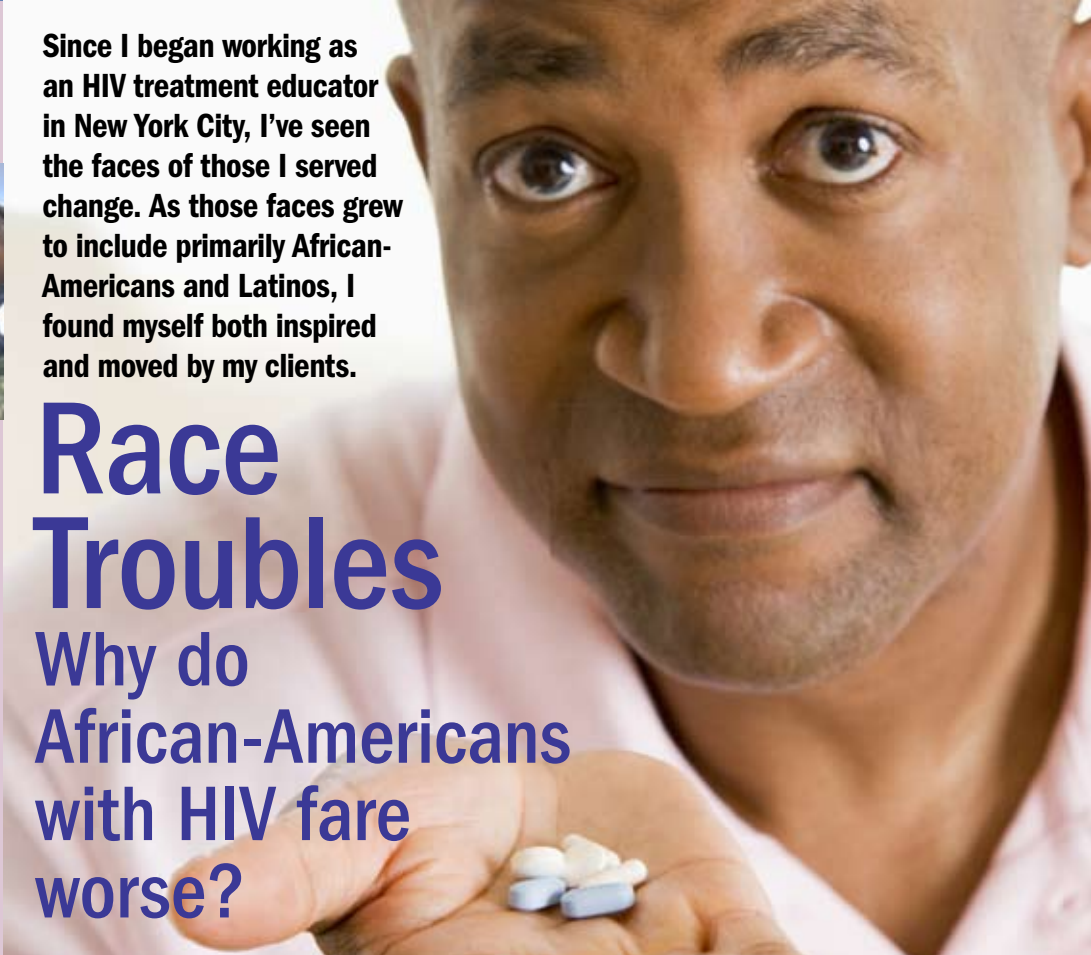
As a whole, they were deeply motivated to do as well on their treatment as possible. Many of them carried little cards logging their viral loads and CD4 counts. And they all knew their HIV meds like the back of their hands.

I found myself inspired by their desire to take charge of their health, but I also noticed that their journeys often had additional challenges. There was the fight to stay off the street, to stay off drugs, to find a place they could call home. Often there was a fight to repair their relationships with children, families, and loved ones. Many also had hepatitis C, diabetes, or high blood pressure. And many felt

they just couldn't trust their doctors, perhaps due to their own experiences in the health system or from the shared distrust passed down from abuses like the infamous Tuskegee Syphilis Study (in which 399 African-American men were denied treatment for over 30 years).

In a nutshell, dealing with HIV meant dealing with each of these issues, in addition to the viral loads, CD4 counts, and medications I was used to talking about. While they shared the same treatment goals as everyone with HIV, their overall HIV and general health care needs were different. They were more complex, with many factors contributing to the overall picture. They included so many additional challenges that it made managing their HIV disease more difficult.

continued on page 3



ACRIA Trials in Progress

Pomegranate Juice

People who have not taken HIV meds for at least 90 days will drink pomegranate juice or placebo juice daily for 10 to 18 weeks to study its effect on the heart, quality of life, and HIV viral load.

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People who have taken HIV drugs will receive infusions of ibalizumab (a monoclonal antibody designed to block HIV entry into CD4 cells) once or twice a month for 48 weeks, along with other HIV drugs.

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People 18 and older who have persistent diarrhea will take crofelemer (a new anti-diarrhea drug) or placebo tablets for 6 weeks. Then everyone will take crofelemer for 5 months.

Isentress in Pregnant Women

Pregnant women who are already taking Isentress will give several blood samples on two separate days in order to find the optimum dose of the drug during pregnancy. Compensation is provided.

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People with insulin resistance will take Avandia or Serostim (growth hormone), or both for 6 months to see how they affect blood sugar, insulin levels, and body shape.

TAK-652

People who have taken HIV meds before will take this new CCR5 inhibitor for 10 days with no other HIV meds.

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People who have not taken HIV meds before will take this new CCR5 inhibitor with other HIV meds for 48 weeks.

For more information on these trials, contact us at 212-924-3934, ext. 121.

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LETTERS TO THE EDITOR

To the Editor:

I would like to congratulate you and your staff for this major achievement with *Achieve*. The recent issue with the young teens and young adults really hit home for me. I read all the stories and experiences of the young children and it touched my heart.

I have been in prison since 2004 and hope to be released next year. If not, in 2012. Then my son will be 17 and I have all these fears of what can happen. I needed to read this publication to open my eyes.

Raven Lopez is a miracle and I have read everything about her and her mother. God bless her.

Great work, ACRIA, GMHC, and all staff.

Sincerely,

William Lopez
Mid-State Correctional Facility

To the Editor:

It's a pleasure to establish communications with you and at the same time congratulate you for your marvelous publication in Spanish. It's an important tool for those living with HIV.

We belong to the Association of Civic Response to AIDS and we offer support to people living with HIV in the state of Tamaulipas, Mexico. We mainly serve people living in rural areas that seek services from public and private institutions.

I'd like to take the opportunity to request copies of your publication in Spanish. It will be of enormous use for our Men's, Women's and Transgender support group members.

Thanking you with humility,

Ulises Molina Cavazos
Group Facilitator

Photos used in *Achieve* imply nothing about the health status, sexual orientation, or life history of the models.

Achieve would love to hear from you! Please send your comments to: Letters to the Editor, *Achieve*, 230 W. 38th St., 17th floor, New York, NY 10018 Or email them to: achieve@acria.org



But I also noticed something else: Many of my clients found themselves frustrated with their treatment results. They just weren't reaching their goals. I, too, could see a difference. In some of my most adherent clients, I saw CD4 counts go up more slowly than I expected. Or the viral loads would linger just above undetectable – low, but still high enough to be picked up by the test. This made me wonder if there was a difference in the way African-Americans respond to HIV treatment. My experience and gut told me yes.

What I have found since my early days working in HIV is that there are indeed differences between ethnic groups, especially African-Americans, in the way they experience and respond to HIV and its treatment. Many of these differences have been documented in the scientific literature. This article will attempt to lay out the studies and findings that support my personal experience with African-Americans living with HIV.

Different Epidemics

African-Americans continue to be the ethnic group most affected by HIV. According to the CDC, almost 84% of new HIV cases in 2006 occurred in African-Americans, even though they make up only 13% of the U.S. population. In one study of men who have sex with men, African-Americans were nine times as likely as Latinos to become infected with HIV, and twice as likely as whites. In terms of sheer numbers, a higher proportion of African-Americans are feeling the impact of the disease than any other ethnic group in the U.S.

African-Americans with HIV also tend to have a harder time on treatment. The Women's Interagency HIV Study (WIHS) showed that African-American women taking HIV meds were less likely to reach an undetectable viral load and more likely to die than other women with HIV. In another study, researchers reviewing over 300,000 hospital admissions found that a higher percentage of African-Americans

with HIV died of diabetes, pneumonia, and heart disease than did Latinos and whites. And both studies found that African-Americans were more likely to be depressed and to stop taking their medications. In fact, the WIHS researchers found race to be the strongest predictor of stopping meds. This left me asking one central question: *Why?*

Differences in Care

Among the many reasons that African-Americans have a greater number of hospitalizations and don't respond as quickly or as positively to HIV treatment as members of other races is that they are more likely to be diagnosed with HIV later in the course of the disease. In one survey of almost 6,000 people with HIV in 16 states, not only were African-Americans more often diagnosed at a later stage of the disease, but they were more likely to be tested for HIV only after having symptoms. This is significant, since those diagnosed later, when their immune system is weaker, have a harder time lowering their viral load and fighting other infections. So this is one reason for the greater impact of HIV among African-Americans, but there are also others.

Another critical factor facing many African-Americans is access to care. In the U.S. it has been found that women, African-Americans, and those with a history of injecting drugs are less likely to receive HIV treatment. While improved access to care has been a target of many programs, it continues to be an issue for African-Americans. In one study of 968 people who stopped or never started HIV treatment, African-Americans were almost twice as likely to change clinics or doctors, and most stopped medications during the study. In addition, African-Americans were almost twice as likely to hide their HIV status, showing that the stigma of HIV may be an obstacle to taking medication.

