



The Atlanta Principles

Researchers from the Emory School of Public Health recently released an estimate: 12% of young black gay men in Atlanta become infected with HIV each year. In the cohort studied, a man who becomes sexually active at age 18 has a 60% chance of seroconverting by the time he's 30. The most recent figures on the wider epidemic from the Centers for Disease Control and Prevention (CDC)—which makes its home in Atlanta—are almost as alarming. Over a two-year period new infections rose by about 12% among all men who have sex with men (MSM, a category that includes transgender women), and by 22% for young MSM. A gay man was thirty times likelier to become HIV-positive than a straight man. Though domestic data on transgender people are not strong enough to cite with confidence, international figures tell us of a significant rise in new cases of HIV among transgender women. Last month a prominent NIH researcher summarized long-term HIV incidence data to an audience at Columbia University: “Among MSM,” he said, “new HIV infections are out of control.”

Just a few years ago, prevention of the sexual transmission of HIV meant one thing: using a condom for intercourse. Today there are multiple means of HIV prevention, and they involve both people who are living with HIV and people who are HIV-negative. Treating people living with HIV has a prevention benefit: someone living with HIV who has an undetectable viral load is extremely unlikely to transmit HIV. And the Food & Drug Administration (FDA) has approved Truvada as Pre-Exposure Prophylaxis (PrEP), a pharmaceutical HIV prevention for HIV-negative people at risk.

To HIV activists and service providers from affected communities, CDC has often seemed eerily absent from this freshly challenging, rapidly changing prevention landscape. Communities have the right to benefit from the knowledge obtained through research on them. This is a fundamental principle of human subject research. Community members have been subjected to a huge amount of HIV-related research over the past thirty years. Now that this research has shown just how crucial TasP, PEP, and PrEP could be for lowering the number of new infections, this knowledge must be translated quickly into policies and programs that could help relieve our communities of the massive burden of disease into the foreseeable future. Toward this end, ACT UP NY and our community allies are asking CDC to change the way it conducts HIV prevention:

Sexually Frank HIV Prevention Messaging

Effective HIV prevention requires informational materials that deal frankly with sex and discuss the realities of maintaining bodily health. When these materials ignore the human body, those who need to practice sexual health ignore it too. The 1987 Helms Amendment prohibits federal funding for materials that promote homosexual activity. To protect itself, CDC drafted content guidelines that prevent the agency from producing openly sexual materials and from funding the production of such materials by local health departments. In silencing itself and its partners, CDC has abandoned its mandate to keep the nation healthy. Current content guidelines deprive the nation of necessary health information and contribute to an atmosphere that discourages sex research. The resulting gaps in our knowledge hamper the ability to target prevention efforts. Promoting sexual health will require the persistence of healthcare agencies in the face of attempts to censor and suppress its efforts, sometimes sustained by traditional beliefs. CDC has an ethical responsibility to promote the health of its constituents and their rights as individuals, even when this proves inconvenient, controversial, unpopular or difficult.

- ***CDC must rewrite content guidelines to allow the production and promotion of sexually explicit materials in the interest of public health. It must collaborate with the communities most affected by HIV to design those materials.***

Treatment as Prevention (TasP)

Diagnosing and treating HIV as soon as possible improves the long-term health of a person living with HIV, and sustaining an undetectable viral load means a person is very unlikely to transmit the virus. TasP has the potential to radically change HIV prevention. Yet, due to substantial leaks in the HIV treatment cascade, only one in four US residents living with HIV has currently achieved sustained undetectability. Were knowledge of TasP widespread, it could help de-stigmatize HIV and empower people living with HIV by helping them make decisions about treatment and helping them and their partners make decisions about sex. Yet the message about TasP has not been getting through to communities most affected by HIV.

- ***CDC has to aid local health departments in exploiting the Affordable Care Act (ACA) and expanded Medicaid to plug leaks in the treatment cascade so that more people living with HIV can live better and achieve undetectability.***
- ***CDC should collaborate with the communities with the highest HIV prevalence to design a national information campaign about the prevention benefits of HIV treatment. The campaign should target both HIV(+) and HIV(-) individuals and include social media channels.***
- ***CDC should design and deliver a national TasP information campaign for the general population to de-stigmatize HIV by dispelling misinformation about its transmission.***

Pharmaceutical Prophylaxes: PrEP & PEP

On May 14, 2014, twenty-two months after the FDA approved the antiretroviral Truvada as PrEP for HIV, CDC released final guidelines for clinical practice. Yet many people in HIV-affected communities are unaware of or confused about PrEP, and many community practitioners are advising their patients to stay away from it. CDC has produced useful PrEP materials, but it has yet to invest in PrEP education that targets practitioners and members of communities where HIV incidence remains high. In the absence of CDC action, community-based activists and service organizations have had to set up local PrEP education efforts without much guidance, funding, or technical assistance. For many years PEP— Post-Exposure Prophylaxis— has been standard of care for possible non-occupational expo-

sure to HIV, yet PEP is hardly better known than PrEP among community members and practitioners. Although pharmaceutical prevention has generated controversy within communities affected by HIV, this should not be an excuse for CDC inaction. It should instead spur the agency to be very clear in its promotion of a highly effective, scientifically supported method of HIV prevention.

