



# AIDS Foundation OF CHICAGO

**May 2008**  
**SPECIAL ISSUE**

## **PREPARING FOR THE NEW U.S. HIV INCIDENCE ESTIMATE** **Talking Points for Community Organizations**

AIDS Foundation of Chicago (AFC)

Community HIV/AIDS Mobilization Project (CHAMP)

*With thanks to National Association of State and Territorial AIDS Directors (NASTAD)*

Since 1994, Centers for Disease Control and Prevention (CDC) has estimated that 40,000 new HIV infections occur each year in the United States. This figure is known as incidence, while the overall number of people living with HIV is known as prevalence. The AIDS community has been waiting for an updated incidence estimate, knowing that it is unlikely that incidence has remained the same for 14 years.

In November and December 2007, national media outlets confirmed that CDC has developed a new incidence estimate that might be as high as 60,000 infections per year, but was delaying publication of this number in order to have it appear first in a peer-reviewed medical or scientific journal. CDC has now removed the 40,000 estimate from its website.

Some sources are now speculating that the numbers will be released in early summer, while others believe they will not be announced until after the November election. Clearly, the release of new

incidence numbers will be news. The announcement serves as an opportunity to highlight key issues in the epidemic in the United States and in our local areas. It also means that there may be backlash from conservative politicians and others opposed to evidence-based HIV prevention who will claim that prevention has "failed." Therefore, it is imperative that we offer clear explanations to our constituents, clients and supporters.

CDC has said they will alert members of the AIDS sector at least two days before a new incidence figure is made public, which will not allow much time for preparation. For this reason, AFC and CHAMP recommend that organizations prepare clear, concise talking points well in advance of this announcement. Below, you will find general information and talking points that may be helpful.

For more information, contact Coco Jervis, CHAMP Director of Policy and Leadership Development, at 212-937-7955 x 50 or [coco@champnetwork.org](mailto:coco@champnetwork.org).

## I. Introduction: Reframing the debate

The release of the new incidence estimate is an opportunity and challenge for our organizations.

For example, we may be contacted by press or politicians who see an increase in incidence as proof that “prevention doesn't work.”

We know that prevention efforts work, and also that our efforts have been hampered by a lack of funding for education and interventions, research into new prevention options, and community infrastructure challenges.

The amount of funding has not gone up to match the number of people in need of services — those infected and at risk for infection. **In fact, adjusted for inflation, prevention funding has declined each year since 2001.**

*Thus, we can and must reframe the debate that may be sparked by the new incidence estimate.*

The talking points below will help with that reframing. For example, they show that the CDC has stated that the main obstacle in meeting its strategic goal of reducing HIV incidence by 50% was a lack of funding.

Overall, we believe that an effective way to communicate about the new figures is to frame the announcement in the **larger context**. We believe that the massive challenge of the AIDS epidemic in our nation requires a **strong, sustained and coordinated national strategy**. We can reframe the discussion on incidence to aim the gaze of the public and policymakers upward to state and federal responsibilities to fund and coordinate HIV/AIDS prevention efforts.

An example of framing the larger context:

*“We don't know whether infection rates are rising or they've just been higher than we thought... But either way, this shows that prevention efforts are insufficient.”*

Julie Davids, CHAMP Executive Director,  
*New York Times, December 2, 2007*

In framing the larger context, we must resist the impulse to assign blame to individuals or inadvertently play into stereotypes that further stigmatize at-risk individuals and communities. For example, if a reporter asks, “How come young people are still taking chances when we've known for decades how HIV is transmitted?,” we may think of our daily prevention outreach efforts and reply, “Young people think they are invincible, they think they are superman. Peer-based education led by young people is the best way to help educate youth about the realities of HIV and ways to prevent transmission.”

Although this response may reflect what we've noticed in our work, and makes a great point about peer-led education, it feeds into the stigmatization of young people by

labeling them as careless. It also means we may have missed an opportunity to *aim upward in our language and critique*. A way to reframe the question to speak out for more resources for our work could be to say:

*“Funding cuts to our programs prevent us from offering enough of the peer-led education and support that helps young people make healthy decisions. Meanwhile, the federal government continues to support misleading abstinence-only education programs that forbid offering accurate information about the role of condoms for young people who may be sexually active.”*

Others may use the release of the new estimate as an excuse to call out for the end of prevention efforts, saying we should re-direct all funds to testing, treatment and care. Again, we suggest aiming upward and frame the broader context by responding that, “the worst epidemic the world has ever known requires coordination and resources for our response. We need a national AIDS strategy that understands that testing, prevention, treatment and care are all connected, and that doesn't pit us against each other to fight over scarce resources when all parts are necessary to control the epidemic and allow people to have healthier lives.”

