

September 2009

# HIV/AIDS

## Federal and State Efforts to Identify Infected Individuals and Connect Them to Care



GAO

Accountability \* Integrity \* Reliability



Highlights of [GAO-09-985](#), a report to congressional requesters

## Why GAO Did This Study

Of the estimated 1.1 million Americans living with HIV, not all are aware of their HIV-positive status. Timely testing of HIV-positive individuals is important to improve health outcomes and to slow the disease's transmission. It is also important that individuals have access to HIV care after being diagnosed, but not all diagnosed individuals are receiving such care.

The Centers for Disease Control and Prevention (CDC) provides grants to state and local health departments for HIV prevention and collects data on HIV. In 2006, CDC recommended routine HIV testing for all individuals ages 13-64. The Health Resources and Services Administration (HRSA) provides grants to states and localities for HIV care and services.

GAO was asked to examine issues related to identifying individuals with HIV and connecting them to care. This report examines: 1) CDC and HRSA's coordination on HIV activities and steps they have taken to encourage routine HIV testing; 2) implementation of routine HIV testing by select state and local health departments; 3) available information on CDC funding for HIV testing; and 4) available data on the number of HIV-positive individuals not receiving care for HIV. GAO reviewed reports and agency documents and analyzed CDC, HRSA, and national survey data. GAO interviewed federal officials, officials from nine state and five local health departments chosen by geographic location and number of HIV cases, and others knowledgeable about HIV.

[View GAO-09-985 or key components.](#)  
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## HIV/AIDS

### Federal and State Efforts to Identify Infected Individuals and Connect Them to Care

#### What GAO Found

The Secretary of Health and Human Services (HHS) is required to ensure that HHS agencies, including CDC and HRSA, coordinate HIV programs to enhance the continuity of prevention and care services. CDC and HRSA have coordinated to assist health care professionals who provide HIV-related services. For example, in 2007 and 2008, CDC provided funding to HRSA to expand consultation services at the National HIV/AIDS Clinicians' Consultation Center. Both CDC and HRSA have taken steps to encourage routine HIV testing—that is, testing all individuals in a health care setting without regard to risk. For example, CDC has funded initiatives on routine HIV testing and HRSA has provided for training as part of these initiatives.

Officials from over half of the 14 selected state and local health departments in GAO's review reported implementing routine HIV testing in their jurisdictions. However, according to officials we interviewed, those that implemented it generally did so at a limited number of sites. Officials from most of the selected health departments and other sources knowledgeable about HIV have identified barriers that exist to implementing routine HIV testing, including lack of funding and legal barriers.

CDC officials estimated that approximately 30 percent of the agency's annual HIV prevention funding is spent on HIV testing. For example, according to CDC officials, in fiscal 2008, this would make the total amount spent on HIV testing about \$200 million out of the \$652.8 million CDC allocated for domestic HIV prevention to its Division of HIV/AIDS Prevention. However, CDC officials said that they could not provide the exact amount the Division spends on HIV testing, because they do not routinely aggregate how much all grantees spend on a given activity, including HIV testing.

CDC estimated that 232,700 individuals with HIV were undiagnosed—that is, unaware that they were HIV positive—in 2006, and were therefore not receiving care for HIV. CDC has not estimated the total number of diagnosed HIV-positive individuals not receiving care, but has estimated that 32.4 percent, or approximately 12,000, of HIV-positive individuals diagnosed in 2003 did not receive care for HIV within a year of diagnosis. State-level estimates of the number of undiagnosed and diagnosed HIV-positive individuals not receiving care for HIV are not available from CDC. HRSA collects states' estimates of the number of diagnosed individuals not receiving care, but data are not consistently collected or reported by states, and therefore estimates are not available for comparison across all states.

HHS provided technical comments on a draft of this report, which GAO incorporated as appropriate.

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**Abbreviations**

AETC	AIDS Education and Training Centers
AIDS	acquired immunodeficiency syndrome
CARE Act	Ryan White Comprehensive AIDS Resources Emergency Act of 1990
CDC	Centers for Disease Control and Prevention
HAART	highly active antiretroviral therapy
HHS	Department of Health and Human Services
HIV	human immunodeficiency virus
HMO	health maintenance organization
HRSA	Health Resources and Services Administration
NASTAD	National Alliance of State and Territorial AIDS Directors
NHIS	National Health Interview Survey
STD	sexually transmitted disease

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United States Government Accountability Office  
Washington, DC 20548

September 23, 2009

The Honorable Michael B. Enzi  
Ranking Member  
Committee on Health, Education, Labor, and Pensions  
United States Senate

The Honorable Richard Burr  
United States Senate

The Honorable Tom A. Coburn  
United States Senate

The Honorable Lisa Murkowski  
United States Senate

It has been more than 28 years since the first cases of acquired immunodeficiency syndrome (AIDS) in the United States were reported in June 1981. Since that time, approximately 1.7 million Americans have been infected with human immunodeficiency virus (HIV), including more than 580,000 who have died.<sup>1</sup> The most recent data available from the Department of Health and Human Services' (HHS) Centers for Disease Control and Prevention (CDC) estimates that there were 1.1 million people living with HIV in the United States at the end of 2006, and that 56,300 new HIV infections occurred that year.<sup>2</sup>

Not all of those living with HIV are aware of their HIV-positive status. Timely testing of individuals who are HIV positive but have not yet been diagnosed is important both in improving health outcomes for those individuals and in slowing transmission of the disease. Research has shown that the earlier individuals are treated for HIV the better their prognosis becomes. In addition, many individuals who know that they are HIV positive adopt behaviors that reduce their risk of spreading the

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<sup>1</sup>HIV is the virus that causes AIDS. In this report, except where noted, we use the term HIV to refer to HIV disease, inclusive of cases that have and have not progressed to AIDS. When we use the term AIDS alone it refers exclusively to HIV disease that has progressed to AIDS.

<sup>2</sup>CDC estimates HIV case counts based on information it receives from states, the District of Columbia, and the U.S. territories and associated jurisdictions.

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disease, while those who are unaware of their status are more likely to pass HIV on to others. According to CDC, it has been estimated that the majority of new HIV infections are transmitted from individuals who are unaware of their status.

Testing for HIV can occur in health care settings,<sup>3</sup> such as public health clinics, private doctors' offices, health maintenance organizations (HMO), and emergency rooms, or in non-health care settings, such as community-based organizations.<sup>4</sup> According to data from the 2007 National Health Interview Survey (NHIS), less than 40 percent of adults in the United States reported having ever been tested for HIV.<sup>5</sup> Further, CDC estimates that in 2006, 36 percent of those who were diagnosed with HIV were not tested until late in the course of their disease, meaning that they were diagnosed with AIDS within 1 year of receiving an HIV-positive result. A number of studies have shown that late testing can occur after HIV-positive individuals have made numerous visits to health care settings, indicating missed opportunities to test for HIV.

HIV testing is the first step to connecting HIV-positive individuals to the care that they need. Connecting HIV-positive individuals to care can occur through, for example, assistance in scheduling appointments and by providing transportation to and from appointments. It is also important to ensure that individuals have access to and remain in care after they have been diagnosed. New advances in HIV treatments have reduced mortality rates and have the potential to extend the lives of individuals diagnosed with HIV. However, not all diagnosed HIV-positive individuals are accessing care options.

CDC provides funding to state and local health departments for HIV prevention, including counseling, testing, and referral services, through

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<sup>3</sup>For the purposes of this report, we use the term setting to refer to a type of facility, for example, emergency rooms. Settings can include multiple sites. We use the term site to refer to an individual facility, for example, a specific hospital's emergency room.

<sup>4</sup>Community-based organizations are organizations that provide social services at the local level.

<sup>5</sup>NHIS, which has been conducted since 1957, collects information on a broad range of health topics through personal household interviews. Information on HIV testing has been included in the NHIS since 1997. The survey is one of the major data collection programs of the National Center for Health Statistics, which is part of CDC.

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cooperative agreements, grants, and contracts.<sup>6</sup> CDC also provides funding to community-based organizations and a smaller amount to national professional organizations such as the National Medical Association. In addition to providing funding, CDC conducts research, surveillance, and epidemiologic studies on HIV.<sup>7</sup> CDC has also issued a series of recommendations related to HIV testing in health care settings, the most recent of which were released in 2006.<sup>8</sup> A major component of the 2006 recommendations is for all health care settings to test all individuals for HIV without regard to risk—a practice called routine HIV testing.<sup>9</sup> This represents a significant change from prior CDC guidance, which generally recommended that health care settings target testing to groups at high risk of contracting HIV or to high-prevalence areas.<sup>10</sup> Additionally, CDC has identified the requirement for separate written informed consent or pretest counseling as barriers to routine HIV testing.<sup>11</sup> While the 2006 recommendations suggest these practices not be required for HIV testing, there is some disagreement over whether this would take away important protections. States and localities are not required to adopt CDC's recommendations, and state HIV testing laws vary. For example, according

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<sup>6</sup>A cooperative agreement is a mechanism used to provide financial support when substantial interaction is expected between a federal agency and a state, local government, or other funded entity. In this report, except where noted, we use the term state to include all 50 states, the District of Columbia, and the U.S. territories and associated jurisdictions.

<sup>7</sup>Surveillance is an ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event. CDC's HIV surveillance system observes, records, and disseminates reports about cases of HIV and AIDS.

<sup>8</sup>CDC has also issued HIV testing recommendations for non-health care settings, such as community-based organizations. CDC is currently working on revising these recommendations, which were last updated in 2001. For more information on the 2001 recommendations, see CDC, "Revised guidelines for HIV counseling, testing, and referral," *Morbidity and Mortality Weekly Report*, Vol. 50, No. RR-19 (2001).

<sup>9</sup>These CDC recommendations apply to adults and adolescents ages 13-64 and specify that routine HIV testing should be done on an opt-out basis. Opt-out testing is a type of routine testing where a patient is notified that testing will be performed unless the patient elects to decline testing and consent is inferred unless the patient declines.

<sup>10</sup>CDC defines high prevalence of HIV as greater than 1 percent. However, CDC now recommends conducting routine HIV testing unless the prevalence of undiagnosed HIV infection has been shown to be less than 0.1 percent.

<sup>11</sup>According to CDC, informed consent is a process of communication between a patient and a health care provider through which an informed patient can choose whether to undergo HIV testing or decline to do so. CDC defines counseling as a process of assessing risk, recognizing specific behaviors that increase the risk of acquiring or transmitting HIV, and developing a plan to reduce risks.

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to a study on state HIV testing laws, some states' laws require separate written informed consent for HIV testing and others do not.<sup>12</sup>

While CDC is the federal agency primarily responsible for HIV prevention, HHS' Health Resources and Services Administration (HRSA) is the agency responsible for administering grant programs authorized by the Ryan White Comprehensive AIDS Resources Emergency Act of 1990 (CARE Act) and subsequent legislation that provide funding to states, localities, and others for HIV-related services. The CARE Act was enacted to address the needs of jurisdictions, health care providers, and people with HIV and their family members.<sup>13</sup> Each year, assistance to over 530,000 mostly low-income, underinsured, or uninsured individuals living with HIV is provided through CARE Act programs. The 2006 reauthorization of CARE Act programs, like the 2000 reauthorization, required states to submit an estimate of the size and demographics of the population with HIV within the state and a determination of those who have HIV but are not receiving HIV-related services. HRSA characterizes this as an unmet need estimate, that is, the number of individuals in a state who know their HIV-positive status but who are not receiving care for HIV.<sup>14</sup> In addition to administering CARE Act programs, HRSA provides training to health care providers and community service workers who work with people with HIV and evaluates best-practice models of health care delivery.

Given their respective roles in funding HIV prevention and care, CDC and HRSA have coordinated on HIV activities in the past. Additionally, the CARE Act requires the Secretary of HHS to ensure that HHS agencies, including CDC and HRSA, coordinate HIV programs to enhance the

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<sup>12</sup>For more information on this study see, A. Mahajan, et al., "Consistency of State Statutes with the Centers for Disease Control and Prevention HIV Testing Recommendations for Health Care Settings," *Annals of Internal Medicine*, Vol. 150, No. 4 (2009). In addition, the National HIV/AIDS Clinicians' Consultation Center continuously revises and releases an online Compendium of State HIV Testing Laws. See <http://www.nccc.ucsf.edu/StateLaws/Index.html>.