African-American women in WIHS reported significant levels of depression, but the study found that they were less likely to receive mental health treatment than other women. Other studies have shown that poverty, inadequate health insurance, racial discrimination, and

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mistrust of the medical establishment make access to care difficult and in some cases impossible. Age is also a factor – at the recent Conference on Retroviruses and Opportunistic Infections (CROI) in Montreal, Alexandra Oster of the CDC reported on a study showing that age may be associated with limited access to care. When she looked at why 556 women with HIV had missed their first or annual Pap smears (a screening test for cervical cancer), she found that older age and lower CD4 counts were highly associated with not having the test. This is of particular concern, as we are seeing more people over 50 living with HIV.

Other Health Concerns

African-Americans are also often battling other diseases while living with HIV. From 1997 to 1999, the HIV Research Epidemiology Research Study (HERS) followed 1,300 women, mostly African-American, some of whom had HIV and some of whom did not. What they found was that there were fewer hospitalizations due to HIV than in earlier years, but the women with HIV in the study were hospitalized more often due to liver disease.

Co-infection with HIV and hepatitis C virus (HCV) has also affected African-Americans more than other ethnic groups. They are more often infected with HCV genotype 1, a type that is harder to treat, but that alone doesn't explain why they don't do as well on treatment. One study of standard HCV treatment (interferon and ribavirin) found that significantly fewer African-Americans responded well than did whites, even though both groups had genotype 1. And this study was not the only one to find this. In another study, as few as 26% of African-Americans on treatment maintained an undetectable viral load for six months, compared with 39% of whites. A larger number of African-Americans also reported HCV complications and were more likely to suffer from liver cancer.

Genetic Differences?

All this suggests that there may be genetic factors at play in some of the differences

in response to treatment. One study found that African-Americans were more likely to have a genetic mutation called a CYP 2B6 allelic variant. People who have this mutation have difficulty breaking down Sustiva, which can build up in their blood and lead to more side effects like vivid dreams or difficulty concentrating. Not surprisingly, more African-Americans stop taking Sustiva, and that could lead to other problems. Having the CYP 2B6 mutation may cause Sustiva to linger in the body after it is stopped, increasing the risk of resistance.

African-Americans with HIV are at greater risk for other illness and diseases. One group of researchers noted that they were twelve times more likely than whites to develop end-stage kidney disease. This was true even for those doing well on HIV treatment.

ACTG 384, a study reported at the 2009 CROI, looked at 156 African Americans who had peripheral neuropathy (numbness or pain in their hands and feet). The researchers looked at the DNA of their mitochondria (the energy centers of cells). What they found was fascinating: people who had the L1c mutation in their mitochondria had a higher risk of having peripheral neuropathy. This mutation is different than one previously found among whites, and suggests there may be genetic reasons why different ethnic groups have a greater risk of certain side effects. A high number of African Americans (29%) experience peripheral neuropathy, and this research is

the first step in understanding why. More studies are planned.

Another genetic factor found to affect the way African-Americans react to HIV treatment is the ApoC-III mutation. One group of researchers looked at gene mutations and the race or ethnicity of 626 patients enrolled in ACTG studies. While African-Americans had lower levels of triglycerides (a type of fat in the blood), those with the ApoC-III mutation had higher triglyceride levels after taking an HIV protease inhibitor. Latinos and other ethnic groups with this same mutation didn't see their triglycerides rise as high. This suggests that both race and genetics play a role in the way people fare on treatment.

African-Americans with HIV are also at greater risk for other illness and diseases. For example, one group of researchers from Baltimore noted that they were twelve times more likely than whites to develop end-stage kidney disease. This was true even for those doing well on HIV treatment. So HIV in itself seems to put African-Americans at greater risk for kidney disease, as well as diabetes and hypertension. In fact, a large European study (EuroSIDA) has found that people with HIV are more likely to also have diabetes and hypertension if they have kidney disease. Like the CDC study, they found this linked to lower CD4 counts, an AIDS diagnosis, and older age.

These results are disheartening, since African-Americans overall are harder hit by both diabetes and heart disease. Over 2.5 million African-Americans live with diabetes – they are 60% more likely to have it than whites. African-American men die from diabetes complications 20% more often than do white men, and that number is 40% for African-American women. African-Americans are 30% more likely to die of heart disease than whites – shocking, since in 1950, the two groups had equal levels of risk. There is no doubt that heart disease and diabetes are a problem even for African-Americans without HIV, and that these become further complicated by HIV.

The research is clear: African Americans face a host of genetic, physical and emotional factors that deeply affect their HIV treatment. While the CYP 2B6, L1c, and ApoC-III mutations have been found, there may be other mutations

continued on page 7

by Giovanni Koll and Jaime Gutierrez

Stigma, discrimination, and homophobia harm efforts to prevent HIV and to care for those living with the virus. HIV stigma consists of prejudice, discrimination, and harassment directed at people thought to have HIV. HIV stigma and discrimination show themselves in large part because of antigay bias and homophobia, particularly in communities of color. Homophobia is the irrational fear of, or aversion to, people who are thought to be homosexual. Both homophobia and HIV stigma can be expressed in a multitude of harmful and detrimental ways. This can be verbal or emotional abuse, rejection, ridicule, isolation, or physical violence.

Homophobia and HIV stigma often lead to a lack of participation by people of color in HIV prevention services, a reluctance to test for HIV or to use condoms, and difficulty talking about HIV and sex. Addressing homophobia and HIV stigma is critical to decreasing the spread of HIV in communities of color.

Anti-gay bias

Whether through the media or casual conversation, discrimination against gay and lesbian people remains socially acceptable throughout the U.S. Anti-gay sentiment can be especially strong in communities of color, which leads to both homophobia in the community and the internalized homophobia experienced by lesbian, gay, bisexual, or transgender (LGBT) people. This antigay bias is rooted in community and family norms, attitudes, and values.

In the Latino community, for example, homosexuality is equated to weakness and is perceived to run counter to notions of machismo (community norms on what it means to be a man). As such, homosexuality in the Latino community is thought to hurt or embarrass the family. The African-American community sees homosexuality as an embarrassment to the African-American race as a whole, as well as to the family structure. More specifically, homosexuality in the African-American community is often perceived as conflicting with gender roles and community norms about sexuality, and even to being sinful and unnatural.



Stigma and Homophobia: Fueling the Fire

Rejection and discrimination by family and friends can lead to loss of employment, dropping out of school, or young people having to leave their homes. This may cause LGBT people to feel as if they have no options and are no longer part of their community. Some young people who are forced out of their homes end up living on the street. Over 40% of homeless youth are LGBT and many turn to sex work. This not only puts them at a higher risk for HIV, but may also increase their feelings of helplessness and loss of community. (Of course, some people who engage in sex work feel empowered and want to be seen as legitimate businesspeople.) The stigma surrounding sex work makes reaching out to them with HIV education, prevention, and service provision even more challenging.

Internalized homophobia

LGBT people who feel shunned by their community because of homophobia often internalize those negative feelings. They may experience hatred toward gays before

they become aware of their own attraction to the same sex. When they do recognize it, they begin to see themselves as different and socially unacceptable, which can damage their own sense of self-worth. Low self-esteem and depression often follow suit. When coupled with isolation, the foundation for long-lasting self-hatred is laid, making it difficult to move beyond negative attitudes toward both homosexuality and themselves. Stigma also prevents conversations about bisexual behavior. Homophobia can lead to low self-esteem, anxiety, depression, isolation, and loss of self-efficacy among LGBT people. Many turn to substance use to ease the pain and lessen anxiety.

Fear of contagion

Another contributor to HIV stigma is the fear of contagion, an irrational fear of contracting HIV through casual contact. Many people are fearful of getting HIV through sex, but several studies show that fear of contagion is one of the key contributors to HIV stigma for both children and adults.

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For example, a national survey that measured HIV stigma in the U.S. in 2002 found that, while most people do not advocate the segregation of people with HIV from the general public, many still believe that HIV can be transmitted through casual contact. This is shown by some parents' fear of sending their children to school with an HIV-positive child. These parents explained that they were concerned that HIV could be transmitted through sneezing and coughing, which is scientifically untrue. Similarly, young people who were uncomfortable with HIV-positive students in their schools thought that the children with HIV were responsible for contracting the disease. In addition, inaccurate HIV edu-

cation contributed to the students' fear of contracting HIV through casual contact.

HIV-related stigma

Despite this fear of contagion, HIV stigma and discrimination relates most closely with homophobia in the U.S. Because gay men were the hardest hit at the beginning of the epidemic, and because 57% of new infections in 2006 were among gay and bisexual men, there is still a strong belief that HIV is a gay disease. As such, many communities of color equate HIV with a variety of behaviors considered unacceptable. Men who have sex with men or with both sexes, drug users, and those who have multiple partners are those whose behaviors are most com-

monly linked with HIV infection in black and Latino communities.

HIV forces us to talk about sex and sexuality, which is rife with morality issues. Since HIV is transmitted primarily through sexual contact or sharing needles, people with the virus are often viewed as morally inferior or shameful. Today, much stigma is directed toward the person who "should have known better" or who "brought it on himself." The young child, on the other hand, is seen as an innocent victim, as are women with cheating husbands.

HIV-positive sex workers are also considered responsible for their HIV status. Indeed, some people assume that having multiple sexual partners automatically leads to HIV infection. This is scientifically untrue; HIV transmission is purely a function of biology. Although the risk for getting HIV increases with the number of partners, the chances are greatly influenced by the availability and consistent use of safer sex tools like condoms.

Ignoring, or being ignorant of, how the virus is actually transmitted, some community members judge people with HIV based on personal characteristics: being gay, a substance user, black or racially different, poor, or uneducated, or having multiple partners.

