

Estimating Unmet Need for HIV-Related Primary Medical Care: Summary of Findings from FY 2006 Ryan White Title I and II Applications

Scope: This document provides a brief overview of the estimates of unmet need provided by Title I and Title II grantees in their funding applications for FY 2006, and brief comparisons with the FY 2005 data.

Review and analysis: Mosaica: The Center for Nonprofit Development and Pluralism reviewed and analyzed the FY 2006 Title I and Title II estimates. This document compares estimates from FY 2006 with estimates from FY 2005.

Definition of Unmet Need: The Unmet Need Framework used to make these estimates defines a person living with HIV or AIDS and aware of his/her condition as having unmet need for HIV-related primary medical care if s/he has not received any of the following within a specified 12-month period: a CD4 count, a viral load test, and/or provision of anti-retroviral therapy (ART).

Population with HIV and AIDS: In the FY 2006 application, Title II grantees estimated that **764,988** people diagnosed with HIV and AIDS lived in the United States, including the States, the District of Columbia, Puerto Rico, and the territories. Title I programs estimated that **594,342** people diagnosed with HIV and AIDS lived in the 51 Eligible Metropolitan Areas (EMAs). Most but not all grantees based their population estimates on surveillance data as of the end of 2004 or 2005*.

Comparison with CDC data: The Title II estimates are similar to rough CDC estimates, which suggest that at least 750,000 people were HIV-positive and aware of their status at the end of 2003. Assuming a net increase of about 15,000 diagnosed cases in 2004 (40,000 new cases, 76% aware, minus 15,000 deaths), the total HIV-positive/aware population was **765,000** at the end of 2004.†

Unmet need estimates: Table 1 summarizes key findings on unmet need. Data are provided separately by Title; the Title II estimates cover the entire country.

Table 1

Unmet Need Estimates	Title I	Title II
Range of unmet need estimates:		
HIV and AIDS	16% - 71%	9% - 87%
HIV/non-AIDS-aware	12% - 80%	14% - 85%
AIDS	9% - 60%	0% - 75%
Median estimate of unmet need:		
HIV and AIDS	36%	43%
HIV/non-AIDS-aware	42%	52%
AIDS	29%	38%
Aggregate estimate of unmet need (percent and number):		
HIV and AIDS	37% (220,666)	43% (325,228)
HIV/non-AIDS-aware	47% (135,475)	52% (185,706)
AIDS	27% (79,934)	33% (128,354)

The data include:

- **Range:** The first segment of Table 1 provides the *range* of grantee estimates of unmet need, first for people with HIV and AIDS together and then for HIV/non-AIDS-aware and for AIDS separately.
- **Median:** The second segment provides the *median* estimates of unmet need for each category.
- **Aggregate:** The third segment provides an *aggregate* estimate of unmet need. It adds together the estimated number of people out of care in each of the three categories, and provides a combined calculation of unmet need based on the reported population of people with HIV and AIDS. This aggregation provides an extremely rough national estimate of unmet need as reported by all Title I and all Title II grantees. The 43% total estimate for HIV/AIDS is well above the CDC estimate of about one-third of HIV-positive/aware individuals out of care.

The median and aggregated estimates of unmet need are very similar. The range of unmet need estimates is, however, extremely large. Most of the very high or very low estimates come from jurisdictions that encountered significant methodological problems with their unmet need estimates, had estimates that reflected the jurisdiction's very low or very high HIV/AIDS incidence, or the estimate did not adequately consider people in private care.

The findings from FY 2005 identified four major trends. The same trends were found in the unmet need estimates from FY 2006, which are:

- People who have HIV/non-AIDS appear more likely to be out of care than people with AIDS. The unmet need estimate for persons with HIV/non-AIDS is approximately 20% higher than the estimate for people with AIDS.
- Reported unmet need rates are approximately 15% higher in States as a whole than in EMAs – overall, Title II grantees reported higher unmet need than Title I grantees.
- Estimates of the percentage of people with AIDS who are out of care are most often in the high 20s or low 30s, while estimates of the percentage of people with HIV/non-AIDS who are out of care are most often in the high 40s or low 50s.
- Some jurisdictions using sound estimation methods reported levels of unmet need that are higher or lower than these medians or averages. Levels of unmet need are likely to vary considerably across States and EMAs.