<sup>13</sup>Pub. L. No. 101-381, 104 Stat. 576 (codified as amended at 42 U.S.C. §§ 300ff through 300ff-121). The 1990 CARE Act added title XXVI to the Public Health Service Act. Unless otherwise indicated, references to the CARE Act are to the current title XXVI.

<sup>14</sup>Pub. L. No. 106-345, § 205(a)(2), 114 Stat. 1319, 1332 (codified at 42 U.S.C. § 300ff-27(b)(2)-(3)(A)).

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continuity of prevention and care services for individuals with HIV or those at risk of the disease.<sup>15</sup>

As Congress prepares to reauthorize CARE Act programs, you asked us to examine various issues related to identifying and caring for individuals with HIV. In this report, we examine: (1) the actions taken by CDC and HRSA since 2006 to coordinate on HIV-related activities, and steps the agencies have taken to encourage implementation of routine HIV testing; (2) the extent to which select state and local health departments have implemented routine HIV testing in their jurisdictions and what barriers exist to its implementation; (3) available information on how much of CDC's HIV prevention funding is spent on HIV testing;<sup>16</sup> (4) national data on the types of settings where HIV tests are conducted and the types of settings where HIV-positive results occur; (5) available data on national and state estimates of the number of undiagnosed and diagnosed HIV-positive individuals who are not receiving care for HIV; and (6) what barriers exist to care for HIV and what initiatives are being implemented to connect diagnosed HIV-positive individuals to such care. In this report, we also provide information on transitioning prisoners with HIV to care upon their release. This information is provided in appendix I.<sup>17</sup>

To examine the actions taken by CDC and HRSA to coordinate on HIV-related activities, and steps the agencies have taken to encourage implementation of routine HIV testing, we reviewed reports that describe programs administered by the two agencies. We also reviewed meeting minutes from the CDC/HRSA Advisory Committee on HIV and Sexually Transmitted Diseases (STD) Prevention to identify HIV activities coordinated by CDC and HRSA. In addition, we interviewed officials at CDC and HRSA as well as a judgmental sample of officials from 14 state

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<sup>15</sup>See 42 U.S.C. § 300ff-81.

<sup>16</sup>Federal funding for HIV testing can come from sources other than HIV prevention funding, such as Medicaid reimbursement. Medicaid is a joint federal-state health care financing program for certain categories of low-income individuals. However, for this report, we focus exclusively on how much of CDC's HIV prevention funding is spent on testing. We focus on CDC because the agency spent more than 85 percent of the nearly \$900 million that the federal government spent on domestic HIV prevention in fiscal year 2008.

<sup>17</sup>For additional information on the implementation of the CARE Act see GAO, *Ryan White CARE Act: Effects of Certain Funding Provisions on Grant Awards*, [GAO-09-894](#) (Washington, D.C.: Sept. 18, 2009).

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and local health departments knowledgeable about these topics.<sup>18</sup> We selected health departments based on their geographic location and the number of HIV cases in their jurisdiction. Our sample is not generalizable to all state and local health departments.

To examine the extent to which select state and local health departments have implemented routine HIV testing in their jurisdictions and what barriers exist to its implementation, we interviewed our sample of officials from state and local health departments as well as officials from the Henry J. Kaiser Family Foundation, the National Alliance of State and Territorial AIDS Directors (NASTAD), and other organizations that work on HIV-related issues, including an organization that contracts with state and local health departments to coordinate HIV-related issues and an association for HIV providers. We also reviewed medical journal articles and reports by the Henry J. Kaiser Family Foundation and NASTAD on the implementation of routine testing. We did not conduct a state-by-state review of all laws related to HIV testing or independently verify information related to state laws.

To examine available information on how much of CDC's HIV prevention funding is spent on HIV testing, we reviewed CDC budget information and interviewed officials at CDC.

To examine national data on the types of settings where HIV tests are conducted, we examined NHIS data from 2007 on the number of HIV tests conducted by setting type. We performed data reliability checks by testing for missing data and outliers and compared our results to published data on this topic and determined that these data were sufficiently reliable for our purposes. To examine available data on the types of settings where HIV-positive results occur, we obtained and reviewed 2007 CDC surveillance data on the number of HIV-positive results by facility of diagnosis. We reviewed related documentation and interviewed agency officials and determined these data were sufficiently reliable for our purposes.

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<sup>18</sup>We interviewed officials from nine state health departments and five local health departments. We interviewed officials from the following state health departments: California, Florida, Hawaii, Indiana, Missouri, North Carolina, Pennsylvania, Rhode Island, and Washington. We interviewed officials from the following local health departments: Harris County, Tex.; Maricopa County, Ariz.; Memphis, Tenn.; New York, N.Y.; and Sacramento County, Calif.

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To examine available data on national and state estimates of the number of undiagnosed and diagnosed HIV-positive individuals who are not receiving care for HIV, we reviewed CDC surveillance data and the unmet need estimates reported by CARE Act grantees to HRSA. We also obtained and reviewed information from CDC and HRSA on how these estimates are calculated. We reviewed related documentation and interviewed agency officials to determine if national- and state-level data were reliable for our purposes. We determined that national data on undiagnosed HIV-positive individuals not receiving care were sufficiently reliable for our purposes. We also determined that national data on the number of diagnosed HIV-positive individuals not receiving care were reliable, but not comprehensive. Finally, we determined that state-level data on the number of diagnosed HIV-positive individuals not receiving care are not consistently collected or reported across states, and therefore were not reliable for our purposes.

To examine what barriers exist to care for HIV and what initiatives are being implemented to connect diagnosed HIV-positive individuals to such care, we interviewed officials at CDC and HRSA and our sample of officials from state and local health departments.

We conducted this performance audit from April 2009 through September 2009 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

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## Background

According to 2007 NHIS data, fewer than 40 percent of adults in the United States reported ever having been tested for HIV. In a recent survey by the Henry J. Kaiser Family Foundation, the primary reason people gave for not being tested is that they do not think they are at risk.<sup>19</sup> The second most common reason was that their doctor never recommended HIV testing. While 38 percent of adults said that they had talked to their doctor about HIV, only 17 percent said that their doctor had suggested an HIV test. According to this survey, African Americans and Latinos were more likely

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<sup>19</sup>The Henry J. Kaiser Family Foundation, *Survey Brief: Views and Experiences with HIV Testing in the U.S.* (Menlo Park, CA: June 2009).

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than adults overall to have had such a conversation with their doctor and for the doctor to have suggested testing. Sixty-seven percent of African Americans and 45 percent of Latinos said that they had talked to their doctor about HIV and 29 percent of African Americans and 28 percent of Latinos said that their doctor had suggested an HIV test.

Technological advances have increased the benefits associated with HIV testing as well as with regular care and treatment for HIV. First, advances in testing methods, such as rapid HIV tests, have made testing more feasible in a variety of different settings and increased the likelihood that individuals will receive their results. Rapid tests differ from conventional HIV tests in that results are ready sometime from immediately after the test is performed to 20 minutes after the test is performed, which means that individuals can get tested and receive their results in the same visit.<sup>20</sup> Second, the advent of highly active antiretroviral therapy (HAART) has transformed HIV from a fatal disease to a treatable condition.<sup>21</sup> For example, a 25-year-old individual who is in care for HIV can expect to live only 12 years less than a 25-year-old individual who does not have HIV.

In addition, studies have found that people generally reduce risky behaviors once they learn of their HIV-positive status. According to one study, people who are unaware that they are HIV positive are 3.5 times more likely to transmit the disease to their partners than people who know their status.<sup>22</sup> At the same time, research has shown that individuals are often unaware of their status until late in the course of the disease despite visits to health care settings. For example, one study looked at HIV case reporting in a state over a 4-year period. The study found that of people who were diagnosed with HIV late in the course of the disease, 73 percent

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<sup>20</sup>Rapid tests also do not require any special equipment and thus can be performed outside of health care settings. Rapid test results require further testing to confirm a positive test result.

<sup>21</sup>HAART means any combination of three or more antiretroviral drugs. While HAART has greatly improved survival rates of individuals living with HIV, there is currently no cure for the disease.

<sup>22</sup>G. Marks, N. Crepaz, and R.S. Janssen, "Estimating Sexual Transmission of HIV from Persons Aware and Unaware that they are Infected with the Virus in the USA," *AIDS*, Vol. 20, No. 10 (2006).

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made at least one visit to a health care setting prior to their first reported positive HIV test, and the median number of prior visits was four.<sup>23</sup>

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## Funding for HIV Testing

Funding for HIV testing can come from insurance reimbursement by private insurers as well as Medicaid and Medicare, although these payers do not cover HIV testing under all circumstances.<sup>24</sup> Funding for HIV testing can also come from other government sources, such as CDC, CARE Act programs, or state and local funding. A study by CDC and the Henry J. Kaiser Family Foundation that looked at the insurance coverage of individuals at the time of their HIV diagnosis from 1994-2000 found that 22 percent were covered by Medicaid, 19 percent were covered by other public-sector programs, and 27 percent were uninsured.

The cost of an HIV test varies based on a number of factors, including the type of test performed, the test result, and the amount of counseling that is associated with the test. For example, from a payer's perspective, the costs of a rapid HIV test are higher for someone who is HIV positive than for someone who is not, primarily because rapid testing requires an initial rapid test and a confirmatory test when the result is positive with counseling conducted after both tests. Additionally, eliminating pretest counseling can lower the cost of HIV testing by about \$10, regardless of the type of test. According to the most recent data available from CDC, in 2006, the cost of an HIV test could range from \$10.16 to \$86.84 depending on these and other factors.

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## CDC HIV Testing Recommendations

CDC issued its first recommendations for HIV testing in health care settings in 1987. These recommendations focused on individuals engaged in high-risk behaviors and specifically recommended that people who were seeking treatment for STDs be tested for HIV on a routine basis. Throughout the 1990s and 2000s CDC updated these recommendations periodically to reflect new information about HIV. For example, in 2001, CDC modified its recommendations for pregnant women to emphasize that HIV testing should be a routine part of prenatal care and that the

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<sup>23</sup>CDC, "Missed Opportunities for Earlier Diagnosis of HIV Infection—South Carolina, 1997–2005," *Morbidity and Mortality Weekly Report*, Vol. 55, No. 47 (2006).

<sup>24</sup>Medicare is the federal health care financing program for elderly and certain disabled individuals. Medicaid is a joint federal-state health care financing program for certain categories of low-income individuals.

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testing process should be simplified to eliminate barriers to testing, such as requiring pretest counseling.<sup>25</sup> CDC's 2001 recommendations also recommended that HIV testing be conducted routinely in all health care settings with a high prevalence of HIV; in low-prevalence settings it was recommended that HIV testing be conducted based on an assessment of risk. In 2003, CDC introduced a new initiative called "Advancing HIV Prevention: New Strategies for a Changing Epidemic." The initiative had a number of strategies, including two that specifically applied to health care settings: (1) making HIV testing a routine part of medical care; and (2) further reducing perinatal transmission of HIV by universally testing all pregnant women and by using HIV rapid tests during labor and delivery or postpartum if the mother had not been tested previously.

Elements of the Advancing HIV Prevention initiative were incorporated into CDC's revised HIV testing recommendations for health care settings in 2006.<sup>26</sup> The 2006 recommendations represent a major shift from prior recommendations for health care settings in that they no longer base HIV testing guidelines on risk factors. Rather, they recommend that routine HIV testing be conducted for all patients ages 13 through 64 in all health care settings on an opt-out basis.<sup>27</sup> CDC also recommends that persons at high risk of HIV be tested annually; that general consent for medical care encompass consent for HIV testing (i.e., separate written consent is not necessary); and that pretest information, but not pretest counseling be required.<sup>28</sup>

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## CDC HIV and AIDS Surveillance

According to CDC, tracking the prevalence of HIV is necessary to help prevent the spread of the disease. CDC's surveillance system consists of case counts submitted by states on the number of HIV and AIDS

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<sup>25</sup> According to CDC, many health care providers have since adopted these recommendations leading to increased prenatal screening and a 95 percent decline in perinatally acquired AIDS cases.