Stigma and public health

Negative attitudes toward HIV and homosexuality in communities of color can hamper HIV prevention and treatment efforts. The social isolation that homophobia and HIV stigma cause results in silence around HIV. Many Latino and African-American men refuse to get tested, as they equate taking an HIV test with an admission of risky behavior, most commonly having sex with other men. In African-American communities, a condom is sometimes seen as a threat to masculinity, as admission of having sex outside a relationship, or as having a sexually transmitted infection (STI). People who don't know their HIV status often avoid HIV testing, and some begin to deny that they can get HIV or that it poses any health risk.

Public health efforts in communities of color would fare better if homophobia and HIV stigma did not exist. If indi-

viduals were more willing to get tested for HIV, more people would know their status and be more likely to obtain care and protect their partners. If more people were able to disclose their status without fear of rejection, their partners would be much more likely to use protection. If people with HIV had easier access to treatment, they would be more likely to adhere to their regimens and their viral loads would drop, reducing (but not eliminating) the risk of transmission. This could reduce the overall transmission rates in black and Latino communities. If gay and/or HIV-positive men felt supported in their families, at work, at school, at church, and on the street, they would be more likely to care about their health and the health of others.

What can we do?

We need to counter homophobia and HIV stigma by doing away with all expressions of stigma, subtle and overt, if we want to reduce HIV transmission in communities of color. What is needed are meaningful interventions that address the love, acceptance, and intimacy that gay men seek – interventions that look to shift community attitudes and encourage support and dialogue. Service providers should not be afraid to deal with these issues directly. Whatever forms the interventions take – social marketing, support groups, or community events – HIV prevention should expressly address these factors. There is a tremendous need for increased education and for efforts to raise awareness of HIV stigma in communities of color.

As if the shame of having HIV or the feeling of being “damaged goods” is not enough, HIV stigma and homophobia affect the mental, physical, and spiritual health of HIV-positive men of color.

Culturally competent and appropriate images that allow members of communities of color to identify themselves are more successful in transmitting the prevention message. Relatable role models also have a positive effect on an audience’s ability to embrace a campaign’s message.

Conclusion

A recent study of New York City black men concluded that stigma surrounding both HIV and homosexuality may ensure that non-heterosexual preferences and practices remain hidden. Other research has found the same to be true for Latinos. HIV stigma and homophobia are rooted in fear, lack

of information, and prejudice. As if the shame of having HIV or the feeling of being “damaged goods” is not enough, HIV stigma and homophobia affect the mental, physical, and spiritual health of HIV-positive men of color. If we look deeper, we will find that preventing HIV and other STIs requires initiatives that go beyond campaigns promoting safer sex and HIV testing. Although these are crucial, addressing homophobia and HIV stigma can have a profoundly positive impact on HIV transmission and public health.

We still live in a pervasively homophobic society, one that erects high barriers to community health, especially among people of color. When gay men live with the shame, isolation, and self-hatred they have picked up from those around them, they often stop caring about themselves enough to want to engage in safer sex. When gay men live with depression, anxiety, and anger caused by being denied a job or promotion, being constantly harassed at school, or being rejected by family, they stop seeing themselves as worthy of a loving relationship with supportive friends, of maintaining healthy habits, and of caring about their sexual partners. Even more worrisome, homophobia and discrimination can lead to addiction, abuse, and violence. Greater risk of HIV is just one of the many public health costs. ■

Jaime Gutierrez has an MPH from John Hopkins University.

Giovanni Koll has worked for GMHC’s Institute for Gay Men’s Health.

Race Troubles *continued from page 4*

responsible for the differences in the way African-Americans respond to treatment. In addition, we also need larger studies to learn how best to modify treatment in people with these mutations. For example, one group started adjusting HCV treatment doses in African-Americans by weight. Another study of 362 African-Americans found that when their ribavirin dose was adjusted they were twice as likely to bring their HCV levels to undetectable and keep them there than

those on the standard dose. Approaches like these may prove to be essential for African-Americans.

Looking Ahead

Much of this information supports what I already felt inside: that race does matter and that in many ways, African Americans experience HIV differently. So how do we address these differences? While it is clear that we need more information, the first step is acknowledging that there is a differ-

ence, and that it is complex. It is biological, social, and cultural – a combination of factors that affects every African-American living with the virus. Some of the answers will come as more studies are done. Others will come from within each one of us, as we learn from each person with HIV and work to meet their needs. ■

Donna M. Kaminski, ACRIA’s former Associate Director of Treatment Education, is a fourth year medical and MPH student.



Fighting HIV in Communities of Color

Effective HIV prevention requires a variety of tools and approaches tailored for each person or community. To discuss the issues facing people of color, *Achieve* asked experts from four communities to weigh in on the problems facing those communities, and what could be done to address them. They were also asked to comment on the current CDC efforts to effectively reach people of color with prevention messages.

African-Americans

By Daryl J. Cochrane, MPA and Lyndel Urbano

In 2008, new data on the impact of HIV in communities of color revealed a widening gap in prevalence. Specifically, African-Americans, who make up 13% of the nation's population, account for the greatest number of people living with HIV. Of newly diagnosed AIDS cases in 2007, African-Americans account for almost 47%. This is a horrific trend, and the racial disparities among those affected by HIV continue to grow at alarming rates. African-Americans have comprised over 40% of all AIDS cases in the U.S. since the beginning of the epidemic. They also make up almost 43% of those currently living with AIDS.

HIV-related illness is the leading cause of death for African-American women aged 25 to 34. They are 20 times more likely to become infected with HIV than white women. And nearly half of African-American girls aged 14 to 19 have had at least one sexually transmitted infection – double the rate for all teenage girls.

MSM

HIV also has had a great impact on African-American men who have sex with men (MSM). Men account for nearly 2/3 of new infections among African-Americans; and nearly 2/3 of them said they had sex with other men. Strangely, African-American MSM are at greater risk of HIV despite reporting lower instances of risky behavior. A 2007 study found that African-American MSM reported less substance use and fewer sexual partners than white MSM, but had significantly higher rates of STDs than white MSM. Additionally, African-American MSM with HIV were less likely than white MSM to be taking HIV drugs.

Several factors play a part in this problem: marginalized social status, poverty, homophobia, HIV stigma, incarceration, and inadequate educational and employment opportunities. These issues contribute to poor health outcomes among those with lower incomes, particularly African-American and Latino populations.

High rates of undiagnosed HIV infection among African-Americans may also play a role. People with HIV who take meds



lower their risk of transmitting the virus. But African-American MSM with HIV are less likely to be on treatment than whites – a reality that may contribute to the higher HIV rates in this community. Also, having an STD increases the chances of HIV transmission, and African-American MSM are more likely than white MSM to have an STD. High rates of unprotected anal intercourse early in the epidemic may also have increased the number of black MSM with HIV.

HIV is the leading cause of death for African-American women aged 25 to 34. They are 20 times more likely to become infected with HIV than white women.

It is important to develop a national plan of action to reduce the epidemic affecting African-American women and MSM. Such a plan should be implemented with accountability, evidence-based policy, and a focus on improved prevention and treatment outcomes. Approaches that prioritize community needs are needed to address the factors that create an environment where HIV thrives. These approaches must iden-

tify what makes some groups more susceptible to HIV and build on the strengths of communities. If they do, they will have a greater impact than approaches that focus merely on individual behavior.

More interventions are needed to foster acceptance of African-American gays and lesbians by their families and communities. This is especially needed for gay youth. Families that throw gay children out of their homes do immense harm. But gay young

people who are accepted by their families are 3½ times less likely to engage in HIV risk behavior than those who are rejected. Concepts of what constitutes a “normal” family also need to be challenged.

Youth

Youth need to be provided with targeted and comprehensive sex education that includes discussions of both gay and

straight sexuality. Community leaders must be educated to promote the acceptance, positive health, and wellness of gay youth. School-based interventions that promote tolerance and acceptance are especially needed. In order for gay and bisexual men to decrease their risk for HIV and to ensure that men with HIV get care, they must have access to mental health and substance use services.

Recommendations

Since the creation of the Minority AIDS Initiative in 1998, there has been a marked increase in the number of prevention efforts developed by organizations serving communities of color, resulting in increased awareness of the scope of the problem in those communities. This is seen, for example, in the CDC’s Diffusion of Effective Behavioral Interventions (DEBIs) and its programs “Many Men, Many Voices” and SISTA (Sisters Informing Sisters on Topics about AIDS). Each has shown successes and proven effectiveness.

But despite such successes, only 10% of all DEBIs are geared specifically toward the African-American community, not fully addressing the racial disparities. The CDC recently announced the “Act Against AIDS Campaign,” a \$10 million, five-year partnership with 14 African-American groups. Each group will organize its own education and public awareness campaigns, but none of the groups focus their efforts toward black gay men.

Unmet HIV prevention needs clearly remain in the African-American community. It is vital that our public health response to HIV acknowledge that structural barriers drive rates of infection, especially in communities of color, and that these require targeted interventions. While HIV prevention tools have improved over time, dramatically increased resources are needed to slow the virus’s spread in African-Americans.

Daryl J. Cochrane and Lyndel Urbano work in the Public Policy Department of GMHC.

Asians

by Vincent Du

The Asian population in the U.S. is incredibly diverse, with over forty different nationalities and over a hundred languages. In addition, Asian and Pacific Islanders

continued on next page

Fighting HIV in Communities of Color

continued from previous page

(APIs) have a history of being linguistically, socially, and politically isolated in the U.S. This adds to the challenge of reaching out to this population, which is often underserved and unaware of the resources available. Many of the barriers that APIs encounter revolve around stigma, lack of social support and unreported HIV cases. Our response to the epidemic must include language-appropriate and culturally competent outreach and care.

APIs account for 1% of reported AIDS cases in the U.S. Although the number seems small, the number of AIDS diagnoses among APIs nearly doubled from 1980 to 1994. And the lack of detailed studies, coupled with the stigma of HIV, makes it

education, are living in poverty, and are uneducated about their risks for HIV. In addition, many APIs look at disease differently than Westerners, and only see doctors when they are ill. Because APIs are generally not proactive about their health care, important health issues can go undetected.