And of course, it is very important to use these opportunities to speak out in very specific ways about the challenges your organizations are experiencing because of funding cuts. Please contact us if you'd like to practice these points to help them be as compelling as possible to outside ears.

## **II. Talking Points on What We Know and Don't Know Right Now about the Incidence Estimate**

### **How the New Estimates Were Derived:**

- CDC funded 34 states and cities to conduct incidence surveillance and began collecting data in 2005.
- CDC used data from 19 states in its mathematical models to update the annual estimate of new infections. (It should be noted that CDC has cut incidence surveillance funding by almost \$3 million and dropped the number of funded sites to 25).
- The estimates are based on both actual HIV testing and on statistical techniques called “modeling.”

### **What We Think the Data Will Show:**

- There are more people becoming infected with HIV on an annual basis than was believed previously.
- The number of new infections over the past decade has likely gone up and down from year to year.
- These estimates are based on the best available information and on modeling but

the incidence numbers remain far from exact.

- HIV incidence or the number of persons recently infected with HIV is very helpful in predicting where the epidemic is headed which in turn may allow for better targeting of scarce HIV prevention resources.

### What the Data Will Not Show:

- This does not necessarily mean that more people are living with HIV/AIDS in the United States. CDC has not revised its estimate of HIV prevalence since 2003 when it calculated that 1 million to 1.2 million Americans are believed to be living with HIV/AIDS.
- **This does not mean that there is suddenly a large influx of new cases in 2008.** The estimate of the number of people newly infected on an annual basis likely went up and down from year to year.

### What This Means Relative to Current HIV Prevention Efforts:

- CDC prevention has not been adequately funded to sufficiently reduce the number of new infections.
  - Prevention funding makes up only **3%** of domestic federal HIV/AIDS spending.
  - The amount of funding has not gone up to match the number of people in need of services — those infected and at risk for infection. **In fact, adjusted for inflation, prevention funding has declined each year since 2001.**
  - State and local HIV prevention cooperative agreements have been cut by \$26 million from FY2003 - FY2007 and may be cut by an additional 1.747% or \$5 million in FY2008.
  - The only new resources (\$45 million) have been for HIV testing expansion rather than for interventions to reduce the risk of infection for high-risk individuals.
- When given sufficient resources and not hindered by political or legal impediments, successes are achieved.
  - Perinatally acquired (mother-to-child transmission) HIV cases decreased by 95% from a peak of 954 cases in 1992 to an all-time low of 48 cases in 2004.
  - In communities where access to sterile syringes is supported, transmission of HIV in injecting drug users has declined as a proportion of all cases by mode of transmission. Decreases have also been documented among the sex partners and children of injection drug users.
  - There has been a drastic decrease in HIV/AIDS mortality due to testing and treatment.
  - Research has shown that prevention programs have averted between 204,000 and 1,585,500 HIV infections between 1978 and 2000.

### What Will Be Included in the New Incidence Estimate?

- According to press reports, CDC may likely estimate that 55,000 to 60,000 HIV infections occurred in the U.S. in 2005.
- This would be a 35% to 50% increase over the longstanding estimate of 40,000

annual HIV transmissions.

- In its briefing in December, CDC said the primary data source for the new national estimates was new laboratory analysis conducted on HIV-positive blood samples in 19 jurisdictions using the STARHS method, which can identify recent infections from longstanding ones.
- CDC researchers may include regional breakdowns in their analysis.
- It is unlikely that there will be further breakdown by gender, race or ethnicity in this first analysis.
- There will be a later release of a second data set and analysis, including 2006 data, at the end of 2008 or later.
- Data from 2007 and trends analysis are slated for release in 2009.
- The CDC will not be able to draw any conclusions about whether incidence is going up or down, and in which populations, until after at least three years' worth of the new incidence data are available in 2009.
  - Until then, we cannot say whether the new, higher incidence estimate is merely a result of more sophisticated estimating methods or a sign of climbing rates of transmission (or possibly both).

### **III. Talking Points on the Context of HIV Incidence in the United States**

#### **The HIV epidemic in the U.S. is even worse than previously thought.**

- The estimates clearly support one sobering and alarming conclusion: more aggressive efforts based in evidence must be undertaken immediately to slow HIV transmissions in the U.S.