<sup>26</sup> CDC, "Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings," *Morbidity and Mortality Weekly Report*, Vol. 55, No. RR-14 (September 2006). In this report we refer to these recommendations as CDC's 2006 routine HIV testing recommendations.

<sup>27</sup> CDC specified that if routine testing yields a prevalence of undiagnosed HIV infection of less than 0.1 percent in a health care setting, routine testing is no longer necessary.

<sup>28</sup> The 2006 recommendations also included updated recommendations regarding HIV testing for pregnant women. However, for the purposes of this report we focus on HIV testing for the general population.

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diagnoses, the number of deaths among persons with HIV, the number of persons living with HIV or AIDS, and the estimated number of new HIV infections. HIV laboratory tests, specifically CD4 or viral load tests, can be used to determine the stage of the disease, measure unmet health care needs among HIV-infected persons, and evaluate HIV testing and screening activities.<sup>29</sup>

Current CDC estimates related to HIV are not based on data from all states because not all states have been reporting such data by name long enough to be included in CDC's estimates. While all states collect AIDS case counts through name-based systems, prior to 2008 states collected HIV data in one of two different formats, either by name or by code.<sup>30</sup> CDC does not accept code-based case counts for counting HIV cases because CDC does not consider them to be accurate and reliable, primarily because they include duplicate case counts. In order for CDC to use HIV case counts from a state for CDC's estimated diagnoses of HIV infection, the name-based system must be mature, meaning that the state has been reporting HIV name-based data to CDC for 4 full calendar years. CDC requires this time period to allow for the stabilization of data collection and for adjustment of the data in order to monitor trends. In its most recent surveillance report, CDC used the name-based HIV case counts from 34 states and 5 territories and associated jurisdictions in its national

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<sup>29</sup>CD4 cells help the body fight infection and are susceptible to attack by the HIV virus. A CD4 test is used to determine the number of CD4 cells in the blood to assess the functioning of the immune system. An HIV-positive individual will have a lower CD4 cell count than an individual without HIV. A viral load test measures the amount of HIV in the blood.

<sup>30</sup>In name-based systems, cases are collected by name, while in a code-based system cases are collected using a code identifier. Even though all states collect AIDS cases by name, some states had to transition their reporting systems for cases of HIV that have not progressed to AIDS from code to name. Due to the differences in reporting and CDC's use of these data, when we refer to name-based HIV reporting systems or the data collected through those systems, we are referring to cases of HIV that have not progressed to AIDS.

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estimates.<sup>31</sup> Name-based HIV reporting had been in place in these jurisdictions since the end of 2003 or earlier.

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## The CARE Act

Under the CARE Act, approximately \$2.2 billion in grants were made to states, localities, and others in fiscal year 2009. Part A of the CARE Act provides for grants to selected metropolitan areas that have been disproportionately affected by the HIV epidemic to provide care for HIV-positive individuals. Part B provides for grants to states and territories and associated jurisdictions to improve quality, availability, and organization of HIV services. Part A and Part B base grants are determined by formula based on the number of individuals living with HIV and AIDS in the grantee's jurisdiction.<sup>32</sup> For the living HIV/AIDS case counts HRSA used to determine fiscal year 2009 Part A and Part B base grants, see appendices II and III. Part C provides for grants to public and private nonprofit entities to provide early intervention services, such as HIV testing and ambulatory care.<sup>33</sup> Part F provides for grants for demonstration and evaluation of innovative models of HIV care delivery for hard-to-reach populations, training of health care providers, and for Minority AIDS Initiative grants.<sup>34</sup>

Since the 2006 reauthorization of CARE Act programs, HRSA has placed an emphasis on states' unmet need, which is the number of individuals in a state's jurisdiction who know they are HIV positive but who are not receiving care for HIV. According to the framework used by HRSA, addressing unmet need is a three-step process. First, states are required to produce an unmet need estimate, which is submitted to HRSA on the

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<sup>31</sup>The 34 states and 5 territories and associated jurisdictions that had mature name-based HIV reporting systems were: Alabama, Alaska, Arizona, Arkansas, Colorado, Florida, Georgia, Idaho, Indiana, Iowa, Kansas, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Texas, Utah, Virginia, West Virginia, Wisconsin, Wyoming, American Samoa, the Commonwealth of the Northern Mariana Islands, the Commonwealth of Puerto Rico, Guam, and the U.S. Virgin Islands. See CDC, *HIV/AIDS Surveillance Report, 2007*, Vol. 19 (2009).

<sup>32</sup>Most other Part A and Part B grants are distributed competitively. For more information on Part A and Part B grants, see [GAO-09-894](#), 2-4.

<sup>33</sup>The CARE Act also allows Part A and B grantees some flexibility to use funding for HIV testing through early intervention services.

<sup>34</sup>There is also a Part D, which provides for grants to private nonprofit and public entities for family-centered comprehensive care to children, youth, and women and their families, and a Part E, which does not provide for funding for HIV services, but rather includes provisions to address various administrative functions.

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state's annual Part B grant application.<sup>35</sup> To calculate the unmet need, the state must determine the total number of individuals who are aware of their HIV positive status in their jurisdiction, and then subtract the number of individuals who are receiving care for HIV.<sup>36</sup> Second, the state must assess the service needs and barriers to care for individuals who are not receiving care for HIV, including finding out who they are and where they live. Third, the state must address unmet need by connecting these individuals to care.

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## CDC and HRSA Have Coordinated on HIV Activities to Assist Health Care Professionals, and Both Agencies Have Taken Steps to Encourage Routine HIV Testing

CDC and HRSA have coordinated on activities to assist health care professionals who provide HIV-related services. HRSA has encouraged routine HIV testing by providing for training for health care providers, as part of CDC-funded initiatives. CDC has taken other steps to encourage routine HIV testing by funding special initiatives that focus on certain populations.

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## CDC and HRSA Have Coordinated Activities to Assist Health Care Professionals Who Provide HIV-Related Services

Since 2006, CDC and HRSA have coordinated activities to assist health care professionals who provide HIV-related services. In 2007, CDC and HRSA initiated a clinic-based research study to develop, implement, and test the efficiency and effectiveness of an intervention designed to increase client appointment attendance among patients at risk of missing scheduled appointments in HIV clinics, "Increasing Retention in Care among Patients Being Treated for HIV Infection." An interagency agreement outlined the responsibilities of CDC and HRSA with respect to

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<sup>35</sup>For purposes of this report, we look only at the unmet need estimates of states that are reported in their CARE Act Part B grant applications.

<sup>36</sup>According to HRSA's unmet need framework, an individual diagnosed with HIV is considered to be in care if there is evidence that the individual has received a viral load test, CD4 count, or provision of antiretroviral therapy within a 12-month time frame. Reported CD4 or viral load tests can be used to determine if an individual has entered into care because these tests are monitored routinely in the clinical setting.

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the study.<sup>37</sup> For example, under the agreement, CDC is responsible for maintaining data gathered from the study and HRSA is responsible for presenting their findings at national and international conferences. Each agency provided \$1.3 million for the study in fiscal year 2009 and will continue to provide funds for the study until its final year of operation in 2011.

In coordination with a federal interagency work group, CDC and HRSA have also participated in the development and publication of a document for case managers who work with individuals with HIV.<sup>38</sup> The document, “Recommendations for Case Management Collaboration and Coordination in Federally Funded HIV/AIDS Programs,” outlines best practices for, and six recommended components of, HIV case management for federally funded HIV case management agencies.<sup>39</sup> The document also describes how case management is practiced in different settings and methods for strengthening linkages among case management programs.<sup>40</sup> CDC and HRSA were the lead authors of the document and shared staff time and production expenses. The agencies published the document in February 2009.

CDC also provided HRSA with funding to expand HIV consultation services offered to health care professionals at the National HIV/AIDS Clinicians’ Consultation Center. The National HIV/AIDS Clinicians’ Consultation Center is a component of the HRSA-administered AIDS

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<sup>37</sup>Interagency Agreement Numbers: HAB0700301 (HRSA) and ST07-012.01(CDC), *Retaining HIV Positive Patients in Medical Care* (August 2008).

<sup>38</sup>The interagency work group included HRSA’s HIV/AIDS Bureau; CDC’s Division on HIV/AIDS Prevention; Centers for Medicare & Medicaid Services; the Substance Abuse and Mental Health Services Administration’s Center for Mental Health Services; the National Institutes of Health’s National Institute on Drug Abuse; the Department of Housing and Urban Development’s Housing Opportunities for Persons with AIDS; and the National Association of Social Workers.

<sup>39</sup>HHS, *Recommendations for Case Management Collaboration and Coordination in Federally Funded HIV Programs* (Washington, D.C.: August 2008).  
<http://www.cdcnpin.org/scripts/features/CaseManagement.pdf>.

<sup>40</sup>In the context of HIV, case management is a process through which programs facilitate access to care, stable housing, and support services for individuals with HIV and their families.

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Education and Training Centers (AETC) program.<sup>41</sup> The Consultation Center operates hotline systems to provide consultation to health care professionals, including the PEpline and Perinatal Hotline. Health care professionals access the PEpline to receive information on post-exposure management for health care professionals exposed to blood-borne pathogens and the Perinatal Hotline for information on treatment and care for HIV-diagnosed pregnant women and their infants. CDC provided HRSA with \$169,000 to support the PEpline and Perinatal Hotline in fiscal year 2007 and \$90,000 to support the PEpline in fiscal year 2008. In addition, CDC provided HRSA with \$180,000 during fiscal years 2007 and 2008 for the enhancement of existing consultation services at the Consultation Center for health care professionals who expand HIV testing and need assistance in managing a resulting increase in patients who are HIV positive.

In addition, CDC and HRSA have coordinated to prevent duplication of HIV training provided to health care professionals. The CDC-funded National Network of STD/HIV Prevention Training Centers, HRSA-funded AETCs, and other federal training centers, participate in the Federal Training Centers Collaboration to ensure that HIV training opportunities are not duplicated among the centers.<sup>42</sup> The agencies hold biennial national meetings to increase training coordination of STD/HIV prevention and treatment, family planning/reproductive health, and substance abuse prevention to maximize the use of training resources.<sup>43</sup>

In addition to coordinating on HIV activities that assist health care professionals, CDC and HRSA have participated in the CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment. The Advisory Committee was established by the Secretary of HHS in November 2002 to assess HRSA and CDC objectives, strategies, policies,

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<sup>41</sup>HRSA funds AETCs under Part F of the CARE Act. Specifically, HRSA provides grants to a network of 11 regional AETCs that conduct training programs for health care providers treating individuals with HIV. HRSA oversees AETCs by conducting a number of activities, including reviewing grantee progress reports, conducting site visits at AETC locations, and scheduling meetings to discuss AETCs activities.

<sup>42</sup>In addition to the National Network of STD/HIV Prevention Training Centers and AETCs, other organizations that participate in the Federal Training Centers Collaboration include the Regional Training Centers for Family Planning, Addiction Technology Transfer Centers, Viral Hepatitis Education and Training Projects, and Tuberculosis Regional Training and Medical Consultation Centers.

<sup>43</sup>The participating agencies held meetings in 2002, 2004, 2006, and 2008.

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and priorities for HIV and STD prevention and care and serves as a forum to discuss coordination of HIV activities. The committee meets twice a year and is comprised of 18 individuals who are nominated by the HHS Secretary to serve 2- to 4-year terms and are knowledgeable in such public health fields as epidemiology, infectious diseases, drug abuse, behavioral science, health care delivery and financing, state health programs, clinical care, preventive health, and clinical research. The members assess the activities administered by HRSA and CDC, including HIV testing initiatives and training programs, and make recommendations for improving coordination between the two agencies to senior department officials, including the HHS Secretary. Officials from CDC and HRSA regularly attend the meetings to present current HIV initiatives administered by their agencies.