Immigration Issues

Immigration status is another barrier to HIV prevention, since many Asian immigrants are afraid to seek help due to the fear of deportation. They are unaware that there is no link between confidential HIV testing and deportation. All immigrants risk deportation if they are undocumented and don't have valid immigration papers, regardless of their HIV status. But the Immigration and Naturalization Service is not notified when they get an HIV test or seek treatment.

Gender Issues

HIV stigma is a significant barrier for many API men who need testing and treatment. Within the Asian culture, it is generally taboo to discuss sex, illness, and death, and there is little chance of an open dialogue regarding HIV. Acknowledging homosexuality may also be seen as taboo when talking to a doctor. Many API men feel as if they cannot get infected, increasing the chance they will engage in risky behavior. A study by K. Choi and colleagues found that 85% of the gay male API population in San Francisco felt they were not likely to get HIV, and 95% felt unlikely to transmit HIV. The existence of these stigmas makes it difficult to talk to gay API men about their sexual behaviors and to identify the factors that put them at risk for HIV.

In 2005, heterosexual women made up 80% of API HIV cases. Commercial sex and massage parlor workers are at the highest risk. For most of these women, daily survival takes priority over health needs. Condom usage can be difficult since it may affect their earnings, and they may not know how to initiate safer sex conversations with clients. Additionally, they may have been illegally trafficked into the U.S. and are kept isolated from the communities that could assist them.

Recommendations

There are many ways HIV interventions for APIs could be improved. First, we need comprehensive surveillance in order to truly understand how HIV affects APIs. Without the proper data, government agencies and health departments will never know the true scope of HIV in all minority populations. Secondly, more efforts must be made to provide linguistic services for APIs. Without proper translation and interpretation, APIs will continue to be uneducated about HIV and their risk factors. Finally, culturally appropriate interventions must be directed at specific risk behaviors, such as not proactively seeking health care and not using condoms. Unless we understand the size and scope of the epidemic in Asian communities, HIV will persist.

Vincent Du is a Risk Reduction Counselor at AIDS Services In Asian Communities in Philadelphia



challenging to find all API cases. Low HIV testing rates also contribute to the lack of awareness in the community. Furthermore, 29% of APIs with HIV (many of whom have progressed to AIDS) are unaware of their status and may continue risky behaviors.

APIs are often stereotyped as the “model minority” in terms of health, academics, and finances. The misconception that they do not engage in the same risk behaviors as other groups persists both within and outside the community. The perception that they are all educated and wealthy ignores the reality that many recent API immigrants have less than a 12th grade

Due to the linguistic and cultural diversity of the Asian community, HIV outreach is complicated. About 40% of new API immigrants have limited English skills – a major barrier to HIV education. With over 40 API languages and 100 dialects, many agencies have difficulty providing translation services. Attempting HIV counseling without the correct interpreter and culturally appropriate interventions can lead to misinterpretation and difficulty in creating a personalized risk reduction plan. Without the proper support systems, clients don't get the assistance they need to deal with their life-changing diagnosis.

Latinos

by Oscar Raúl López

Latinos make up 15.3% of the U.S. population, but account for 17% of new HIV infections and 19% those living with AIDS. The highest rate of HIV transmission among Latinos is found in men who have sex with men (MSM), who make up 57% of cases.

The stigma associated with HIV and homosexuality, known as “rechazo” (rejection), is a major obstacle to prevention efforts. It can lead Latino MSM to carry on a secret sex life, cut off from the support of family networks necessary to overcome isolation. Racism, homophobia, and poverty can lead to a sense of powerlessness and lack of control in their personal lives and in sexual situations, leading to alcohol and drug use and increasing their risk for HIV.

Additionally, traditional rigid gender roles and norms such as “machismo” contribute to Latino gay and bisexual men seeing themselves as “failed men.” The longer they have been in the U.S. the better Latinos tend to cope with HIV. This is largely because they have improved access to education, resources, friends, and external networks, and because they have absorbed the U.S. culture, where being gay and bisexual may carry its own stigma but not as heavily as it does in Latin American countries.

Women

Latinas confront several obstacles when it comes to HIV: embarrassment, fear of rejection, stigma, their partner’s objection to testing, and lack of access to health care. Sex and sexuality are not discussed in traditional Latino cultures. Because of their social status, many Latinas lack the ability to determine much about the course of their lives. Limited economic resources and fear of violence may force them to yield control over their sexual relations to men. This economic dependence plagues both single women and married women, who are unable to support their families without help from their male partners (traditionally the heads of Latino households). Finally, for many Latinas the health of the family comes first and remains the highest priority. This leads them to focus on HIV only when it affects other family members.

When women cannot control their sexual behavior, they can not reject their male partners even if they suspect that their partners may have been unfaithful. Afraid of vio-



Meaningful prevention for young Latinas would have at its heart the concept of empowerment and helping them gain control over their economic, social, and sexual lives.

lence or abandonment, they cannot insist on condom use. Without a prevention method they can control, millions of women face the threat of HIV infection every day. Safer sex education promotes the use of condoms but often sidesteps the question of who controls the decision to use them. Because so many standard prevention approaches fail to reach them, Latinas are often uneducated about HIV. Meaningful prevention programming for young Latinas requires a different kind of approach, one that would have at its heart the concept of empowerment and helping them gain control over their economic, social, and sexual lives.

Adopting U.S. cultural norms has been shown to have a mixed effect on HIV risk among Latinas. It can lead to a greater knowledge of health issues, and a greater

likelihood of seeking treatment. But it can also lead to an increased number of sex partners, higher rates of unprotected sex, and a higher number of unplanned pregnancies.

Youth

HIV has taken a toll on the lives of Latino youth and young adults. In 2005, they were the second most likely racial/ethnic group to contract HIV, with Latino teens accounting for 17% of AIDS cases among teens. Latinos aged 20 to 24 made up 22% of new AIDS cases reported among young adults, but represented only 18% of U.S. young adults. Similar to Latinas, the low socioeconomic status of Latino youth, coupled with cultural stigma around sex and gender roles contribute to behaviors that increase risk for HIV.

continued on next page
achieve SPRING 2009 **11**

Fighting HIV in Communities of Color

continued from previous page

Young Latinos in the U.S. are exposed to many cultural stressors – discrimination, language barriers, and conflict between Latino and Anglo traditions and values – which make them more vulnerable to negative behaviors that increase their risk of HIV. In addition, sexuality and condom use are typically not discussed in traditional Latino families, making teens less comfortable and less successful in condom negotiation. This lack of communication is concerning because studies show that open dialogue between teens and their parents is associated with lower rates of sexual activity, less risky sexual behavior, and lower rates of teen pregnancy.

Recommendations

We need culturally relevant public health interventions for Latino MSM that address the unique factors that hinder current prevention efforts. In 2002, the CDC launched the DEBI project (Diffusion of Effective Behavioral Interventions), designed to bring science-based HIV prevention interventions to community-based organizations (CBOs) and health departments.

Many Latino CBOs, however, are using promising home-grown approaches, since none of the DEBIs were developed specifically for Latinos. For example, an organization in Texas has successfully adapted the MPowerment DEBI model for use with Latino MSM, and the Latino Commission on AIDS in New York is working to adapt Insights for Latinas. Insights consists of two mailings of a self-help magazine, male and female condoms, and prevention messages that are tailored to each client based on a risk assessment survey. But there is a critical need for more prevention and treatment programs designed by Latinos rather than programs for white MSM that are simply translated into Spanish.

Latino youth and women need to be encouraged to speak more openly about sexuality, safer sex, and HIV



testing. The dialogue must be intergenerational and culturally relevant. The high importance of family in the Latino community should be used to encourage healthy behaviors and dialogue. For Latinas, political empowerment should be used as a health education strategy. Generally, the level of comfort in discussing sexual issues can be improved by a program that focuses on empowering Latinas generally rather than solely on HIV prevention.

Finally, we should turn to families in preventing the spread of HIV. Families have a profound affect on an individual's values, which shape decisions about sexual behavior and health. Effective communication between parents and children has been shown to influence teens' sexual behavior. Encouraging discussions about sex, drugs, and STDs within families has the potential to promote safer sex practices among Latinos. Overall, there needs to be a multifaceted approach to HIV prevention for Latinos, which includes individual, peer, family, school, church, and community programs.

Oscar Raúl López is the Director of Health Policy for the Latino Commission on AIDS.

Native Peoples

By Elton Naswood and Harlan Pruden

The growing epidemic of HIV in Native American and Alaskan Natives (NA/AN) is reason for concern. Over 4 million people identify as Native in the U.S. – about 1.5% of the total population. While they make up less than 1% of reported HIV cases, they have the third highest rate of HIV, after African-Americans and Latinos, and the shortest life expectancy following an AIDS diagnosis of any race or ethnicity.

An estimated 68% of NA/AN live in urban settings, not on reservations. The Indian Health Service (IHS) contracts with 34 Indian-controlled non-profits to run urban Indian health organizations. But in 2006, Congress spent only about 1% of IHS's \$3 billion annual budget on these facilities.

Not much is known about urban native peoples, and what is known can be called into question. In a 2003 study, the percentage of racially mis-

identified Native peoples ranged from 4% in Alaska to 56% in California. The study raised significant concerns about the validity of current data and suggests that HIV statistics in these populations may be inaccurate.

Health disparities have historically been most pronounced in urban populations, and HIV infection follows that pattern. While Native peoples represent less than 1% of the HIV cases in Los Angeles County, they rank second in rates of AIDS diagnoses there, after African-Americans.