#### **Health disparities persist in populations disproportionately affected by HIV/AIDS.**

- As early as 15 years ago, the numbers showed an epidemic growing steadily among African-Americans and Latinos through unprotected sexual contact and syringe sharing.
- Lacking urgency, national efforts have failed tragically to make any measurable difference halting the force of these inequitable trends.
  - Today, 70% of all people known to be living with HIV/AIDS in the U.S. are people of color.
  - Infections among young African American men increased by 80% from 2001-2005.
  - The proportion of HIV/AIDS that is among women (predominately black and Latina) grew from 11% to 25% between 1990 and 2005.
  - Gay, bisexual, and other men who have sex with men — of all races and ethnicities — continue to comprise the single largest group affected by HIV/AIDS, with no abatement in sight.
- Immediate action and resolve is needed to dramatically expand the availability of

science-based interventions in order to come up with innovative, more effective ways to lower new infections. Without a truly "heightened national response" that addresses the socio-economic conditions that fuel HIV transmission, the disparities will only continue to widen.

**Failed federal public health policies are complicit in allowing high rates of HIV transmission to rise and persist in the U.S. Quite simply, failure to invest in proven interventions has allowed HIV rates to increase.**

- Not only has the federal government failed to make HIV prevention a priority but ideological agendas have prevented scarce federal funds from supporting proven strategies such as needle exchange, comprehensive sex education, condom promotion, and sexually explicit and age-appropriate messages especially for youth and gay men of all race/ethnic backgrounds and age groups.
- A scale-up in HIV prevention investment must be accompanied by a commitment to the strategies best positioned to achieve specific, measurable goals.

**Pitting prevention against other areas of the AIDS response, such as treatment and care, will further harm our efforts.**

- Effective efforts to stem the epidemic require a coordination and integration of efforts, rather than creating "silos" of services forced to compete with each other for scarce funding.
- HIV prevention, treatment and care services overlap and complement each other. For example, ensuring that HIV-positive people receive safe, affordable housing helps them adhere to their treatment regimes, receive nutritious foods and adequate rest, and lower their viral load, which decrease the chance of HIV transmission, and can help them connect to prevention services.

**Urgency is needed at the highest level to invest in HIV prevention strategies.**

- CDC's own 2001 HIV Prevention Strategic Plan, which set the important goal of reducing new HIV infections to a level of 20,000 per year by 2005 (a 50 % reduction), quietly expired two years ago with scarcely any progress. The CDC recently extended the 2001 plan but lowered the goal, seeking now to reduce new infections by 10 % by 2010 — a goal ostensibly resigned to infection rates 35% higher than 2001, at best.
- Even this un-ambitious goal will be difficult to achieve under the weight of another \$1 million funding cut slated for HIV prevention in President Bush's FY09 budget and a decade of divestment in behavioral interventions and surveillance.

**The U.S. must develop a comprehensive and measurable national AIDS strategy.**

- The U.S. requires other countries to develop national AIDS plans as a condition to receive AIDS relief funding — a standard our own nation ignores. It's time the U.S. took an outcomes-based approach to HIV/AIDS and developed a single and

comprehensive plan to address the domestic epidemic.

- Developed with community stakeholder involvement, the plan should include measurable goals, objectives, and accountability mechanisms. In fact, Congress and the American people should demand annual progress reports on efforts to implement the plan, which must include provisions to decrease annual HIV infections.
- More information on the call for a National AIDS Strategy is available at [www.nationalaidsstrategy.org](http://www.nationalaidsstrategy.org).

### **The new HIV incidence data will likely have ripple effects.**

- New incidence data call into question other data assumptions such as HIV prevalence figures (the estimated number of people living with HIV/AIDS in the U.S.) The most recent figures for the end of 2003, estimate between 1 million and 1.2 million people are living with HIV/AIDS in the U.S.
- Researchers may need to re-evaluate these estimates as well as the number of HIV-positive people not in HIV medical care and those who do not know their HIV status.

***HHSWatch**, a watchdog newsletter from CHAMP, monitors and reports on activities related to HIV prevention at Health and Human Services agencies, including CDC, NIH, HRSA and SAMHSA.*

*HHSWatch is a resource for community members, policy advocates, researchers and anyone interested in more fully understanding and tracking the committees, panels and administrators whose recommendations and decisions affect our work.*

*HHSWatch is committed to providing an outlet for those concerned about infringements upon science-based HIV prevention and treatment, and will respect your wishes for confidentiality. If you are interested in contributing information or suggesting a story, please contact [champ@champnetwork.org](mailto:champ@champnetwork.org).*



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