Officials from 6 of the 14 state and local health departments we interviewed said that CDC and HRSA coordination on HIV activities could be improved. For example, officials from 3 of these health departments attributed the lack of coordination to differing guidelines CDC and HRSA use for their grantees. Officials from 1 health department stated that although they have the same desired outcome, CDC and HRSA do not always coordinate on activities that they fund. They noted that the two agencies have inconsistent policies for HIV-related activities, such as confidentiality guidelines and policies for data sharing. Officials from another health department stated that the two agencies could improve coordination on HIV testing and guidelines for funding HIV testing initiatives.

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## HRSA Has Encouraged Routine HIV Testing by Providing for Training for Health Care Providers as Part of CDC-Funded Initiatives

Since the release of CDC's 2006 routine HIV testing recommendations, HRSA has encouraged routine HIV testing by providing for training for health care providers, as part of CDC-funded initiatives. CDC and HRSA developed interagency agreements through which CDC provided \$1.75 million in 2007 and \$1.72 million in 2008 to HRSA-funded AETCs to develop curricula, training, and technical assistance for health care providers interested in implementing CDC's 2006 routine HIV testing recommendations.<sup>44</sup> As of June 2008, AETCs had conducted over 2,500

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<sup>44</sup>Interagency Agreement Numbers: HAB0600521 (HRSA) and 07FED705251(CDC), *Training and Technical Assistance to Support the Adoption of CDC's Recommendation for HIV Testing in Health-Care Settings* (August 2007) and Interagency Agreement Numbers: HAB0700403 (HRSA) and 07FED705251-1(CDC), *Training and Technical Assistance to Support the Adoption of CDC's Recommendation for HIV Testing in Health-Care Settings* (August 2008).

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training sessions to more than 40,000 health care providers on the recommendations.

HRSA provided for training during CDC-funded strategic planning workshops on routine HIV testing for hospital staff. CDC officials said that in 2007, the agency allocated over \$900,000 for workshops in eight regions across the country on implementing routine HIV testing in emergency departments. CDC reported that 748 attendees from 165 hospitals participated in these workshops. HRSA-funded AETCs from each of the eight regions provided information on services they offer hospitals as they prepare to implement routine HIV testing, and also served as facilitators during the development of hospital-specific strategic plans.

In addition, HRSA provided for training as part of a CDC-funded pilot project to integrate routine HIV testing into primary care at community health centers. HRSA officials said that their primary role in this project, called “Routine HIV Screening within Primary Care in Six Southeastern Community Health Centers,” was to provide for training on routine HIV testing and to ensure that HIV-positive individuals were connected to care, and that CDC provided all funding for the project. CDC officials told us that the first phase of the project funded routine HIV testing in two sites in Mississippi, two sites in South Carolina, and two sites in North Carolina. The CDC officials said that in 2008 four sites in Ohio were added and that these sites are receiving funding through CDC’s Expanded HIV Testing initiative. CDC officials said that they plan to start a second phase of the project with additional testing sites.

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### CDC Has Taken Other Steps to Encourage Routine HIV Testing

CDC has taken other steps to encourage routine HIV testing by funding special initiatives that focus on certain populations. In 2007, CDC initiated a 3-year project for state and local health departments called the “Expanded and Integrated Human Immunodeficiency Virus (HIV) Testing for Populations Disproportionately Affected by HIV, Primarily African Americans” initiative or the Expanded HIV Testing initiative. In the first year of the initiative, CDC awarded just under \$35 million to 23 state and local health departments that had an estimated 140 or more AIDS cases diagnosed among African Americans in 2005. Individual awards were proportionately based on the number of cases, with amounts to each jurisdiction ranging from about \$700,000 to over \$5 million. Funding after the first year of the initiative was to be awarded to these same health

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departments on a noncompetitive basis assuming availability of funds and satisfactory performance.<sup>45</sup> Funding for the second year of the initiative was just over \$36 million and included funding for 2 additional health departments, bringing the total number of funded departments to 25.

CDC asked health departments participating in the Expanded HIV Testing initiative to develop innovative pilot programs to expand testing opportunities for populations disproportionately affected by HIV—primarily African Americans—who are unaware of their status. CDC required health departments to spend all funding on HIV testing and related activities, including the purchase of HIV rapid tests and connecting HIV-positive individuals to care. CDC strongly encouraged applicants to focus at least 80 percent of their pilot program activities on health care settings, including settings to which CDC had not previously awarded funding for HIV testing, such as emergency rooms, inpatient medical units, and urgent care clinics. Additionally, CDC required that programs in health care settings follow the agency’s 2006 routine HIV testing recommendations to the extent permitted by law. Programs in non-health care settings were to have a demonstrated history of at least a 2 percent rate of HIV-positive test results.

The 2006 reauthorization of CARE Act programs included a provision for the Early Diagnosis Grant program under which CDC would make HIV prevention funding for each of fiscal years 2007 through 2009 available to states that had implemented policies related to routine HIV testing for certain populations.<sup>46</sup> These policies were (1) voluntary opt-out testing of all pregnant women and universal testing of newborns or (2) voluntary opt-out testing of patients at STD clinics and substance abuse treatment centers.<sup>47</sup> CDC’s fiscal year 2007 appropriation prohibited it from using funding for Early Diagnosis grants. In fiscal year 2008, CDC’s appropriation provided up to \$30 million for the grants. CDC officials told us that in 2008, the agency awarded \$4.5 million to the six states that had implemented at least one of the two specified policies as of December 31,

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<sup>45</sup>CDC plans to hold a new competition for the Expanded HIV Testing initiative after the first 3-year funding cycle. CDC also plans to expand the initiative to better meet the needs of the Latino population and gay and bisexual men.

<sup>46</sup>Pub. L. No. 109-415, § 209, 120 Stat. 2767, 2802-03 (codified at 42 U.S.C. § 300ff-33).

<sup>47</sup>Opt-out testing is a type of routine testing where a patient is notified that testing will be performed unless the patient elects to decline testing and consent is inferred unless the patient declines.

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2007. In fiscal year 2009, CDC's appropriation provided up to \$15 million for grants to states newly eligible for the program.<sup>48</sup> CDC officials said that in 2009, one state received funding for implementing voluntary opt-out testing at STD clinics and substance abuse treatment centers.<sup>49</sup> CDC officials also told us that they provided HRSA with information on how the Early Diagnosis Grant program would be implemented, but have not coordinated with the agency on administration of the program.

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## Most Selected State and Local Health Departments Reported Not Widely Implementing Routine HIV Testing in Their Jurisdictions and Barriers Exist to Its Implementation

Officials from just over half of the state and local health departments we interviewed said that their departments had implemented routine HIV testing in their jurisdictions, but that they generally did so in a limited number of sites. Officials from most of the health departments we interviewed and other sources knowledgeable about HIV have identified barriers to routine HIV testing, including lack of funding.

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<sup>48</sup>Appropriations in 2008 and 2009 limited the amount that could be made available to any one state to \$1 million.

<sup>49</sup>States that received funding for implementing a policy in 2008 could not receive funding for that same policy in 2009. For example, if a state received funding for implementing voluntary opt-out testing of patients at STD clinics and substance abuse treatment centers in 2008 it could not receive funding for having implemented this policy in 2009.

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Over Half of the Selected State and Local Health Departments Reported Implementing Routine HIV Testing in Their Jurisdictions, but Generally Did So in a Limited Number of Sites

Officials from 9 of the 14 state and local health departments we interviewed said that their departments had implemented routine HIV testing, but 7 said that they did so in a limited number of sites. Specifically, officials from 5 of the state health departments we interviewed said that their departments had implemented routine HIV testing in anywhere from one to nine sites and officials from 2 of the local health departments said that their departments had implemented it in two and four sites, respectively. Officials from all but 1 of these 7 departments said that their departments used funding from CDC's Expanded HIV Testing initiative to implement routine HIV testing.<sup>50</sup> CDC's goal for its Expanded HIV Testing initiative is to test 1.5 million individuals for HIV in areas disproportionately affected by the disease and identify 20,000 HIV-infected persons who are unaware of their status per year. During the first year of the initiative,<sup>51</sup> health departments that received funding under the CDC initiative reported conducting just under 450,000 HIV tests and identifying approximately 4,000 new HIV-positive results.<sup>52</sup>

The two other health departments that had implemented routine HIV testing—one state health department and one local health department located in a large city—had been able to implement routine HIV testing more broadly. These departments had implemented routine HIV testing prior to receiving funding through the Expanded HIV testing initiative, and used the additional funding to expand the number of sites where it was implemented. For example, the local health department had started an initiative to achieve universal knowledge of HIV status among residents in an area of the city highly affected by HIV. The department used funding from the Expanded HIV Testing initiative and other funding sources to implement routine HIV testing in this area and other sites throughout the

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<sup>50</sup>Officials from one health department said that they funded routine HIV testing through the Early Intervention Services portion of their CARE Act Part A grant.

<sup>51</sup>Under the Expanded HIV Testing initiative, CDC provided funding to 23 health departments in the first year of the initiative and 2 of these departments did not report data to CDC. Two additional health departments received funding in the second year of the initiative.

<sup>52</sup>Though the initiative did not reach its goal in the first year, this could be related to the time it takes states and local areas to start up routine HIV testing. NASTAD officials we interviewed said that it takes time for states and local areas to build the capacity to conduct routine HIV testing, but that once the infrastructure is in place testing can increase quickly. According to CDC, the number of tests conducted during the second half of the first year of the Expanded HIV Testing initiative was more than four times the number conducted during the first half.

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city, including 20 emergency rooms. An official from the state health department said that while the department had already funded routine HIV testing in some settings, for example STD clinics and community health centers, funding from the Expanded HIV Testing initiative allowed them to fund routine HIV testing in other types of settings, for example emergency rooms.

Officials from five health departments we interviewed said that their departments had not implemented routine HIV testing in their jurisdictions, including three state health departments and two local health departments. None of these health departments received funding through CDC's Expanded HIV Testing initiative, and officials from two of the state health departments specifically cited this as a reason why they had not implemented routine HIV testing. Officials from all of the departments that had not implemented routine HIV testing said that their departments do routinely test certain populations for HIV, including pregnant women, injection drug users, and partners of individuals diagnosed with HIV.

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### Officials from Selected State and Local Health Departments and Other Sources Have Identified Barriers That Exist to Implementing Routine HIV Testing

Officials from 11 of the 14 state and local health departments we interviewed and other sources knowledgeable about HIV have identified barriers that exist to implementing routine HIV testing. Officials from 5 of the 11 health departments cited lack of funding as a barrier to routine HIV testing. For example, an official from 1 state health department told us that health care providers have said that they would do routine HIV testing if they could identify who would pay for the cost of the tests. The need for funding was corroborated by officials from an organization that contracts with state and local health departments to coordinate HIV-related care and services. These officials told us that they had often seen routine HIV testing end when funding streams dried up and noted that there has been little implementation of CDC's 2006 routine HIV testing recommendations in their area outside of STD clinics and programs funded through the Expanded HIV Testing initiative.

Officials from state and local health departments we interviewed and other sources also cited lack of insurance reimbursement as a barrier to routine HIV testing. When identifying lack of funding as a barrier to routine HIV testing, officials from two state health departments we interviewed explained that there is a general lack of insurance reimbursement for this purpose. Other organizations we interviewed and CDC also raised the lack of insurance reimbursement for routine HIV testing as a barrier. For example, one provider group that we spoke with said that many providers

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are hesitant to offer HIV tests without knowing whether they will be reimbursed for it. In a recent presentation, CDC reported that out of 11 insurance companies, as of May 2009, all covered targeted HIV testing,<sup>53</sup> but only 6 reimbursed for routine HIV testing.<sup>54</sup> CDC also reported that as of this same date only one state required that insurers reimburse for HIV tests regardless of whether testing is related to the primary diagnosis.<sup>55</sup> CDC noted that legislation similar to this state's has been introduced, but not passed, in two other states as well as at the federal level.