Challenges

HIV prevention among NA/AN is rife with challenges. Native peoples must deal with many realities that increase HIV risk, including poverty, substance abuse, and sexually transmitted infections. Nationally, Native people have the second highest rates of gonor-

include the legacies of contact and colonization, homophobia and racism in schools and institutional settings, discrimination, poor communication, biological susceptibility in women, and lack of adequate funding. Stereotypes and stigma due to lack of tribal affiliation often hinder access to services, which can create negative impressions about NA/AN. Other issues, such as language and culture, gender identity, and culturally based holistic treatment, are also important to address when providing effective HIV care.

As a colonized population, NA/AN have a long history of mistrust of the government, medical institutions, and service organizations. Native Peoples have endured such traumas as removal from traditional homelands, divided nations, loss of language and culture through forced enrollment of children in boarding schools, rape, disease, etc. This history continues to influence today's generation of NA/AN.

Tribes have endured historical traumas such as removal from traditional homelands, divided nations, loss of language and culture, rape, disease, etc. This history continues to influence today's generation.

rhea, chlamydia, and syphilis among all racial groups. The rate of AIDS in Native women is four times that of all other races. In addition, a third of Native women are victims of domestic violence. The historical trauma suffered by Native people has led to increased rates of alcoholism, drug abuse, and mental illness – increasing the risk of domestic violence and making HIV prevention more difficult. The stigma associated with sexuality and gender within Native communities, along with the nature of these close-knit communities, can make it difficult to confidentially discuss and confront HIV.

Native populations also regularly deal with health and social issues that make it hard to address HIV. These

Two Spirit

One group that is particularly affected by HIV is “two-spirit” individuals. This term did not exist in traditional Native communities, but approximately 165 traditions had other words in their languages that described a blending of the masculine and feminine spirits in a person. The term “two-spirit” came into being at an international gathering for LGBT Native people in 1990. Traditionally, this concept was not as much about sexuality as it was about claiming a certain role within the community. Sexuality was not central to this identity, but two-spirit people did engage in same-sex relationships with heterosexually-identified partners.

Today, “two-spirit” carries two meanings. One is an LGBT Native American (a sexual orientation and racial identity) and

the other is similar to the traditional concept of one's role and responsibilities within the community – a gender identity. Unfortunately, few services for two-spirit people exist. The NorthEast Two-Spirit Society is the only community-based resource in New York State specifically targeted to the two-spirit community, advocating for the two-spirit community in an effort to fill a gap in services.

Recommendations

Urban-based HIV programs designed to serve native people need to be more accessible, and there is a particular need for more prevention education and outreach efforts. The “Strengthening the Circle” curriculum created by AIDS Project Los Angeles (APLA) is one example. It provides HIV education for Native people in urban communities and other cultural groups. The workshops are designed with an understanding of the “medicine wheel,” a symbol of knowledge that enables individuals to live in balance with all aspects of their life. It offers a pathway to understand truth, peace, and harmony, as the circle is never-ending.

Effective and culturally sensitive HIV prevention and education among Native people is essential. Understanding complete wellness as holistic, with aspects of one's physical, mental, emotional and spiritual self is important. Spirituality is central to most native ways of life. Living harmoniously is essential, and this balance is achieved through traditional prayer, songs, and ceremonies. Twenty-eight years since the epidemic began, programs that set a standard of service provision to such an invisible population are necessary to begin healing this community. ■

Elton Naswood is the program coordinator for The Red Circle Project at APLA.

Harlan Pruden is Co-founder and Council Member of the NorthEast Two-Spirit Society.

The Tigers Outside My Window

by Awilde

I arrived in the U.S. in 1999 after being separated from my husband for three years. The marriage wasn't working – he spent too much time and money drinking with his friends. When I spoke up about it, he became more and more abusive. Then he hit me and I decided to leave him. I didn't want my son growing up in this environment. I spoke with a cousin who was living in Chicago and she helped me get a one-way ticket there. I had studied nursing in the Dominican Republic and my goal was to certify myself as a nurse in the U.S.

When I went to the hospital, I felt lost. It was large and there weren't any doctors who spoke Spanish. Each time I went I'd see a different doctor and get a different interpreter.

But in late 2001, I began to feel very tired and noticed I was losing weight. I got tested for everything and the doctor even did an HIV test, although he said it was not something I needed to worry about since I had only had one man and never used drugs. Plus, he said people in my age group weren't at risk – I was 47. When I came back for what I thought was a simple follow-up visit, I was told that I had HIV. My doctor referred me to a hospital that he felt would be able to help me better than he could. But I had developed a relationship with my doctor – he took care of my son and my cousin. He also spoke Spanish and his office wasn't far from where I lived – all of that made me feel at ease.

So when I went to the hospital, I felt lost. It was

large and there weren't any doctors who spoke Spanish. Each time I went I'd see a different doctor and get a different interpreter. And there were times that I was told I couldn't be seen because there weren't any interpreters available. It was also difficult to communicate with my case manager – she didn't speak Spanish and I had to rely on an interpreter, when one was available. But I felt I didn't need any social services, anyway. I was taking care of myself – I decided not to waste my time. I began taking HIV medications and didn't have any problems. I had read that people had problems but I guess I was one of the lucky ones.

But then, my doctor asked that I be admitted to the hospital, and I didn't understand why. Little did I know that I would end up in the psychiatric unit for observation. The entire time I was there I had psychiatrists, interns, students, and residents asking me all sort of questions: "Are you hearing voices now? Do you hear voices inside your head, or outside? What type of voices do you hear? Have you tried to hurt yourself or others?" I responded "no" to everything. When I got out a couple of days later, no one took the time to explain why I had been admitted.

A couple of years later, a case manager introduced himself at my doctor's office. He seemed friendly so I decided to stop by and see what he had to say. We talked about how I was feeling and he asked if I would see him each time I had a doctors appointment. It soon became routine.

But the next couple of times I saw him he began to ask me those same questions I was asked when I was in the psy-

I had psychiatrists, interns, students, and residents asking me all sort of questions: "Are you hearing voices now? Do you hear voices inside your head, or outside? What type of voices do you hear?"

chiatric unit. I again said that I had never heard voices in my life and that I was perfectly fine. He continued to ask if I had still heard “tigres” by my window. I said no, since I now lived on the third floor. He asked me if I heard any other animals. I was confused at first, but then I told him that “tigres” aren’t animals. I explained that when Dominicans say “tigres” we are referring to young men and not any sort of animal. He asked, “So it was young men making noise at your window late at night and not tigers?” I said “Yes, they (los tigres) wouldn’t let me sleep.”

He then asked me if I was taking my medications. I told him I rarely missed a dose. He asked if I took my medications orally or if I had taken hot baths with the medication. I mentioned that before starting my medications, I had decided to take a medicinal bath. It was a belief instilled in me as a child, a custom I had learned from my grandmother. She was an herbalist, a spiritualist and a “curandera.” We mixed our medications and herbs in a hot bath before taking them – it was her belief that it allowed us to take medications without any problems.

The social worker seemed to understand now. He told me that my medical history belonged to me, and that it might be useful for me to request a copy. He said it would help me understand why I was placed in the psychiatric unit. When we read it, I learned that soon after I began to take my medications, one of the doctors wrote that he suspected I was “mentally retarded” or had a psychiatric illness because I was using the medications in a hot bath, when in fact I had only done this once to get my body accustomed to them (and I feel that it has worked won-

ders for me - I have never had any side effects). In a later note, it mentioned that I was “hearing tigers at my window,” so I was being put under psychiatric observation to rule out hallucinations, delusional ideations, or schizophrenia.



It was funny in many ways, and good to finally put all the pieces together. My case manager explained to my medical providers that I really didn’t have a mental health problem, or much less that I was mentally retarded. I was doing all I needed to take care of myself, and the results of that could be seen in my viral load and CD4 counts. They had improved significantly in the first few months after I began taking medications.

I’ve learned that there is a need to have providers and interpreters who not only speak your language but who also are sensitive to your beliefs, customs, and culture. Sometimes it’s not enough to have a person that speaks your language – you need someone who can understand the terms and words you use. If they don’t understand, they should be able to ask.

I’ve also learned to use different Spanish words that the interpreters can understand. There aren’t many Dominicans in Chicago and none of the interpreters were familiar with the terms we use. I’ve since become involved with a health care interpreters project at the hospital, to allow them to include terms that might be misunderstood. I feel so much better knowing that I’m helping people so that the same thing doesn’t happen to others.

And I was finally able to get certified as a nurse. ■

A Legacy of Mistrust

RESEARCH AND PEOPLE OF COLOR

by Cynthia Santos

Clinical trials (the study of new treatments in people) are critical if we are ever to find better ways to treat HIV, and, eventually, a cure. Unfortunately, people of color, women, and IV drug users have been under-represented in these trials for many years. In fact, research for many diseases has often focused on white men, leading to a dangerous lack of data on how treatments work in women and people of color. Why has this occurred? To understand the challenges of encouraging participation by those who have often been overlooked, we must be aware of previous violations of human rights in clinical trials.

The Legacy of Tuskegee

One such notable violation was the Tuskegee Syphilis Study, which began in 1932 in Alabama but continued for 40 years until it was publicly exposed in the New York Times in 1972. Researchers observed the progression of syphilis in hundreds of poor black men who were unaware of their disease and who had not given their informed consent. The most tragic aspect of the study was that even after penicillin was found to cure syphilis in 1940, these men were denied access to it. As a result, many of them died or developed serious complications, including the irreversible neurological effects of end-stage syphilis.

The study's long duration and its clearly unethical design make it one of the most tragic episodes in public health. In communities of color, it has led to a long-lasting mistrust of research, the government and of the medical profession as a whole.

The study's public exposure led to Congressional hearings and the National Research Act in 1974, which created the

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Commission established protective regulations for those viewed as vulnerable to exploitation, including children, mentally retarded individuals, prisoners, and minorities.