Limitations: These findings should be viewed as very rough estimates of unmet need. For most grantees, they represent the second unmet need estimates. Many grantees used methods that need some refinement or were unable to obtain access to some needed data sources (especially data on people receiving care from private physicians paid for with private insurance). In addition, grantees used different methodologies and different time periods for their estimates. Therefore, data aggregated across jurisdictions to provide national unmet need estimates are extremely rough estimates. Estimates of the population living with AIDS typically came from the CDC's HIV/AIDS Reporting System (HARS). Combining these estimates for this review is less problematic, although some grantees did adjust the data, and some grantees used a time period other than 2004. Estimates of the population living with HIV/non-AIDS are more problematic, since many States do not yet have reliable prevalence estimates of HIV/non-AIDS/aware.

Fourteen States now require full laboratory reporting of all CD4 counts and viral load tests, although some have not fully implemented these requirements. Such States were or will be able to use HARS laboratory reports for their care patterns data, obtaining information on people in both public and private care. Estimates of care patterns most often came from linked databases (most often data from Medicaid and/or the AIDS Drug Assistance Program, sometimes combined with Ryan White client data and incomplete HARS laboratory data). Combining these estimates is

somewhat problematic because of the different reporting measures used by each source and data from each source needs to be unduplicated to avoid double-counting clients. Some grantees did adjust these data, often using special studies or existing databases, and some used a time period other than 2004.

Cross-title collaboration: The HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA) encouraged but did not require cross-title collaboration in estimating unmet need. Almost all of the Title I grantees (48) and just over half of the Title II grantees (28) mentioned cross-title collaboration in the unmet need section of their FY 2006 application.

Comparison of FY 2005 and FY 2006 estimates: Table 2 compares findings from the FY 2005 unmet need estimates and FY 2006 estimates. This comparison should be viewed as a very rough analysis of the unmet need estimate over the course of one year. Many grantees are still refining their methodology and addressing the limitations described earlier. A comparison of FY 2005 and FY 2006 unmet need estimates revealed the following:

- **Population size.** The Title I population size estimate increased by 41,396 in 2006. The population size for Title II decreased by 16,601 persons.
- **Unmet need estimate.** For both Title I and Title II grantees the *range*, *median*, and *average* unmet need estimate for persons living with AIDS decreased in 2006. For both Title I and Title II grantees, the unmet need *range* among persons living with HIV decreased in 2006, although the *median* and *average* estimates of unmet need increased. The range of unmet need estimates for both Title I and Title II grantees was extremely wide both years.
- **Inferences.** The four major trends identified in 2005 held true in 2006 despite changes in population size and variations in grantee methodology.

Table 2

Unmet Need Estimates	Title I		Title II	
	2005	2006	2005	2006
Range of unmet need estimates:				
HIV and AIDS	11% - 89%	16% - 71%	11% - 83%	9% - 87%
HIV/non-AIDS-aware	12% - 90%	12% - 80%	0% - 89%	14% - 85%
AIDS	0% - 88%	9% - 60%	1% - 75%	0% - 75%
Median estimate of unmet need:				
HIV and AIDS	40%	36%	41%	43%
HIV/non-AIDS-aware	49%	42%	51%	52%
AIDS	34%	29%	37%	38%
Aggregate estimate of unmet need (percent and number):				
HIV and AIDS	38% (209,306)	37% (220,666)	44% (340,817)	43% (325,228)
HIV/non-AIDS-aware	44% (116,442)	47% (135,475)	55% (205,303)	52% (185,706)
AIDS	32% (92,864)	27% (79,934)	33% (135,514)	33% (128,354)

* Note: One State provided no estimates. Two States did not separate estimates for HIV/non-AIDS and AIDS, and two States did not provide an estimate for HIV/non-AIDS. Two EMAs provided incomplete unmet need estimates.

† Source: Presentation by Matthew T. McKenna, Chief, HIV Incidence and Case Surveillance, March 8, 2006. A more precise calculation can be made from the CDC estimate that 1,039,000 – 1,185,000 people were living with HIV and AIDS at the end of 2003, and that 73-76% (midpoint 74.5%) were aware of their status. The midpoint value of the range is 1,112,000, with about 828,120 aware of their status. Assuming a net increase in the living HIV/AIDS population of about 14,800 in 2004 (40,000 new infections, 74.5% aware, minus 15,000 deaths), there were about **843,240** PLWH/A in the U.S. at the end of 2004.