Medicare does not currently reimburse for routine HIV testing, though the Centers for Medicare & Medicaid Services initiated a national coverage analysis as the first step in determining whether Medicare should reimburse for this service.<sup>56</sup> While federal law allows routine HIV testing as a covered service under Medicaid, individual states decide whether or not they will reimburse for routine HIV testing. According to one study, reimbursement for routine HIV testing has not been widely adopted by state Medicaid programs.<sup>57</sup> Many insurers, including Medicare and Medicaid, base their reimbursement policies on the recommendations of the U.S. Preventive Services Task Force, which is the leading independent panel of private-sector experts in prevention and primary care.<sup>58</sup> While the Task Force has recommended that clinicians conduct routine HIV testing when individuals are at increased risk of HIV infection and for all pregnant

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<sup>53</sup>HIV testing is targeted when it is based on an assessment of risk.

<sup>54</sup>CDC, *Update on HIV Testing* (presentation given at the CDC-HRSA Advisory Committee meeting, Atlanta, GA: May 2009).

<sup>55</sup>Requiring insurers to reimburse for HIV testing regardless of primary diagnosis means that plans have to cover HIV testing for individuals who are asymptomatic and for whom exposure to infection is uncertain. It also requires plans to cover testing done by an emergency or urgent care service provider, even if the testing is unrelated to the reason for the visit.

<sup>56</sup>As a result of this analysis, on September 9, 2009, the Centers for Medicare & Medicaid Services issued a proposal to cover routine HIV testing for certain populations.

<sup>57</sup>L. Cheever, et al., "Ensuring Access to Treatment for HIV Infection," *Clinical Infectious Diseases*, Vol. 45, No. 4 (2007).

<sup>58</sup>The U.S. Preventive Services Task Force was first convened by the U.S. Public Health Service in 1984. Since 1998, the Task Force has been sponsored by HHS' Agency for Healthcare Research and Quality. According to the Agency for Health Care Research and Quality, the Task Force conducts rigorous, impartial assessments of the scientific evidence for the effectiveness of a broad range of clinical preventive services, including screening, counseling, and preventive medications. Its recommendations are considered the "gold standard" for clinical preventive services.

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women, it has not made a recommendation for routine HIV testing when individuals are not at increased risk, saying that the benefit in this case is too small relative to the potential harms.<sup>59</sup>

In addition, officials from three state health departments we interviewed discussed legal barriers to implementing routine testing. For example, officials from one department said that implementation of routine HIV testing would require a change in state law to eliminate the requirement for pretest counseling and written informed consent. Similarly, officials from another department said that while their department had been able to conduct routine testing through the Expanded HIV Testing initiative, expanding it further might require changing state law to no longer require written informed consent for HIV testing. The officials explained that while the initiative did have a written informed consent form, the department had been able to greatly reduce the information included on the form in this instance. The department is currently in the process of looking for ways to further expand HIV testing without having to obtain changes to state law. According to a study published in the *Annals of Internal Medicine*, as of September 2008, 35 states' laws did not present a barrier to implementing routine HIV testing, though the 3 states discussed above were identified as having legal barriers.<sup>60</sup>

Officials from 3 of the state and local health departments we interviewed discussed operational barriers to integrating routine HIV testing with the policies and practices already in place in health care settings. For example, an official from a state health department said that the department tries to work past operational barriers to routine HIV testing, but if after 6 months the barriers prove too great in one site the department moves implementation of routine HIV testing to another site. An official from another state health department noted that in hospital settings it can take a long time to obtain approval for new protocols associated with routine HIV testing. NASTAD conducted a survey of the 25 state and local health departments that received funding through the Expanded HIV Testing initiative and found that health departments

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<sup>59</sup>The U.S. Preventive Services Task Force defines increased risk for HIV infection as reporting one or more individual risk factors or receiving health care in a high-prevalence or high-risk clinical setting.

<sup>60</sup>For more information on this study, see A. Mahajan, et al., "Consistency of State Statutes with the Centers for Disease Control and Prevention HIV Testing Recommendations for Health Care Settings," *Annals of Internal Medicine*, Vol. 150, No. 4 (2009).

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reported some barriers in implementing routine HIV testing, including obtaining buy-in from staff in health care settings and providing adequate training, education, and technical assistance to this staff. Other barriers mentioned by officials from health departments we interviewed included health care providers not being comfortable testing everyone for HIV and the ability of providers to provide care for the increased number of people who might be diagnosed through expanded HIV testing.

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## CDC Officials Estimated That About 30 Percent of the Agency's Annual HIV Prevention Funding Is Spent on HIV Testing

CDC officials estimated that approximately 30 percent of the agency's annual HIV prevention funding is spent on HIV testing. For example, according to CDC officials, in fiscal year 2008 this would make the total amount spent on HIV testing about \$200 million out of the \$652.8 million CDC allocated for domestic HIV prevention to its Division of HIV/AIDS Prevention.<sup>61</sup> Of the \$200 million CDC officials estimated was spent on testing, CDC did report that, in fiscal year 2008, \$51.1 million was spent on special HIV testing initiatives, such as the Expanded HIV testing initiative and the Early Diagnosis Grant program.<sup>62</sup>

CDC officials said that, outside of special testing initiatives, they could not provide the exact amount CDC spent on HIV testing. CDC's Division of HIV/AIDS Prevention spends the majority of its domestic HIV prevention budget in connection with cooperative agreements, grants, and contracts to state and local health departments and other funded entities. CDC officials explained that grantees submit reports to CDC on the activities they fund at the middle and end of the year. The officials said that while project officers check to see that these reports are consistent with how grantees planned to spend their funding, CDC does not routinely aggregate how much all grantees spent on a given activity, including HIV testing. In addition, outside of the Expanded HIV Testing initiative, CDC does not maintain data on how funds for HIV testing are distributed to different

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<sup>61</sup>According to CDC officials, in fiscal year 2008 CDC allocated approximately \$79 million in domestic HIV prevention funding to other divisions in the agency, including the Division of Adolescent and School Health, the Division of STD Prevention, the Division of Reproductive Health, and the Division of TB Elimination. For the purposes of this report, we focus on the Division of HIV/AIDS Prevention because it received nearly 90 percent of CDC's HIV prevention funding.

<sup>62</sup>Other federal agencies have also provided funding for special HIV testing initiatives. For example, HHS' Office of Population Affairs provided \$10 million to 77 projects in 34 states to expand HIV testing in family planning projects over 2 years. The Substance Abuse and Mental Health Services Administration has committed \$60 million from 2007-2012 to expand routine HIV testing in 22 states.

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settings within jurisdictions. For example, this would mean that CDC does not have data on how much money a state health department spends on testing in emergency rooms, versus how much money it spends on testing in community-based organizations.

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## National Data Suggest That Most HIV Tests and Nearly Half of HIV-Positive Results Occur in a Private Doctor's Office, HMO, or Hospital Setting, but the Data on Settings Where People Test Positive Have Limitations

According to data from NHIS, nearly 70 percent of all HIV tests in the United States were conducted in a private doctor's office, HMO, or hospital setting in 2007. Specifically, 50 percent of all HIV tests were conducted in a private doctor's office or HMO and nearly 20 percent of all HIV tests were conducted in a hospital setting, including emergency departments. The remaining tests were conducted in a variety of settings, including public clinics and HIV counseling and testing sites. Less than 1 percent of all HIV tests were conducted in a correctional facility, STD clinic, or a drug treatment facility. These data are similar to earlier data from NHIS. In 2002, NHIS found that 44 percent of all HIV tests were conducted in a private doctor's office or HMO and 22 percent of all HIV tests were conducted in a hospital setting.

Analysis of CDC surveillance data on the settings in which HIV-positive individuals are diagnosed suggests that approximately 40 percent of all HIV-positive results in the United States occurred in a private doctor's office, HMO, or hospital setting in 2007,<sup>63</sup> the most recent year for which data were available.<sup>64</sup> These data also suggest that hospital inpatient settings account for a disproportionate number of HIV-positive results discovered late in the course of the disease. In 2007, hospital inpatient settings accounted for 16 percent of all HIV-positive results. Among HIV cases diagnosed in 2006, these same settings accounted for 31 percent of HIV-positive results that occurred within 1 year of an AIDS diagnosis.

While CDC surveillance data can provide some indication of the types of settings where the greatest percentage of HIV-positive results occur, data limitations did not permit a more detailed analysis of HIV-positive results by setting type. Specifically, information on facility of diagnosis was

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<sup>63</sup>CDC officials noted that the settings where HIV diagnoses are reported can sometimes differ from the settings where individuals test positive for HIV. Specifically, they said that in the 2007 surveillance data, individuals who tested positive for HIV in the emergency room were included in the HIV diagnoses reported for hospital inpatient settings.

<sup>64</sup>CDC surveillance data on the settings in which HIV-positive individuals were diagnosed in 2007 are from the 34 states that had mature name-based HIV reporting systems that year.

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missing or unknown for nearly one out of every four HIV cases reported through the surveillance system in 2007.<sup>65</sup> CDC officials told us that in the past the agency used data from the Supplement to HIV/AIDS Surveillance project to examine the types of settings where individuals test positive for HIV, but this project ended in 2004.<sup>66</sup> CDC reported that in place of the Supplement to HIV/AIDS Surveillance project, the agency has implemented the Medical Monitoring Project.<sup>67</sup> However, data from the Medical Monitoring Project were not available at the time of our analysis.<sup>68</sup>

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<sup>65</sup>CDC surveillance data also exclude states that do not have mature name-based HIV reporting systems. In 2007, 16 states and the District of Columbia did not have a mature name-based HIV reporting system, including some large states such as California and Massachusetts. In addition, name-based data do not include individuals taking an anonymous HIV test. As of April 2008, 41 states and 4 territories and associated jurisdictions offered anonymous testing.

<sup>66</sup>The Supplement to HIV/AIDS Surveillance project was a collaborative effort between CDC and 19 state and local areas that conducted cross-sectional interviews with individuals with HIV from 1990 to 2004.

<sup>67</sup>The Medical Monitoring Project is conducted in 23 participating project areas that are estimated to include over 80 percent of the total HIV cases in the United States.

<sup>68</sup>Data from the first year of CDC's Expanded HIV Testing initiative can also provide information on the types of settings where HIV-positive results occur. For example, these data suggest that HIV testing in emergency rooms may yield a disproportionate number of positive results per HIV test conducted. However, data from this initiative are not generalizable, because the types of settings funded through the initiative are not representative of the types of settings where HIV testing is conducted in the United States.

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**A National Estimate of the Number of Undiagnosed HIV-Positive Individuals Is Available, but an Estimate Is Not Available for the Total Number of Diagnosed Individuals Not Receiving Care Nationally and Neither Estimate Is Available at the State Level**

CDC has calculated a national estimate of more than 200,000 undiagnosed HIV-positive individuals—that is, individuals who were unaware they are HIV positive and were therefore not receiving care for HIV. CDC estimated that 232,700 individuals, or 21 percent of the 1.1 million people living with HIV at the end of 2006, were unaware that they were HIV positive.<sup>69</sup>

CDC does not have a national estimate of the total number of diagnosed individuals not receiving care, but CDC has calculated a national estimate of more than 12,000 diagnosed HIV-positive individuals who did not receive care within a year after they were diagnosed with HIV in 2003. CDC reported that the estimated proportion of individuals with HIV who did not receive care within a year of diagnosis—which CDC measures by the number of HIV-positive individuals who did not have a reported CD4 or viral load test within this time—was 32.4 percent, or 12,285 of the 37,880 individuals who were diagnosed with HIV in 2003.<sup>70</sup> Since this estimate is based on the number of HIV-positive individuals who did not receive care within a year of diagnosis, this estimate does not include all individuals diagnosed with HIV who are not receiving care. For example, an individual may receive care within a year of diagnosis, but subsequently drop out of care 2 years later. Or an individual may receive care 2 years after diagnosis. In these examples, the individuals' change in status as receiving care or not receiving care is not included in CDC's estimate of the proportion of diagnosed individuals not receiving care.