Despite this legislation and the creation of organizations whose purpose is to

African Americans were initially excluded from a clinical trial of a new treatment for hepatitis C, because they are less likely to respond to current treatments and might affect the study results.

improve the recruitment of minorities into clinical trials, barriers remain, both from patients and researchers. For example, African Americans were initially excluded from a clinical trial of a new treatment for hepatitis C, because they are less likely to respond to current treatments and might affect the study results. Following pressure by advocacy groups, 15 African Americans were included in the study – a number too small to provide meaningful findings.

Women and Thalidomide

The history of regulations regarding women in trials – particularly pregnant women or women of childbearing age – is complicated, in part because of the thalidomide tragedy. Thalidomide had been used in Germany as an anti-nausea drug for pregnant women since 1956, but in 1962 it was withdrawn when more than 10,000 babies worldwide were born with deformities after their mothers took it. The most prominent U.S. response was the 1962 “Kefauver Amendments” that made it mandatory for

drug companies to prove the effectiveness of their drugs to the FDA. The amendments also required drugs to undergo animal studies and human trials, including trials in pregnant women, to ensure a drug's safety. But in 1977, amid growing concern about the harm caused to fetuses when testing new drugs in pregnant women, the FDA created a policy excluding even potentially pregnant women from clinical trials.

But the resulting low number of women in clinical trials eventually led to laws to encourage their participation. For example, the inclusion of women improved after the flawed 1982 “Aspirin Study” (which included only men) found that aspirin could lower the risk of heart attack. But since there were no women in the study, doctors were faced with the dilemma of how to apply the results to them. As a result, Congress passed the NIH Revitalization Act of 1993 to guarantee that women and minorities were included in clinical research.

Barriers

Even though the struggle to push forward the women's health agenda helped pave the way for minority health rights, there are still significant challenges to the inclusion of minorities in research. The legacy of Tuskegee, the mistrust of the medical establishment, unequal access to care, lack of awareness of clinical trials, and inadequate involvement of minority researchers are just some of the obstacles we must confront.

Although patient mistrust of the medical system is often cited as a barrier to enrolling minorities in clinical trials, distrust of medical researchers by minority physicians has also been found to be an important barrier. Studies have found that although the level of trust in medical researchers is greater than that found in patients, an ethnic community difference may exist. This mistrust is a major contributing factor to the lack of patient referrals to clinical trials, and has been found to be related to the physicians' previous experience with clinical trials.

The National Medical Association, an organization of African-American physicians, founded Project IMPACT (Increase Minority Participation and Awareness of Clinical Trials) in an effort to improve minority involvement in clinical trials. One of the primary aims of the project is to increase the involvement of minority physicians in clinical trials by identifying barriers and offering education to physicians. In 2008, 200 African-American physicians were asked about their involvement in clinical research. The survey showed that their participation was generally low—less than 25%. Their participation in clinical research during medical school, residency, and fellowships was also low. Reasons included a lack of time, lack of patients that fit the study criteria, and lack of a study coordinator or information management systems.

In order to increase their involvement as investigators in clinical trials, formal education workshops were offered by Project IMPACT to the physicians who had completed the survey. A total of 84 individuals participated. The most common reason given for participation was to gather information on clinical trials and the belief that participation would increase opportunities to become involved. After attending the workshops, almost 20% reported that they became involved with a clinical trial. Although this was not a large increase, the attitudes of the majority (68%) toward clinical trials were more positive after participating.

Next Steps

Including minorities in clinical trials is particularly important in HIV prevention trials, as minorities account for most new HIV cases in the U.S. In 1999, the NIH Division of AIDS established the HIV Prevention Trials Network (HPTN) to develop and test non-vaccine methods to prevent HIV transmission through a worldwide clinical trial network.

A 2004 HPTN study, Explore, studied the use of various counseling strategies to reduce HIV acquisition and risky sexual behaviors. Special planning sessions were held to assist sites improve recruiting of minorities. For example, study materials were translated to ensure that language was not a barrier. Even so, not all sites had equal success in recruiting minorities. Future HPTN studies need to focus on increasing the retention of younger men of color, especially men who

engage in high-risk behavior. This may be challenging, since they may have lifestyles or values that are at odds with the intervention being studied.

HPTN recommends that any research effort should include community advisors to help design methods that will improve recruitment of minorities. Studies have shown that research interventions are most likely to succeed when everyone involved—investigators, agencies, manufacturers, and community members—sees the research as relevant and the process as collaborative. HPTN also states that community mem-

includes internet resources and printed pamphlets to support efforts for community participation. Finally, the CORE Community Involvement Program manages community participation processes. Its staff provide technical assistance and other mechanisms for sharing information throughout the HPTN.

Conclusion

Addressing the greater impact of HIV on minorities requires a robust research agenda designed to shed light on the reasons for their vulnerability and identify new prevention strategies. The success of



bers should play an integral role in the development of trials in their community. To ensure this, HPTN has created several working groups and resources.

The Community Working Group advocates for community participation at all levels of the research process and ensures community participation. The Regional Working Groups in Africa, Eurasia, and the Americas provide an opportunity for community representatives and site staff to work with other sites in their region. Community Activities & Research Staff should be included at every site to support community involvement, as should Community Educators. A variety of resources for community educators should be available. For example, the Community Involvement Toolbox

these studies will rely on the support of and partnerships with the communities involved. Studies that focus on minority groups must include specifically designed strategies for community involvement aimed at closing the historic shortage of minority involvement in trials.

The lessons we have learned from history make it clear that to correct past wrongs, trials need to make alliances within the communities in which the studies are carried out. These alliances require the inclusion of programs within each trial specifically designed to establish a connection with the community. Only through such collaboration can we overcome the chronic disparities in health. ■

Cynthia Santos is a third-year medical student at Weill Cornell Medical School.

“Come Back When You’re Dressed Like A Man”

by Janice Rodriguez

I am a 26-year-old Latina transgender woman. I was mostly raised by my aunt after I was taken away from my mom and dad due to their drug use and street lifestyle. Things were hard because there were seven children in the house and a lack of love and attention. My father was constantly in and out of prison, died at the age of 28 from the AIDS virus, and infected my mom. Once she found out, she totally gave up. After that, I was sexually abused by my grandmother’s boyfriend. But when I told my grandmother she didn’t believe me. Instead, she told her boyfriend and he went into the bathroom, filled the tub with freezing cold water and threw me in. I couldn’t do anything but cry.

At the age of ten I began to notice that I was different from other boys. I would play with dolls and play house, fashion show, and talent show. I always played the girl, dressing up in my aunt’s clothes, shoes, and makeup. And when I looked at boys, I found them attractive.

In the seventh grade I began to get into fights when people called me names because of the way I acted. After a while I got tired of fighting so I began to cut school. My aunt was notified and I was punished and beaten with belts. She sat me down and asked me what was wrong, but I felt she wouldn’t understand so I kept my mouth shut. I told her I didn’t want to be there anymore, so I was put in group homes. I felt I was alone and like I was the only person who felt his way. I even cut my arms up and wanted to die. That led to me being put in the hospital for suicidal thoughts and depression. I was given medication, but to me it didn’t work so I stopped it.

I finally told my social worker what I was going through. She was understanding and placed me in a home with all gay people where I felt better because I met people I could relate to. But one day I was dressed as a girl and the staff told me that if I was going to dress as a girl I had to leave. I felt like I still couldn’t be myself.

Then I met another resident there and we got cool. He introduced me to Greenwich Village and I fell in love with it. For once I felt accepted and like I wasn’t the only one going through this. Once he asked me if I wanted to make money. I said yes, so he introduced me to “the stroll.” I began to work the streets every night. It was exciting, because I was wanted by guys and I got a lot of attention and money. I liked the Village and prostituting so much that I left the group home and ended up homeless.

I started drugs for the first time at the age of 16. My habit got so bad I was using every night, robbing people, and doing unprotected sex for drugs and money. I would be on the stroll and “boosting” stores for days at a time without eating or sleeping. I would get locked up and come back out and go right back to the same things – drinking and drugging and sleeping in the streets.

One night people from Housing Works came and told me that I should get tested for HIV. I really didn’t want to, but I went to take a shower and get something to eat and while I was there I took the test. I was HIV positive. So I said to myself, if I was gonna die anyway I might as well continue to do what I’d been doing. And that’s what I did for four years – drug, sleep in the street, rob, and steal.

I finally decided it was time for a change and went into the transgender housing program at Housing Works. I stopped the drugs and got medical care there. But after a while I

I told the city worker that I was a transgender woman, but he said I was a man and that the next time I should dress like a man or I would not get services.

started the drugs again and ran from parole. Fortunately I went back to jail. They weren’t giving me hormone therapy or my HIV medications, so I went to sick call. I explained to the doctor that I was a transgender woman and I would like to get back on my medication. I gave him verification of my hormone therapy and HIV meds from Housing Works. But then he told me he wasn’t going to give me hormones because he didn’t condone it. We argued about the situation, but for nine months I went without my hormone therapy or HIV meds. Things like that discourage transgender people from getting health care because we feel that we should be treated equally and respected for who we are, not what we are.

When I was released I had to get housing and emergency services, so I went to a city agency for help. Mind you I wasn’t dressed like I usually do because I was just out. I was told to come back in a week and came back dressed as a girl. The worker called my name but when I sat down he asked me why I

I've had gay friends who just didn't get what I was going through and would ask why I couldn't just be a "regular" gay guy.

was dressed like I was. I told him that I was a transgender woman, but he said I was a man and that the next time I should dress like a man or I would not get services. You would think the people who work for the city would understand that all kinds of people come for services. So I said I wanted to see his supervisor, and she was very understanding. She helped me with what I was there for and assigned me to another worker who assisted me with everything I needed. But there still is a need for more education. For example, it would help if workers were able to refer transgender clients to specialized service providers, like they would for a woman who was a domestic violence victim.

