



July 18, 2008

The Worst Kept Non-Secret in Public Health

by David Ernesto Munar

Since the fall of last year, rumors have been circulating that the Centers for Disease Control and Prevention (CDC) will release revised statistics indicating that the number of people living with HIV in the United States is actually higher than previously reported. Some say the number could be as much as 50 percent higher. But, nearly three-quarters of a year later, there is still no indication of when we might see a new report documenting the likely number of HIV infections occurring each year in America. David Ernesto Munar, a vice president at the AIDS Foundation of Chicago and chairman of the board of the National Association of People with AIDS, writes the following piece in response to the CDC's continued silence on the matter.

For more than a year, U.S. federal officials have attempted—sometimes in vain—to quell rumors that the number of new HIV infections in the United States is on the rise. The Washington Blade first broke the story in November 2007, reporting that the CDC was poised to raise the official estimate for the number of HIV infections believed to occur in the United States to a range as high as 58,000 to 63,000 per year—a greater than 50 percent increase over the current estimate of 40,000 annual HIV infections.

By December 2007, World AIDS Day media coverage in The New York Times, The Washington Post, Bloomberg News, The Associated Press and other outlets amplified the leaks. They also described growing frustration among AIDS community advocates with delays in making the important research findings public.

Under community and media pressure, CDC officials conducted a hastily organized briefing in December at the 2007 National HIV Prevention Conference held in Atlanta. Dr. Kevin Fenton, chief of the CDC's HIV, STD and TB prevention branch, and Dr. Robert Janssen, then-chief for HIV prevention, said the research findings had yet to be independently validated and would be published in a scientific journal in early 2008.

According to Fenton and Janssen, the first data release would not include detailed analysis of infection rates for different at-risk populations or regions of the country.

In fact, CDC officials cautioned against even describing the new findings as evidence of an actual increase in transmission rates, noting that a new, more sensitive screening tool and refined methodology were likely able to measure longstanding trends in the epidemic with greater accuracy.

The new technology, called a “detuned assay,” has allowed a select number of funded jurisdictions to determine whether people testing HIV positive acquired HIV recently or long ago. Data on cases determined to have occurred recently form the basis for the CDC’s new methodology to estimate national HIV incidence.

Accordingly, the revised estimate will only reflect data analyzed for 2006, CDC officials said. Future comparisons against 2007 and 2008 data on detuned cases would eventually show the extent to which behavioral trends drive annual infections rates up or down. According to the CDC, such comparisons cannot be made until at least 2010 or later—long after the current administration is out of office.

Given the significance of such data on HIV prevention legislation and appropriations, some AIDS community advocates have sharply criticized delays in publicizing the research findings.

We may never know whether this delay is due to legitimate scientific concerns, deliberate suppression or both. But with every month of delay, the CDC is missing opportunities to sound a much-needed alarm to those who have allowed inadequate funding and ill-advised policy to perpetuate high rates of HIV transmission.

At the 2007 National HIV Prevention Conference, participants noted that CDC officials had hoped to release results at their previous biannual summit in 2005. Others speculated openly whether government officials were delaying a release of the data in a deliberate attempt to shield the Bush administration from criticism for its failure to prioritize HIV prevention. While widely discounted by CDC officials and prominent HIV researchers, such speculations have gained traction as news emerged this summer that Vice President Dick Cheney’s staff had censored portions of CDC director Julie Gerberding’s congressional testimony to deliberately downplay the health threats posed by global warming.

Conspiracy rumors were further fueled by an undeniable record of underfunding. A recent analysis by Johns Hopkins University shows that, adjusted for inflation, the buying power of the CDC’s domestic HIV prevention budget declined 19 percent between fiscal 2002 and 2007. Still, President George W. Bush’s budget request to Congress for fiscal 2009 seeks a \$1 million reduction for domestic HIV prevention activities at the CDC.

Despite official delays, glimpses of the new data have surfaced nonetheless from apparent (or calculated) missteps by government officials themselves. In June, Dr.

Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases, told U.N. members assembled in New York City for a “high level meeting on AIDS” that new measuring methods showed that HIV infections in the United States are more common than previously estimated. Fauci, the government’s highest ranking HIV researcher, said the adjustment raises HIV rates by at least 25 percent to an estimated 50,000 infections per year. The following day, his office retracted the statement and said his remarks had been misquoted.

In another apparent misstep, the journal *Statistics in Medicine* mistakenly posted on its website a CDC-authored scientific paper describing the statistical methodology used to calculate the new estimate. The article, “Estimating HIV Incidence in the United States,” was subsequently removed from the site in mid-June, pending publication.

“Perhaps most troubling with the CDC’s protracted stalling and foot-dragging is how non-shocking the eventual release will be,” said Julie Davids, executive director of the Community HIV/AIDS Mobilization Project (CHAMP). “Anyone paying attention whatsoever to HIV in the U.S. knows that the epidemic is far from diminished. In fact, we’ve known it is rising in distinct populations. Lacking adequate resources and leadership, this crisis has been allowed to become bigger than we ever imagined.”