Although CDC has published these estimates, the agency has noted limitations to the data used to calculate the number of diagnosed HIV-positive individuals not receiving care for HIV. First, not all states require laboratories to report all CD4 and viral load test results; without this information being reported, CDC's estimates may overstate the number of

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<sup>69</sup> CDC uses a statistical method to calculate these estimates. For more information on this method, see CDC, "HIV Prevalence Estimates—United States," *2006, Morbidity and Mortality Weekly Report*, Vol. 57, No. 39 (2008).

<sup>70</sup> These estimates are based on the 33 states with mature confidential name-based HIV reporting used in CDC's 2005 surveillance report. These states have had name-based HIV reporting systems in place since at least 2000. See CDC, "Reported CD4+ T-lymphocyte results for adults and adolescents with HIV/AIDS—33 states, 2005," *HIV/AIDS Surveillance Supplemental Report*, Vol. 11, No. 2 (2005).

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individuals who did not enter into care within 1 year of HIV diagnosis.<sup>71</sup> Additionally, in the past, CDC only required jurisdictions to report an individual's first CD4 or viral load test, which did not allow CDC to provide an estimate of all HIV-positive individuals who are not receiving care for HIV after the first year. CDC is currently disseminating updated data collection software which will permit the collection and reporting of all results collected by states. However, CDC officials told us that this software is still going through quality control checks.

While CDC calculates national estimates of the number of undiagnosed HIV-positive individuals not receiving care for HIV and the number of diagnosed HIV-positive individuals who did not receive care within a year of diagnosis, the agency does not calculate these estimates at the state level. CDC officials said that these estimates are not available at the state level because not all states have mature name-based HIV reporting systems.<sup>72</sup> CDC officials said that the agency is determining what it will need to estimate the number of undiagnosed individuals at the state level once all states have mature HIV reporting systems. CDC officials also said that once the new data collection software to collect CD4 and viral load test results from states is ready, data on all diagnosed HIV-positive individuals not receiving care may be available at the state level for those states with mature name-based HIV reporting systems with laboratory reporting requirements.<sup>73</sup>

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<sup>71</sup>According to CDC, not all states require laboratories to report CD4 and viral load results at all levels. Individuals whose tests are not reported are included in the number of HIV-positive individuals not receiving care for HIV because CDC has no indication that these individuals are in care. As of December 2008, 26 states, the District of Columbia, and Puerto Rico required laboratory reporting of all CD4 and viral load test results.

<sup>72</sup>Even though all states are collecting AIDS cases by name, some states are transitioning their reporting systems for cases of HIV that have not progressed to AIDS from code- to name-based. Due to the differences in reporting and CDC's use of these data, when we refer to name-based HIV reporting systems or the data collected through those systems, we are referring to cases of HIV that have not progressed to AIDS. Although all states and territories and associated jurisdictions, with the exception of the Federated States of Micronesia, Palau, and the Republic of the Marshall Islands, have switched to a name-based HIV reporting system, not all systems are mature. Systems are required to be mature in order to be used in CDC's surveillance estimates. All systems in which name-based HIV counts are being collected will be mature by 2012 and case counts will be available in 2014.

<sup>73</sup>CDC officials noted that underreporting of CD4 and viral load test results may continue to occur under the new data collection software, and additional study may be required to provide estimates of the number of diagnosed HIV-positive individuals not receiving care at the state level.

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HRSA also collects states' estimates of the number of diagnosed HIV-positive individuals not receiving care for HIV, but data are not consistently collected or reported by states, and therefore estimates are not available for comparison across all states. States report their estimates of the number of diagnosed HIV-positive individuals who are not receiving care as unmet need estimates to HRSA as a part of the states' CARE Act Part B grant applications. However, these estimates have limitations and are not comparable across states. One limitation is that not all states require laboratory reporting of CD4 and viral load results for all individuals who receive the tests. States use reported CD4 and viral load test results to calculate their unmet need, and, according to HRSA, without data for all individuals who receive CD4 or viral load tests, a state may overestimate its unmet need. Another limitation is that the estimates submitted in the states' fiscal year 2009 grant applications were calculated using differing time periods. For example, New Hampshire calculated its unmet need estimate using HIV cases collected as of December 31, 2004, while Colorado calculated its estimate using data collected as of June 30, 2008. Additionally, not all states have access to information on the number of individuals receiving care through private insurance; therefore, these individuals are counted as part of the state's unmet need.

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## Officials We Interviewed Identified Barriers to Care That Exist for HIV, but Agencies Have Implemented Initiatives to Connect HIV-Positive Individuals to Care

According to officials we interviewed, several barriers exist that could prevent HIV-positive individuals from receiving care. HRSA officials told us that structural barriers within the health care system, such as no or limited availability of services, inconvenient service locations and clinic hours, and long wait times for appointments can influence whether an individual is receiving care for HIV. Other barriers identified by HRSA officials are the quality of communication between the patient and provider, lack of or inadequate insurance, financial barriers, mental illness, and substance abuse. HRSA officials also noted that personal beliefs, attitudes, and cultural barriers such as racism, sexism, homophobia, and stigma can also have an impact on an individual's decision to seek care. Officials from two states and one local health department we spoke with stated that transportation was a barrier, while officials from two state health departments stated that lack of housing was a barrier for access to care. Unstable housing can prevent individuals with HIV from accessing

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health care and adhering to complex HIV treatments because they must attend to the more immediate need of obtaining shelter.<sup>74</sup>

Agencies have implemented initiatives to connect diagnosed individuals to care for HIV. For example, part of CDC's Expanded HIV Testing initiative focused on connecting individuals diagnosed with HIV to care. In the first year of the initiative, 84 percent of newly diagnosed patients received their HIV test results and 80 percent of those newly diagnosed were connected to care. CDC has also funded two studies that evaluated a case management intervention to connect HIV-positive individuals to care for HIV. In these studies, case management was conducted in state and local health departments and community-based organizations and included up to five visits with a case manager over a 3-month period. In one of these studies, 78 percent of individuals who participated in case management were still in care 6 months later.

HRSA has developed two initiatives as Special Projects of National Significance.<sup>75</sup> The first initiative, "Enhancing Access to and Retention in Quality HIV Care for Women of Color," was developed to implement and evaluate the effectiveness of focused interventions designed to improve timely entry and retention into quality HIV care for women of color. The second initiative, the "Targeted HIV Outreach and Intervention Model Development" initiative, was a 5-year, 10-site project implemented to bring underserved HIV-positive individuals into care for HIV. According to HRSA, results of the initiative indicated that individuals are less likely to have a gap of 4 months or more of care when they have had nine or more contacts with an outreach program within the first 3 months of these programs.

In collaboration with AIDS Action, an advocacy organization formed to develop policies for individuals with HIV, HRSA has also funded the "Connecting to Care" initiative. AIDS Action and HRSA developed the initiative to highlight successful methodologies to help connect or reconnect individuals living with HIV to appropriate and ongoing medical care. The methodologies were identified from cities across the country

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<sup>74</sup>See GAO, *Ryan White CARE Act: Implementation of the New Minority AIDS Initiative Provisions*, [GAO-09-315](#) (Washington, D.C.: March 2009), 43-47.

<sup>75</sup>Special Projects of National Significance grants are authorized by Part F of the CARE Act. These grants fund programs to quickly respond to emerging needs and programs to develop a standard electronic data system.

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and are being utilized in different settings. The initiative includes two publications with 42 interventions that have been reported to be successful in connecting HIV-positive individuals to care. The publications provide a description, logistics, strengths and difficulties, and outcomes of each intervention and focus specifically on homeless individuals, Native Americans, immigrant women, low-income individuals in urban and rural areas, and currently or formerly incarcerated individuals. AIDS Action has held training workshops that provided technical assistance to explain the interventions, including how to apply the best practices from successful programs.

HRSA provides grants under Part C of the CARE Act to public and private nonprofit entities to provide early intervention services to HIV-positive individuals on an outpatient basis that can help connect people to care. Part C grantees are required to provide HIV medical care services that can include outpatient care, HIV counseling, testing, and referral, medical evaluation and clinical care, and referrals to other health services. These programs also provide services to improve the likelihood that undiagnosed individuals will be identified and connected to care, such as outreach services to individuals who are at risk of contracting HIV, patient education materials, translation services, patient transportation to medical services, and outreach to educate individuals on the benefits of early intervention.

HRSA and CDC are currently collaborating on a clinic-based research study, "Increasing Retention in Care among Patients Being Treated for HIV Infection." The study is designed to develop, implement, and test the efficacy of an intervention intended to increase appointment attendance among individuals at risk of missing scheduled appointments in HIV clinics.

In addition to CDC and HRSA initiatives, officials we interviewed told us that state and local health departments have implemented their own initiatives to connect HIV-positive individuals to care. Officials from six states and five local health departments we spoke with stated that their departments use case management to assist HIV-positive individuals through the process of making appointments and to help address other needs of the individuals. For example, officials from one of these health departments explained that some case managers sign up qualified individuals for an AIDS Drug Assistance Program and others assist with locating housing or with substance abuse issues, which can also be barriers to staying in care. Case managers make sure individuals are staying in care by finding patients who have missed appointments or who

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providers have been unable to contact. In addition, officials from one state and four local health departments we spoke with told us that their departments use mental health professionals and officials from one state and three local health departments told us that their departments use substance abuse professionals to connect individuals to care, since individuals who need these services are at a high risk of dropping out of care. Officials from two health departments said that their departments use counseling and officials from one health department said that partner counseling is conducted when an individual is diagnosed with HIV.

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## Agency Comments

HHS provided technical comments on a draft of the report, which we incorporated as appropriate.

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We are sending copies of this report to the Secretary of Health and Human Services. The report will be available at no charge on GAO's Web site at <http://www.gao.gov>.

If you or your staffs have any questions, please contact me at (202) 512-7114 or [crossem@gao.gov](mailto:crossem@gao.gov). Contact points for our Offices of Congressional Relations and Public Affairs may found on the last page of this report. Other staff who made major contributions to this report are listed in appendix IV.



Marcia Crosse  
Director, Health Care

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# Appendix I: Information on Transitioning Prisoners with HIV to Care Upon Their Release

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U.S. federal prisons have become a principal screening and treatment venue for thousands of individuals who are at high risk for human immunodeficiency virus (HIV) or who have HIV.<sup>1</sup> According to a 2008 report by the Bureau of Justice Statistics, the overall rate of estimated confirmed acquired immune deficiency syndrome (AIDS) cases among the prison population (.46 percent) was more than 2.5 times the rate of the general U.S. population at the end of calendar year 2006.<sup>2</sup> The Bureau of Justice Statistics also reported that 1.6 percent of male inmates and 2.4 percent of female inmates in state and federal prisons were known to be HIV positive. To ensure that infected individuals are aware of their HIV-positive status and to ensure that they receive care while in prison, 21 states tested all inmates for HIV at admission or at some point during their incarceration. Forty-seven states and all federal prisons tested inmates if they had HIV-related symptoms or if they requested an HIV test.

The Ryan White Comprehensive AIDS Resources Emergency Act of 1990 (CARE Act) was enacted to address the needs of jurisdictions, health care providers, and people with HIV and their family members.<sup>3</sup> CARE Act programs have been reauthorized three times (1996, 2000, and 2006) and are scheduled to be reauthorized again in 2009.<sup>4</sup> The CARE Act Amendments of 2000 required the Health Resources and Services Administration (HRSA) to consult with the Department of Justice and others to develop a plan for the medical case management and provision of support services to individuals with HIV when they are released from the custody of federal and state prisons. The plan was to be submitted to Congress no later than 2 years after the date of enactment of the CARE Act Amendments of 2000.

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<sup>1</sup>HIV is the virus that causes acquired immune deficiency syndrome (AIDS). In this report, except where noted, we use the term HIV to refer to HIV disease, inclusive of cases that have and have not progressed to AIDS. When we use the term AIDS alone it refers exclusively to HIV disease that has progressed to AIDS.