Some providers wonder why a person would want to be transgender. But being transgender is not something we choose. It's something we feel inside – something so overwhelming that no matter what we choose we would still need to do it. Many providers treat us poorly based on what they deem morally right and wrong. More education is needed – the more providers know about us the better they'll be to provide effective services. There should also be more laws that focus specifically on gender identity. Most, if not all, legislation ignores transgender people.

Accessing social services and medical care was hard for me because I didn't like the fact that I was called by my boy name and "him" or "sir." No matter how pretty or passable you are, they still call you what's on your I.D. They don't stop to ask you what you would like to be called. That's embarrassing, because there I am in women's clothes and they're calling me all types of "hims" and "sirs." City policies should be changed to allow transgender people to identify by their chosen name, especially when they are being addressed in front of other clients. If the worker calls the transgender person by their legal name in the waiting area they are outing that person and opening them up for ridicule. So I'm seeing an attorney about getting my I.D. changed.

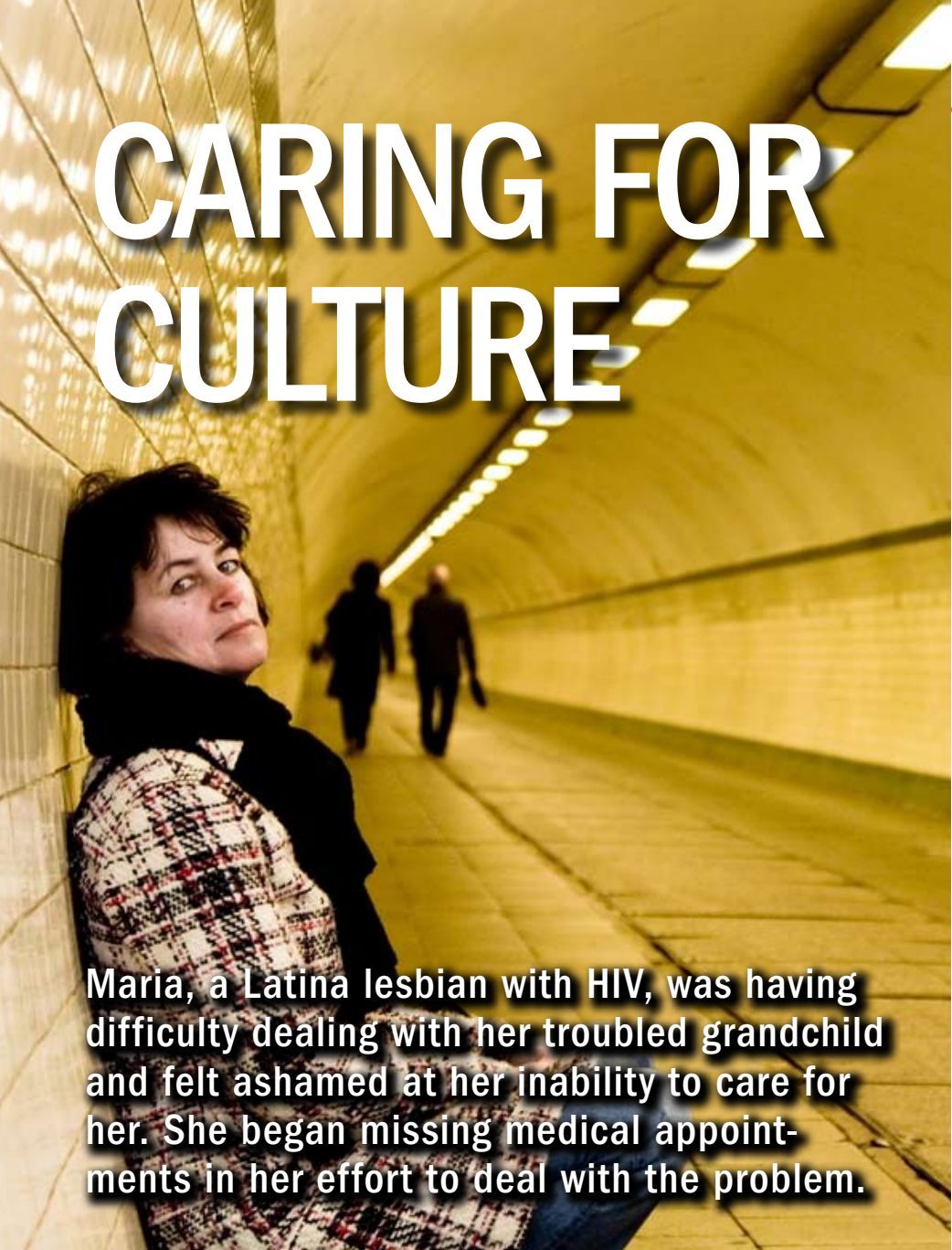
Our lives are much harder than anyone else's. Even gay men are more accepted in society than trans people – people feel we're going too far. Even some gay men think that we're embarrassing the gay community. I've had gay friends who just didn't get what I was going through and would ask why I couldn't just be a "regular" gay guy. In addition, gays have rights that protect them from discrimination while there are no laws that protect transgender people.



Many people think we are mentally ill or only see the ridiculous transgender people on Jerry Springer and that's how they view all of us. Because of these stereotypes many transgender people are never able to live fulfilling lives. And since our access to health care, education, and employment are hampered we often are forced to turn to prostitution.

I still have people who say things when I walk the streets, but I've learned to deal with it. I know what I am and I'm secure with who I am. I take my meds now and get my monthly checkups. I am currently clean off the drugs and alcohol and I don't go out prostituting. I have a safe apartment and I go to groups where I learn a lot about health, substance use, and harm reduction. My mind is in a totally different place now. I guess as you get older things change, especially your mental aspect. You want more out of life. You don't want to die a junkie and you don't want to be known as one. You want to be known as a somebody. Someone who went from a zero to a ten. Someone who succeeded. ■

CARING FOR CULTURE



Maria, a Latina lesbian with HIV, was having difficulty dealing with her troubled grandchild and felt ashamed at her inability to care for her. She began missing medical appointments in her effort to deal with the problem.

by Liz Seidel

Fortunately, her therapist was familiar with the importance of family in the Latino culture and knew that it was crucial to address Maria's feelings of responsibility to her family and as well as her own health. Discussing the situation led Maria to understand that she couldn't care for her granddaughter without also caring for herself.

Maria's case is not uncommon. Many people with HIV find it a struggle to communicate cultural concerns with their health care providers, case managers or mental health profession-

als. These concerns can influence how they think about illness and respond to it, as well as how their community and support systems react. Culture may also shape how they interact with their providers, what information is provided, and how it is communicated.

Studies have shown that ethnicity, race and culture can affect access to health care and health outcomes. Even when insurance status and income are taken into account, minorities receive a lower quality of care and are less likely to be offered new and innovative treatments. Given the diversity of those living with HIV, it is clear that the issue of culture and care needs to be addressed.

Differences in Care

Access to care and good communication during care is associated with better health outcomes, but imbalances exist based on race, ethnicity, and gender. Many studies have shown that African-Americans, Latinos, women, and those with low incomes receive lower-quality HIV care than men with higher incomes. It has also been found that when black and Latinos seek care they have to travel farther and spend more time in the waiting room than whites. One study found that a third of minority physicians had difficulty getting hospital admissions for their patients, compared to 24% of white physicians. Minority physicians also had more trouble getting referrals to high quality specialists (14% vs. 8%).

HIV-positive people of color also experience discrimination in HIV care. While one study found the majority felt discriminated against only part of the time, any perceived discrimination has been shown to be related to lower medication adherence, higher depressive symptoms, and less health care satisfaction.

Sexual orientation and gender can also lead to disparities in HIV care.

MANY STUDIES HAVE SHOWN THAT AFRICAN-AMERICANS, LATINOS, WOMEN, AND THOSE WITH LOW INCOMES RECEIVE LOWER-QUALITY HIV CARE THAN MEN WITH HIGHER INCOMES.

Many gays and lesbians do not feel comfortable disclosing their sexuality to their health care provider, which can hinder both HIV prevention and care. Those who have had negative experiences when discussing their sexuality with a provider may be reluctant to do so in the future. A 2004 study found that 24% of gays and lesbians had deliberately withheld information about their sexual prac-

tices from their doctor, compared to only 6% of heterosexuals.

Transgendered people face great stigma in our society, and this affects their contact with the health care system. Rates of HIV infection are high among male-to-female transgendered persons (up to 11.8%), but many find it difficult to find a transgender-friendly provider. Research has found that many doctors have negative attitudes towards transgendered patients and may refuse to address them by their desired gender, or may not distinguish between gender identity and sexual identity. Some transgendered persons are reluctant to seek care because they have heard about these problems from their peers. Even if a transgender-friendly provider is found, both doctor and patient are faced with a lack of medical literature that addresses transgender people.

People with HIV may also find disparities in mental health care. The majority of mental health treatments have been developed for white middle-class patients, even though they are used in a much more diverse population. And individuals often face more than one health disparity since many people with HIV are part of multiple marginalized groups.

Different Cultures, Different Approaches

Health care professionals need to be prepared for the increasingly diverse group of people living with HIV. Cultural competency supports treating the whole patient and not just the symptoms, by examining the entire context of what is affecting a patient. Health care professionals must also understand that they themselves are part of a culture and need to be aware of their own biases. They should research and utilize available resources, including patients themselves, to provide a higher standard of care.

For example, when working with Latinos it is important to understand the concept of *familismo* – the primacy of the family unit, including the extended family. African-Americans have a long history of the church as a crucial source of social support, and there may be distrust towards the medical community based on years of misuse in clinical studies. As a result, half as many African-Americans use experimental HIV treatments as whites. When working with Asians and Native Americans, the importance of respecting elders as gatekeepers to the community is important. Gender

roles and the significance of authority figures also vary by culture.