- *CDC should expand the PEP and PrEP information it offers, collaborating with community members in designing campaigns that target the populations where HIV incidence remains highest and using the traditional and social media these populations use in their everyday lives.*
- *CDC should tailor PEP and PrEP information for subpopulations historically at risk for HIV, such as injection drug users (IDUs) and women at particular risk because of homelessness or partner abuse.*
- *CDC should host a series of seminars, webinars, workshops and conferences that train medical providers about PEP and PrEP guidelines and their implementation in clinical settings— including how to bill third-party payers.*
- *CDC needs to let medical practitioners know: Truvada as PrEP is approved prophylaxis for individuals at risk for HIV. Responsible practitioners should prescribe pharmaceutical HIV prophylaxis accordingly.*

Funding HIV Prevention: Targeting Populations at Highest Risk, Funding New Prevention Efforts and Older Ones, Funding that Rewards Success

We have many concerns with how CDC funds HIV prevention. A paltry percentage of current prevention funding targets MSM, the population with the highest incidence. In recent years, CDC has cut funding to local HIV prevention efforts substantially. Many older behavioral interventions did not prove effective. But these de-funded condom workshops have not been replaced by other programs, and combination prevention will require a thriving behavioral component, working alongside TasP, PEP, and PrEP if it's ever to make a significant dent in HIV incidence. Currently, whenever a locality performs better than the national average at preventing the spread of HIV, CDC shifts prevention funding away to poorer performing areas. It is bad public health policy to penalize success, starving the very programs that have scored advances against the epidemic.

- *CDC must target prevention funding to populations at highest risk.*
- *CDC has to fund new prevention efforts that exploit TasP, PEP, and PrEP and reach out to people at risk who have been newly enrolled into healthcare by the Affordable Care Act (ACA) and expanded Medicaid.*
- *CDC should continue to fund older prevention efforts that make sense, such as condom availability in bars, sex spaces and places where key populations gather. At the same time, it should support research into new ways of behavioral prevention.*
- *Before cutting funding, CDC must allow local officials and community members to defend the success of programs that have contributed to lowering the number of new infections in states that have invested in prevention efforts.*

HIV Testing and Identifying Acute HIV Infection (Seroconversion Illness)

HIV testing is the ground for individual decisions about HIV treatment and prevention. Yet many members of high risk populations elude testing because they rarely seek care. Officials at CDC have said the agency will need more than a year to reconsider its current recommendation of yearly testing for key populations. Many community HIV workers believe more frequent testing would catch more infections sooner. Local clinicians complain that the lack of a Clinical Laboratory Improvement Amendments (CLIA) waiver from CDC is an obstacle to bringing fourth generation HIV testing to the point of care—testing that could identify infection earlier and narrow the window on the highly infectious period of untreated acute infection. Few people at risk for HIV and their providers know to look for the symptoms of acute infection. This ignorance masks many new infections that could be caught early, a danger to individual and community health.

- ***CDC should consider expanding testing sites beyond traditional points of care, to dental offices and mental health settings, and beyond medical settings to places where key populations gather in their everyday lives.***
- ***CDC must promptly revise HIV testing guidelines for key populations.***
- ***CDC must grant CLIA waivers right away for HIV diagnostics that bring the most sensitive testing to the point of care.***
- ***CDC and its local partners must train practitioners about how to screen for and detect acute HIV infection, as well as educate communities at risk.***

Need for More Sensitive HIV Epidemiology

While the number of new HIV infections has dropped in some communities at risk, the number has flared among subpopulations such as transgender women and young gay men. CDC's incidence estimates currently group transgender women with gay and bisexual men, confounding efforts to quantify the epidemic for trans women. Research suggests that targeting effective prevention interventions to sexual networks would be an effective prevention strategy— but one that will require more precise data on different subpopulations than CDC now provides.

CDC does not furnish incidence estimates for sex workers. CDC has admitted the agency knows little about the sex practices of transgender men.

Although estimated new HIV infections among IDUs have dropped, recent reports warn of a new heroin epidemic, some of it in the suburbs. Among young IDUs incidence of Hepatitis C is reportedly high, a possible early warning sign of a rise in HIV infections. HIV incidence in women has dropped, but workers in the field warn that new infections persist among women at particular risk, including homeless women and women in abusive relationships. We cannot let our success in lowering new infections in some groups blind us from what might be going on in subsets of these populations.