<sup>2</sup>Calendar year 2006 data were the most recent data available at the time of this report. U.S. Department of Justice, Bureau of Justice Statistics, *HIV in Prisons, 2006* (Washington, D.C.: 2008). <http://www.ojp.usdoj.gov/bjs/pub/htm1/hivp/2006/hivp06.htm>.

<sup>3</sup>Pub. L. No. 101-381, 104 Stat. 576 (codified as amended at 42 U.S.C. §§ 300ff through 300ff-121). The 1990 CARE Act added title XXVI to the Public Health Service Act. Unless otherwise indicated, references to the CARE Act are to the current title XXVI.

<sup>4</sup>CARE Act programs were previously reauthorized by the Ryan White CARE Act Amendments of 1996 (Pub. L. No. 104-146, 110 Stat. 1346), the Ryan White CARE Act Amendments of 2000 (Pub. L. No. 106-345, 114 Stat. 1319), and the Ryan White HIV/AIDS Treatment and Modernization Act of 2006 (Pub. L. No. 109-415, 120 Stat. 2767).

You asked us to review the implementation status of the plan and to determine the extent of any continued coordination between HRSA and the Department of Justice to transition prisoners with HIV to CARE Act programs. However, HRSA officials told us that they did not create this plan or coordinate with the Department of Justice to create this plan. Additionally, the requirement for this plan was eliminated by the 2006 Ryan White Treatment Modernization Act. We are therefore providing information related to other steps that HRSA has taken to address the provision of HIV prevention and care for incarcerated persons with HIV transitioning back to the community and into CARE Act funded programs. Additionally, we provide information on steps taken by the Centers for Disease Control and Prevention (CDC) and states to address this issue.<sup>5</sup>

To provide information related to the steps that CDC and HRSA have taken to address the provision of HIV prevention and care for incarcerated persons, we interviewed CDC and HRSA officials. We also interviewed officials from nine state health departments about their programs for incarcerated persons with HIV transitioning back to the community and into CARE Act-funded programs, and the limitations of these programs.<sup>6</sup> From these nine state health departments, officials from eight states provided responses about their programs. The remaining state did not have a transition program in place. Our sample is not generalizable to all state and local health departments.

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## Background

The U.S. prison system has been the focus of many studies on HIV testing for prisoners and care for those with HIV while in prison and upon their release. Studies have been conducted to determine the number of individuals who are accessing HIV testing and treatment for the first time upon their incarceration. Studies have also been conducted to evaluate how infected prisoners fare in their HIV treatment upon release from prison, as inmates often encounter social and economic changes including the need to secure employment and housing, establish connections with family, and manage mental health and substance abuse disorders. For example, one recent study of the Texas state prison system published in

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<sup>5</sup>CDC provides funding to state and local health departments for HIV prevention, including counseling, testing, and referral services, primarily through cooperative agreements and grants.

<sup>6</sup>We interviewed officials from the following state health departments: California, Florida, Hawaii, Indiana, Missouri, North Carolina, Pennsylvania, Rhode Island, and Washington.

the *Journal of the American Medical Association* discussed an evaluation of the proportion of infected individuals who filled a highly active antiretroviral therapy (HAART) prescription within 10, 30, and 60 days after their release from prison, respectively.<sup>7</sup> The study found that 90 percent of recently released inmates did not fill a prescription for HAART therapy soon enough to avoid a treatment interruption (10 days) and more than 80 percent did not fill a prescription within 30 days of release. Only 30 percent of those released filled a prescription within 60 days. Individuals on parole and those who received assistance in completing a Texas AIDS Drug Assistance Program application were more likely to fill a prescription within 30 and 60 days.<sup>8</sup> Because those who discontinue HAART are at increased risk of developing a higher viral burden (resulting in greater infectiousness and higher levels of drug resistance), it is important for public health that HIV-positive prisoners continue their HAART treatment upon release from prison. CDC, HRSA, and several states we interviewed have implemented programs to aid in the transition of HIV-positive persons from prison to the community with emphasis on their continued care and treatment.

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## **CDC, HRSA, and States Have Taken Steps to Address the Provision of HIV Prevention and Care for Prisoners with HIV Upon Their Release**

CDC and HRSA have funded demonstration projects to address HIV prevention and care for prisoners with HIV upon their release from incarceration. Selected state health departments and their respective state departments of corrections have coordinated to help HIV-positive prisoners in their transition back to the community.

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<sup>7</sup>Highly active antiretroviral therapy (HAART) means any combination of three or more antiretroviral drugs. While HAART has greatly improved survival rates of individuals living with HIV/AIDS, there is currently no cure for the disease.

<sup>8</sup>J. Bailargeon, et al., "Accessing Antiretroviral Therapy Following Release from Prison," *Journal of the American Medical Association*, Vol. 301, No. 8 (2009).

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**CDC and HRSA Have  
Funded Demonstration  
Projects to Address HIV  
Prevention and Care for  
Prisoners with HIV and  
Provided Guidance to  
States Regarding HIV-  
Related Programs**

CDC and HRSA have funded various projects to address the provision of HIV prevention and care for prisoners with HIV upon their release from incarceration. CDC and HRSA have also provided guidance to states regarding HIV-related programs. The list below describes the projects and guidance.

- CDC and HRSA jointly funded a national corrections demonstration project in seven states (California, Florida, Georgia, Illinois, Massachusetts, New Jersey, and New York). This demonstration project was funded from 1999 to 2004. The goal of the demonstration project was to increase access to health care and improve the health status of incarcerated and at-risk populations disproportionately affected by the HIV epidemic. The “HIV/AIDS Intervention, Prevention, and Community of Care Demonstration Project for Incarcerated Individuals within Correctional Settings and the Community” involved jail, prison, and juvenile detention settings. The project targeted inmates with HIV, but also those with hepatitis B and hepatitis C, tuberculosis, substance abuse, and sexually transmitted diseases (STD). According to a HRSA report, the project was able to enhance existing programs in facilities, and develop new programs both within facilities and outside of them.<sup>9</sup> Many states integrated lessons learned through the project at varying levels throughout their state.
- CDC funded Project START to develop an HIV, STD, and hepatitis prevention program for young men aged 18-29 who were leaving prison in 2001. The goal of this project was to test the effectiveness of the Project START interventions in reducing sexually risky behaviors for prisoners transitioning back to the community. State prisons in California, Mississippi, Rhode Island, and Wisconsin were selected. A study describing the Project START interventions indicated a multi-session community re-entry intervention can lead to a reduction in sexually risky behavior in recently released prisoners.<sup>10</sup>

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<sup>9</sup>Department of Health and Human Services, Health Services and Resources Administration, *Opening Doors: The HRSA-CDC Corrections Demonstration Project for People Living with HIV/AIDS* (Washington, D.C.: 2007). <http://hab.hrsa.gov/tools/openingdoors/index.htm>.

<sup>10</sup>R. J. Wolitski, et al., “Relative Efficacy of a Multisession Sexual Risk-Reduction Intervention for Young Men Released from Prisons in 4 States,” *American Journal of Public Health*, Vol. 96, No. 10 (2006).

- CDC funded a demonstration project at multiple sites in four states (Florida, Louisiana, New York, and Wisconsin) where prisoners in short-term jail facilities were offered routine rapid initial testing and appropriate referral to care, treatment, and prevention services within the facility or outside of it. From December 2003 through June 2004, more than 5,000 persons had been tested for HIV, and according to a CDC report, 108 (2.1 percent) had received confirmed positive results.<sup>11</sup>
- CDC officials told us that CDC is currently completing three pilot studies which began in September 2006. These studies were conducted to develop interventions for HIV-positive persons being released from several prisons or halfway houses in three states: California (prisons), Connecticut (prisons), and Pennsylvania (halfway houses).
- CDC officials explained that CDC has established a Corrections Workgroup within the National Center for HIV/AIDS, Viral Hepatitis, STD, and Tuberculosis Prevention. In March of 2009, the workgroup hosted a Corrections and Public Health Consultation: “Expanding the Reach of Prevention.” This forum provided an opportunity for subject matter experts in the fields of corrections and academia as well as representatives from health departments and community-based organizations to develop effective prevention strategies for their correctional systems.
- According to a Special Projects of National Significance program update, HRSA’s “Enhancing Linkages to HIV Primary Care and Services in Jail Settings” initiative seeks to develop innovative methods for providing care and treatment to HIV-positive inmates who are reentering the community.<sup>12</sup> This 4-year project, which began in September 2007, is different from the “HIV/AIDS Intervention, Prevention, and Community of Care Demonstration Project for Incarcerated Individuals within Correctional Settings and in the Community” in that it focuses entirely on jails. HRSA defines jails as locally operated facilities whose inmates are typically sentenced for 1 year or less or are awaiting trial or sentencing

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<sup>11</sup>CDC, *Demonstration Projects for State and Local Health Departments: Routine Rapid HIV Testing of Inmates in Short-Stay Correctional Facilities* (Atlanta, GA: 2004). [http://www.cdc.gov/hiv/topics/prev\\_prog/ahp/resources/factsheets/Correctional\\_Facilities.htm](http://www.cdc.gov/hiv/topics/prev_prog/ahp/resources/factsheets/Correctional_Facilities.htm).

<sup>12</sup>Department of Health and Human Services, Health Resources and Services Administration HIV/AIDS Bureau, *What’s Going on @ SPNS. Enhancing Linkages: Opening Doors for Jail Inmates* (Washington, D.C.: 2008). <http://hab.hrsa.gov/special/products2g.htm>.

following trial. Under the initiative, HRSA has awarded grants to 10 demonstration projects in the following areas: Atlanta, Georgia; Chester, Pennsylvania; Chicago, Illinois; Cleveland, Ohio; Columbia, South Carolina; New Haven, Connecticut; New York, New York; Philadelphia, Pennsylvania; Providence, Rhode Island; and Springfield, Massachusetts.

Besides funding demonstration projects and creating workgroups, HRSA and CDC have issued guidance to states. HRSA issued guidance in September 2007 explaining allowable expenditures under CARE Act programs for incarcerated persons.<sup>13</sup> The guidance states that expenditures under the CARE Act are only allowable to help prisoners achieve immediate connections to community-based care and treatment services upon release from custody, where no other services exist for these prisoners, or where these services are not the responsibility of the correctional system. The guidance provides for the use of funds for transitional social services including medical case management and social support services. CARE Act grantees can provide these transitional primary services by delivering the services directly or through the use of contracts. Grantees must also develop a mechanism to report to HRSA on the use of funds to provide transitional social services in correctional settings. In 2009, CDC issued *HIV Testing Implementation Guidance for Correctional Settings*.<sup>14</sup> This guidance recommended routine opt-out HIV testing for correctional settings and made suggestions for how HIV services should be provided and how prisoners should be linked to services.<sup>15</sup> The guidance also addressed challenges that may arise for prison administrators and health care providers who wish to implement the guidelines in their correctional facilities.

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<sup>13</sup>Department of Health and Human Services, Health Resources and Services Administration HIV/AIDS Bureau, *Policy Notice 07-04: The Use of Ryan White HIV/AIDS Program Funds for Transitional Social Support and Primary Care Services for Incarcerated Persons* (Washington, D.C.: 2007). <http://hab.hrsa.gov/law/0704.htm>.

<sup>14</sup>CDC, *HIV Testing Implementation Guidance for Correctional Settings* (Atlanta, GA: 2009). <http://www.cdc.gov/hiv/topics/testing/resources/guidelines/correctional-settings/index.htm>.

<sup>15</sup>Opt-out testing is when a patient is notified that testing is a routine part of medical care and will be performed unless the patient declines.

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**Selected State Health  
Departments Have  
Coordinated with Their  
Respective State  
Departments of  
Corrections on HIV-  
Positive Prisoner  
Transition Programs**

Of the eight state health departments in our review that had HIV transition programs in place, several have implemented programs that coordinate with the state's department of corrections to provide prisoners with support services to help them in their transition back to the community. We provide examples of three of these programs below.