Health care professionals will often have cross-cultural encounters. People who are treated by providers who share their ethnic/cultural background often have better health outcomes, but 40% of people with HIV are African-American, compared to only 3% of physicians. So it is important that providers not form stereotypes around a client's culture. For

MANY DOCTORS HAVE NEGATIVE ATTITUDES TOWARDS TRANSGENDERED PATIENTS AND MAY REFUSE TO ADDRESS THEM BY THEIR DESIRED GENDER, OR MAY NOT DISTINGUISH BETWEEN GENDER IDENTITY AND SEXUAL IDENTITY.

example, a Puerto Rican raised primarily in New York City may have very little in common with a Mexican immigrant. A third-generation Asian-American will most likely not have the same cultural values as recent Asian immigrants.

Cultural competency means gaining knowledge of a person's culture while respecting individual differences. Discussing culture issues may reveal conflicts between a patient's values, standard HIV care, and that of the culture in which they were raised. Clients need to be asked about their cultural values and how they may influence living with HIV. Providers should be patient and understand that the client may have faced discrimination in the health care system and may view it with suspicion. The feeling that a provider is not sensitive to cultural needs is associated with being less likely to return for follow up care. Studies have also shown that when health care providers are educated

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CARING FOR CULTURE

continued from page 21

on cultural competency, they become more aware of barriers that may exist in maintaining proper health care.

Cultural competency is particularly important in HIV care, which involves very sensitive subjects like sexuality and stigma. HIV-related stigma is widespread in the U.S., but in certain cultures HIV risk behaviors and an HIV diagnosis carry even more stigma. This can cause people to avoid disclosing their HIV status for fear it will shame their family or that they will be turned away at their place of worship.

Addressing the Problem

Studies have shown that when interventions address culture or are adapted to meet a different cultural standard, the quality of care improves. Discussing cultural issues or providing health information in the native language can provide real benefits.

STUDIES HAVE SHOWN THAT WHEN INTERVENTIONS ADDRESS CULTURE OR ARE ADAPTED TO MEET A DIFFERENT CULTURAL STANDARD, THE QUALITY OF CARE IMPROVES.

For example, Latinos who are able to access bilingual providers and bicultural information have been found to have better health outcomes.

Areas to be considered in cultural competency programs include age, sex, race/ethnicity, country of origin, religion, sexual orientation, disability status, education level, socioeconomic status, gender identity and languages spoken. Courses should focus on the fact that health views can be linked to culture, that unfamiliar client behavior should not be judged, and that people

have different perspectives on health care, including how they ask for help.

Providers may not be able to address every cultural issue that is presented to them but they can listen to the information clients provide and explore the attitudes they hold towards their HIV diagnosis. Providers should understand that individuals often feel a part of more than one group and may embrace different pieces of each.

Our health care system needs to respond to the growing diversity of the U.S. and of people with HIV. A culturally competent approach will help providers better understand HIV stigma, medication adherence, and family, disclosure and communication issues. Organizations can also implement cultural competency programs and policies and information throughout the practice. ■

Liz Seidel is a research intern at ACRIA and is completing her MSW at Fordham University.

M•A•C AIDS Fund Launches Historic Collaboration

ACRIA and GMHC are proud to be part of a new, M•A•C-funded collaborative effort, along with SAGE and GRIOT Circle, to bring HIV prevention and services to middle-aged and older adults. As the numbers of older people continue to grow, it is vital that their special needs be included in HIV public policy and budget decisions at the federal, state, and local levels, and to ensure they are effectively represented in the promised national domestic AIDS strategy.

One aim of the M•A•C collaboration is to bring the unique HIV prevention needs of older adults into the conversation around health policy and HIV prevention services with the goal of a healthier senior population. While all four of M•A•C's partners are located in New York City, the collaboration is national in scope and promises to have enormous implications for HIV prevention throughout the U.S.

This effort will draw on the individual strengths and experience of each partner organization and will include the integration of evidence-based HIV service models for older adults and the creation of an HIV prevention model for older adults, with an emphasis on cross-agency collaboration. It will feature training, technical assistance and capacity building for community-based groups, direct client services, and advocacy for meaningful change in the policy arena.

“This visionary support from the M•A•C AIDS Fund shows that no matter how challenging the economic environment might be, we can still find creative solutions to our most urgent issues when we work together,” stated GMHC’s CEO, Marjorie J. Hill. “We are particularly grateful to M•A•C AIDS for their willingness to support innovative strategies for prevention models and education at this crucial moment in the epidemic.”

The Single Best Approach to Health Care Reform

President Obama has vowed to bring major health care reform to the U.S. Not since President Clinton's administration has such a major overhaul been attempted. That failure halted any other attempts to date.

There are an estimated 39 to 41 million Americans currently without health insurance, including one-third of all Hispanic-Americans, 19% of all African-Americans, and 10% of white Americans. Millions more are underinsured. In addition, U.S. health care expenses are more than double those of other industrialized nations.

Yet despite this higher cost, we have little to show. The U.S. scores low on a variety of health indicators, such as infant mortality, immunization, and life expectancy. And we spend 31 cents of every health care dollar on administrative costs. This staggering overhead is due in large part to the paperwork involved with billing the numerous private insurers.

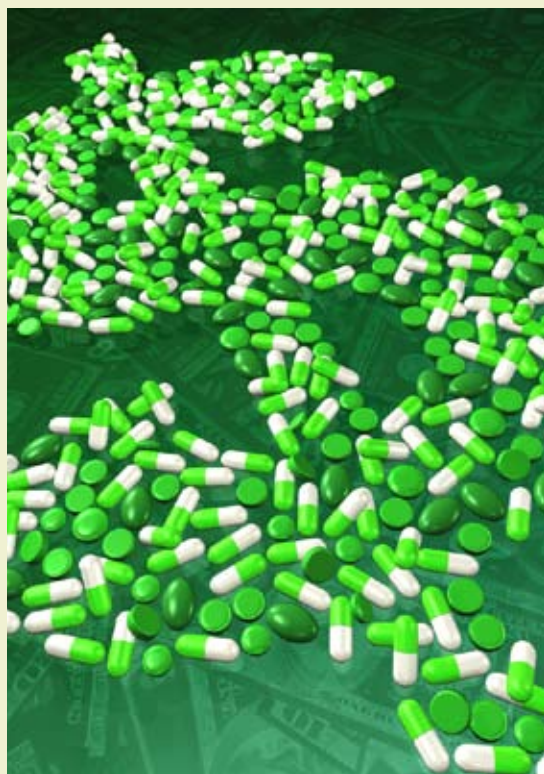
After the economy, health care is poised to be the top issue of the Obama administration. The Obama-Biden plan will build on existing health care systems and promote the following tenets:

- Require insurance companies to cover pre-existing conditions
- Create a Small Business Health Tax Credit to help businesses cover their employees
- Prevent insurers from overcharging doctors for malpractice insurance
- Establish a National Health Insurance Exchange to allow individuals and small businesses to buy affordable private health insurance
- Ensure everyone who needs a tax credit for their premiums will receive one
- Lower drug costs
- Reduce the costs of catastrophic illnesses for employers
- End anti-competitive activity that drives up prices without improving care

Another popular reform plan is known as "single-payer." A single-payer system would create a National Health Insurance (NHI) system. According to Physicians for a National Health Program, single-payer is "a system in which a single public or quasi-public agency organizes health financ-

ing, but delivery of care remains largely private." Single-payer would eliminate private insurers and be financed by ending administrative waste – estimated at \$350 billion each year. Single-payer is guided by five principles:

1. Access to health care is a human right.
2. Health insurance should not be tied to employment.
3. Patients should have free choice of providers.
4. The "free market" and profiteering have no place in health care.
5. Decisions in health policy and budgeting should be made by the public.



Advocates argue that single-payer would ensure universal coverage. In particular the true-out-of-pocket (TrOOP) costs of health care would drop. Currently, most people in the U.S. must pay a deductible or co-payment to obtain care. But even a nominal payment of \$10 is a real barrier for many. Failure to obtain preventive care in order to avoid TrOOP expenses affects the overall health of patients, and raises costs when they must get care later in their illness.

Reform could also have a major impact on HIV care. Many people with AIDS need long-term care, and most prefer to receive it at home or in a community-based setting, avoiding lengthy hospital stays. NHI would increase this option and provide services for friends and family acting as caregivers (an estimated 7 million people). NHI could also significantly lower drug costs by negotiating with

drug companies and purchasing in bulk. The freedom of choosing a provider would mean that people with HIV would no longer be forced into health care networks that may not fit their needs.

One version of single-payer, the National Health Insurance Act (H.R. 676), has been introduced in Congress every year since 2003, and currently has 69 cosponsors in the House of Representatives. The principles outlined in the Obama-Biden plan and the single-payer plan would be advantageous for many people with HIV. We are pleased that Jeffrey Crowley, newly appointed Director of the Office of National AIDS Policy, has strong expertise in Medicaid, Medicare, and health policy. We must ensure that, whichever approach is eventually adopted, the health and well-being of people with HIV is protected. ■

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For a list of all the trainings and to download a registration form, visit:

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You may also contact Gustavo Otto for more information at 212-924-3934, x129.

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Fund Global Health!

A CALL TO ACTION

President Obama has released the 2010 budget for his new Global Health Initiative. However, the only aspect of the plan that appears “new” is a dramatic decrease in funding for programs to address HIV, malaria and TB.

Last year, Congress reauthorized PEPFAR at \$48 billion over 5 years. But the new proposal calls for only \$51 billion for the same programs over six years – a \$6.6 billion cut. This means dramatic reductions in global AIDS funding, with little left for vital expenditures like maternal and child health and health system strengthening.

The Global Fund to Fight AIDS, TB, and Malaria is in particular danger. With a mere \$366 million increase in funding from the U.S., the Fund may have to start cutting existing and future grants.

Call Congressman Nita Lowey and Senator Tom Leahy at (202) 225-3121 and demand that full global AIDS funding be restored.