- ***CDC has to disaggregate HIV incidence data for transgender women from data it collects for gay and bisexual men so it can make separate incidence estimates.***
- ***CDC needs to collect data specific enough for tailoring prevention to the sexual networks of a full range of gay and bisexual men.***

- *CDC has to collect data that will facilitate our understanding of HIV risk for transgender men and for sex workers.*
- *CDC must be careful to monitor HIV incidence for the new wave of young IDUs and for women at particular risk.*

Reforming National HIV Behavioral Surveillance (NHBS)

NHBS, behavioral surveillance among persons at high risk for HIV infection, conducted in rotating annual cycles for MSM, IDUs and at-risk heterosexuals, informs how we think about the evolving epidemic and how we prevent new infections. Yet officials from local health departments in New York and San Francisco routinely point out flaws in NHBS data. A retooled NHBS could help us better understand and deal with the spread of HIV.

- *CDC should introduce real-time PCR sampling of NHBS subjects who report an unknown serostatus to determine incidence of acute infection.*
- *CDC should take the viral load of a subsample of NHBS subjects to help estimate community viral load.*
- *To ensure that NHBS participants who report an unknown serostatus are not simply reluctant to share personal information, CDC should test a subsample for antiretroviral drugs in the blood.*
- *CDC could use NHBS to help discover possible behavioral and biomedical correlates of HIV infection in high-incidence subpopulations.*

CDC and Sex Education

Over the last few decades, a general retreat from sex education in middle schools and high schools across the country has left our young people knowing less about sex in general, about queer sex in particular, about HIV and about which sex acts present risk. Some messages interfere with education. One CDC official recently claimed, without offering evidence, that new infections among gay men occur because they no longer fear the virus. Fear has not stopped the number of new infections among MSM from rising since 1993. Fear will not reverse those numbers in 2014. Young gay men have been taught to fear HIV but have not been given the knowledge and the tools that will help them become functioning, sexual human beings and maintain health at the same time.

- *CDC should issue basic sexual education guidelines, free of prejudice, that normalize sex as part of a healthy life: What do students need to know in order to maintain sexual health? Sex education has to speak openly about heterosexual sex and the full range of queer sex— gay, lesbian, bisexual, and transgender— without stigmatizing language.*
- *CDC should work with local officials to develop or improve a local HIV curriculum that educates students about HIV, its treatment and prevention, behavioral and pharmaceutical, and works to counter HIV fear and stigma. CDC should survey students to help ensure the curriculum's effectiveness.*
- *Fear-based HIV prevention messages only feed stigma: CDC has to abandon them.*

The Lives of People with HIV Inform Clinical Practice

The care of people living with HIV and the success of TasP depend on accurate and thorough data collection in order to inform best clinical practice. Two groups in particular concern us. A whole generation of people living with HIV is entering their senior years. This is uncharted medical territory. Many of these seniors have been living with HIV for decades; many have been taking antiretroviral drugs for almost as long. They are likely to have special needs that only continued surveillance will discover. The number of new HIV infections has fallen among women, but there are still considerable numbers of women living with HIV. Ongoing surveillance will reveal their clinical needs, especially crucial in light of recent efforts by the Social Security Administration (SSA) to shrink the roster of conditions that will qualify a woman for an AIDS diagnosis.

- ***CDC must focus surveillance of subpopulations living with HIV, including seniors and women, so that the information gathered will improve care.***
- ***If CDC believes that SSA's proposed revisions of AIDS criteria jeopardize women's health by curtailing their access to healthcare, CDC has an obligation to oppose these changes and make its opposition known.***

CDC's Ongoing Partnership with HIV-Affected Communities

A generation ago, members of communities devastated by AIDS partnered with traditional healthcare institutions and public officials to rejuvenate public health. We believe that dealing with the current crisis in HIV prevention will require a renewal of this partnership among communities and the public, private and academic segments of the healthcare establishment. Some communities have been chronically underserved by our healthcare system. Homelessness, poverty and ongoing stigma have fueled the HIV epidemic. Yet recent consolidations in healthcare have favored large institutions over smaller, community-based partners that deal every day with the consequences of the social drivers of HIV. CDC's recent funding has traveled a similar trajectory. Yet local organizations know firsthand about HIV in their communities and understand that the wellness of community members requires more than protection from pathogens. Forging partnerships with community organizations will be more crucial than ever as CDC tries to educate key populations in the unfamiliar ways of pharmaceutical prevention and to help community providers connect newly eligible candidates to care.

- ***CDC must partner with communities most affected by HIV and nurture their organizations so they can be full partners in preventing new HIV infection and connecting people to care and wider services.***

The Affordable Care Act (ACA) raises the notion of prevention to the level of statute for the first time in this country. In concert with expanded Medicaid in more than half of the states, ACA affords us an opportunity to extend the HIV treatment cascade across the sero-divide and connect many HIV-negative people at risk to repeat testing and ongoing care. ACT UP NY and our community allies hope that the promise of ACA— in conjunction with TasP, PEP, and PrEP— occasions a renewal of HIV prevention efforts in the US, and that CDC, working with local affected communities, spearheads this renewal. The crisis of the new HIV epidemic will require nothing less.

CONTACT: Jim Eigo, ACT UP NY / jimeigo@aol.com