- Officials from one state health department said that their department uses CARE Act and state funding to provide a prerelease program that uses the state's department of corrections prerelease planners to make sure that prisoners with HIV are linked to care. Prisoners meet with their prerelease planner 60-90 days prior to release, and the planner links them to care services, has them sign up for the AIDS Drug Assistance Program and Medicaid, and follows up with them after their release to ensure that they remain in care. Additionally, the department of corrections provides 30 days of medications to prisoners upon release. The state department of health has been working with the department of corrections to help them transition HIV-positive prisoners for the past 10 years.
- According to officials from another state health department, their department uses state funds to provide transitional case management for HIV prisoners who are transitioning back into the community. Specialized medical case managers meet and counsel prisoners with HIV who are within 6 months of being released. Within 90 days of release, the prisoner and the medical case manager may meet several times to arrange housing, complete a Medicaid application, obtain referrals to HIV specialists and to the AIDS Drug Assistance Program, and provide the prisoner with assistance in obtaining a state identification card. Case managers will also work with the prisoner for 3 months after release so that the prisoner is stable in the community. After 90 days, the person can be transferred into another case management program or they can drop out. The client is kept on the AIDS Drug Assistance Program if they are not disabled.
- According to officials from a third state health department, their department uses "Project Bridge," a nationally recognized program to transition prisoners back into the community and into CARE Act programs. The Project Bridge program provides transition services to prisoners. Ninety-seven percent of the Project Bridge participants receive medical care during the first month of their release from prison. The state attributes the success of this program to the productive relationship between the state health department and the department of corrections. Project Bridge participants are involved in discharge planning with case managers starting 6 months before their discharge. Participants then receive intense case management for approximately 18-24 months after their release. During this period they are connected with medical and

social services. According to state officials, the program has also been effective in decreasing recidivism rates.

Officials we interviewed from state health departments described several limitations to their departments' programs. One state health department official explained that their department does not have the staff to coordinate services for all of the state's 110 jails. Officials from two other state health departments explained that state budget cuts are threatening the continuation of their departments' prisoner transition programs. One state health department official explained that finding the transitioning HIV-positive prisoner housing in the community is often very difficult. The lack of available housing has impacted their HIV care because they are so focused on finding housing that they are unable to focus on taking their medication or going to medical appointments. One state health department official explained that their department's prisoners with HIV are sometimes not interested in being connected to care in the community. Another state health department official explained that the lack of funding for prisoner transition programs is a limitation of their program.

# Appendix II: Part A Grantees' Living HIV/AIDS Cases Used by HRSA to Determine Fiscal Year 2009 CARE Act Base Grants

<b>Part A Grantee</b>	<b>HIV</b>	<b>AIDS</b>	<b>Total</b>
Atlanta, Ga.	6,260	11,571	<b>17,831</b>
Austin, Tex.	1,630	2,458	<b>4,088</b>
Baltimore, Md.	11,901	9,488	<b>21,389</b>
Baton Rouge, La.	1,867	1,888	<b>3,755</b>
Bergen-Passaic, N.J.	1,858	2,190	<b>4,048</b>
Boston, Mass.	6,270	7,748	<b>14,018</b>
Caguas, P.R.	483	761	<b>1,244</b>
Charlotte-Gastonia, N.C.-S.C.	3,216	1,809	<b>5,025</b>
Chicago, Ill.	13,166	13,945	<b>27,111</b>
Cleveland, Ohio	2,020	2,158	<b>4,178</b>
Dallas, Tex.	6,589	8,346	<b>14,935</b>
Denver, Colo.	4,721	3,232	<b>7,953</b>
Detroit, Mich.	3,944	4,635	<b>8,579</b>
Dutchess County, N.Y.	452	803	<b>1,255</b>
Fort Lauderdale, Fla.	6,730	7,724	<b>14,454</b>
Fort Worth, Tex.	1,681	2,238	<b>3,919</b>
Hartford, Conn.	1,085	2,565	<b>3,650</b>
Houston, Tex.	8,047	10,809	<b>18,856</b>
Indianapolis, Ind.	1,825	1,990	<b>3,815</b>
Jacksonville, Fla.	2,169	2,970	<b>5,139</b>
Jersey City, N.J.	2,166	2,528	<b>4,694</b>
Kansas City, Mo.	1,953	2,390	<b>4,343</b>
Las Vegas, Nev.	2,968	2,763	<b>5,731</b>
Los Angeles, Calif.	15,106	22,431	<b>37,537</b>
Memphis, Tenn.	3,421	2,688	<b>6,109</b>
Miami, Fla.	10,877	12,988	<b>23,865</b>
Middlesex-Somerset-Hunterdon, N.J.	1,212	1,442	<b>2,654</b>
Minneapolis-St. Paul, Minn.	2,964	2,173	<b>5,137</b>
Nashville, Tenn.	2,036	2,215	<b>4,251</b>
Nassau-Suffolk, N.Y.	1,877	3,621	<b>5,498</b>
New Haven, Conn.	1,813	4,200	<b>6,013</b>
New Orleans, La.	3,397	4,006	<b>7,403</b>
New York, N.Y.	35,856	59,700	<b>95,556</b>
Newark, N.J.	6,237	6,669	<b>12,906</b>
Norfolk, Va.	3,329	2,353	<b>5,682</b>

**Appendix II: Part A Grantees' Living  
HIV/AIDS Cases Used by HRSA to Determine  
Fiscal Year 2009 CARE Act Base Grants**

<b>Part A Grantee</b>	<b>HIV</b>	<b>AIDS</b>	<b>Total</b>
Oakland, Calif.	2,431	4,173	<b>6,604</b>
Orange County, Calif.	2,370	3,662	<b>6,032</b>
Orlando, Fla.	3,953	4,550	<b>8,503</b>
Philadelphia, Pa.	9,070	13,596	<b>22,666</b>
Phoenix, Ariz.	4,528	3,775	<b>8,303</b>
Ponce, P.R.	627	1,371	<b>1,998</b>
Portland, Ore.	1,508	2,339	<b>3,847</b>
Riverside-San Bernardino, Calif.	3,167	4,686	<b>7,853</b>
Sacramento, Calif.	970	1,699	<b>2,669</b>
San Antonio, Tex.	1,711	2,568	<b>4,279</b>
San Diego, Calif.	5,161	6,403	<b>11,564</b>
San Francisco, Calif.	6,641	10,532	<b>17,173</b>
San Jose, Calif.	1,102	1,816	<b>2,918</b>
San Juan, P.R.	4,029	7,023	<b>11,052</b>
Santa Rosa, Calif.	415	844	<b>1,259</b>
Seattle, Wash.	3,099	3,914	<b>7,013</b>
St. Louis, Mo.	2,897	3,099	<b>5,996</b>
Tampa-St. Petersburg, Fla.	3,975	5,264	<b>9,239</b>
Vineland-Millville-Bridgeton, N.J.	375	461	<b>836</b>
Washington, D.C.	12,678	16,350	<b>29,028</b>
West Palm Beach, Fla.	2,881	4,513	<b>7,394</b>
<b>Total</b>	<b>254,714</b>	<b>334,133</b>	<b>588,847</b>

Source: HRSA.

Note: Fourteen Part A grantees—Baltimore, Md.; Boston, Mass.; Chicago, Ill.; Los Angeles, Calif.; Oakland, Calif.; Orange County, Calif.; Portland, Ore.; Riverside-San Bernardino, Calif.; Sacramento, Calif.; San Diego, Calif.; San Francisco, Calif.; San Jose, Calif.; Santa Rosa, Calif.; and Washington, D.C.—submitted code-based HIV case counts to HRSA for the fiscal year 2009 funding formula and were assessed a 5 percent reduction in their HIV case counts in accordance with the CARE Act. For more information, see [GAO-09-894](#), 8-10.

# Appendix III: Part B Grantees' Living HIV/AIDS Cases Used by HRSA to Determine Fiscal Year 2009 CARE Act Base Grants

<b>Part B Grantee</b>	<b>HIV</b>	<b>AIDS</b>	<b>Total</b>
Alabama	5,702	4,164	<b>9,866</b>
Alaska	278	340	<b>618</b>
Arizona	5,949	5,180	<b>11,129</b>
Arkansas	2,388	2,296	<b>4,684</b>
California	41,730	63,187	<b>104,917</b>
Colorado	5,974	4,313	<b>10,287</b>
Connecticut	3,215	7,403	<b>10,618</b>
Delaware	1,259	1,813	<b>3,072</b>
District of Columbia	6,575	8,559	<b>15,134</b>
Florida	38,303	49,055	<b>87,358</b>
Georgia	10,883	17,447	<b>28,330</b>
Hawaii	845	1,251	<b>2,096</b>
Idaho	356	311	<b>667</b>
Illinois	15,447	16,513	<b>31,960</b>
Indiana	3,953	4,218	<b>8,171</b>
Iowa	637	912	<b>1,549</b>
Kansas	1,260	1,369	<b>2,629</b>
Kentucky	1,635	2,788	<b>4,423</b>
Louisiana	7,663	8,522	<b>16,185</b>
Maine	421	534	<b>955</b>
Maryland	15,793	15,029	<b>30,822</b>
Massachusetts	7,258	8,651	<b>15,909</b>
Michigan	6,177	6,900	<b>13,077</b>
Minnesota	3,370	2,457	<b>5,827</b>
Mississippi	4,575	3,570	<b>8,145</b>
Missouri	5,061	5,751	<b>10,812</b>
Montana	120	205	<b>325</b>
Nebraska	680	784	<b>1,464</b>
Nevada	3,447	3,214	<b>6,661</b>
New Hampshire	480	587	<b>1,067</b>
New Jersey	15,851	17,564	<b>33,415</b>
New Mexico	934	1,330	<b>2,264</b>
New York	44,973	73,879	<b>118,852</b>
North Carolina	12,812	8,718	<b>21,530</b>
North Dakota	83	78	<b>161</b>

**Appendix III: Part B Grantees' Living  
HIV/AIDS Cases Used by HRSA to Determine  
Fiscal Year 2009 CARE Act Base Grants**

<b>Part B Grantee</b>	<b>HIV</b>	<b>AIDS</b>	<b>Total</b>
Ohio	8,274	7,380	<b>15,654</b>
Oklahoma	2,259	2,333	<b>4,592</b>
Oregon	1,746	2,938	<b>4,684</b>
Pennsylvania	12,401	18,647	<b>31,048</b>
Puerto Rico	6,519	11,335	<b>17,854</b>
Rhode Island	985	1,346	<b>2,331</b>
South Carolina	6,591	7,604	<b>14,195</b>
South Dakota	209	144	<b>353</b>
Tennessee	7,032	6,822	<b>13,854</b>
Texas	25,894	34,734	<b>60,628</b>
Utah	932	1,206	<b>2,138</b>
Vermont	206	236	<b>442</b>
Virginia	10,092	8,573	<b>18,665</b>
Washington	4,420	5,734	<b>10,154</b>
West Virginia	662	786	<b>1,448</b>
Wisconsin	2,418	2,283	<b>4,701</b>
Wyoming	98	109	<b>207</b>
American Samoa	2	1	<b>3</b>
Commonwealth of the Northern Mariana Islands	3	3	<b>6</b>
Federated States of Micronesia	8	0	<b>8</b>
Guam	55	35	<b>90</b>
Palau	0	0	<b>0</b>
Republic of the Marshall Islands	0	1	<b>1</b>
U.S. Virgin Islands	235	335	<b>570</b>
<b>Total</b>	<b>367,128</b>	<b>461,477</b>	<b>828,605</b>

Source: HRSA.

Note: Ten Part B grantees—California, the District of Columbia, Hawaii, Illinois, Maryland, Massachusetts, Oregon, Rhode Island, Vermont, and the Federated States of Micronesia—submitted code-based HIV case counts to HRSA for the fiscal year 2009 funding formula and were assessed a 5 percent reduction in their HIV case counts in accordance with the CARE Act. For more information, see [GAO-09-894](#), 8-10.

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# Appendix IV: GAO Contact and Staff Acknowledgments

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## GAO Contact

Marcia Crosse, (202) 512-7114 or [crossem@gao.gov](mailto:crossem@gao.gov)

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