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RYAN WHITE CARE ACT

Opportunities to Enhance Funding Equity

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Ryan White Care Act: Opportunities to Enhance Funding Equity

Mr. Chairman and Members of the Subcommittee:

I am pleased to be here today as you discuss ways to distribute Ryan White CARE Act funds to states and localities. As you know, the program is facing new challenges as the epidemic of the human immunodeficiency virus (HIV) changes and spreads to new segments of the American population. At the same time, new medicines and treatments have lengthened the life expectancy of infected persons. This, in turn, emphasizes the need to insure that program funding reflects the changing pattern of the epidemic.

In fiscal year 2000, Ryan White grants have provided nearly $1.6 billion in federal funding to assist state and local service providers in delivering health care and support services to individuals and families affected by HIV infection. Title I of the Act provides assistance to metropolitan areas most affected by the disease and Title II primarily provides funding for state agencies responsible for persons not served under Title I and for funding drug therapies. Although the Ryan White program serves individuals with HIV, funds are distributed on the basis of the number of individuals whose disease has progressed to acquired immunodeficiency syndrome (AIDS).

At the request of the Subcommittee, I will focus on three issues:

- the potential for distributing funds on the basis of counts of persons with HIV infection in each geographic area rather than on counts of only persons whose disease has progressed to AIDS;
- the differences in funds for states with an eligible metropolitan area (EMA), which receive grants under both title I and title II of the Act, and states without an EMA, which receive only title II grants;[1] and
- the current effect of the hold-harmless provision adopted in the 1996 reauthorization, when the method of counting living AIDS cases replaced the practice of counting cumulative AIDS cases.

To address these issues, we have analyzed data from the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) in the Department of Health and Human

[1]Eligible metropolitan areas are urban areas with at least 500,000 population and at least 2,000 living AIDS cases reported in the past five years.

Services (HHS) and have developed computer models to calculate how funding would change under alternative formula scenarios.

In brief, we found that only about 60 percent of the states include HIV cases that have not progressed to AIDS in their reports to CDC. To ensure that the formulas provide an equitable distribution, all states would need to report HIV cases. CDC officials told us that they expect all states to be reporting new HIV cases by 2003 and that an additional 1 to 3 years may be needed to allow cases that existed before then to be entered into their reporting systems. However, the states' ability to completely identify past cases is not known.

We also found substantial differences in funding between states with an EMA and those without one. For example, in fiscal year 2000 states that had no eligible EMA received on average of $3,340 per person suffering from AIDS. In contrast, the states with more than 75 percent of their AIDS cases in an EMA received nearly 50 percent more, averaging $4,954 per AIDS case. States such as California and New York with more than 90 percent of their cases in EMAs received $5,240 per case or almost 60 percent more than states without an EMA. GAO has in the past recommended changes to the Ryan White Funding Formulas that would result in more comparable funding across states.

Finally, a hold-harmless provision was included in the 1996 reauthorization to help with the transition of the EMAs that would receive less by using living AIDS rather than cumulative AIDS cases, which included both living and deceased cases. The transition has been very gradual and has had the effect of providing some EMAs with more funding on a per-person-with-AIDS basis than other similarly situated EMAs. Currently, only one EMA, San Francisco, continues to benefit from the hold-harmless provision, and it received substantially more aid than other similarly situated EMAs. For example, San Francisco received more than 80 percent greater title I funding per person with AIDS than other EMAs. Oakland, across the bay from San Francisco, and all other EMAs received $1,289 per person in fiscal year 2000 title I funding compared with San Francisco's $2,359 per person. San Francisco continues to benefit from the hold-harmless provision because a large proportion of its cumulative AIDS cases were deceased under the formula used before fiscal year 1996 and because there have been smaller increases in new AIDS cases compared with other EMAs. GAO has in the past recommended changes to the Ryan White funding formulas that would enhance comparable funding across states.

Background

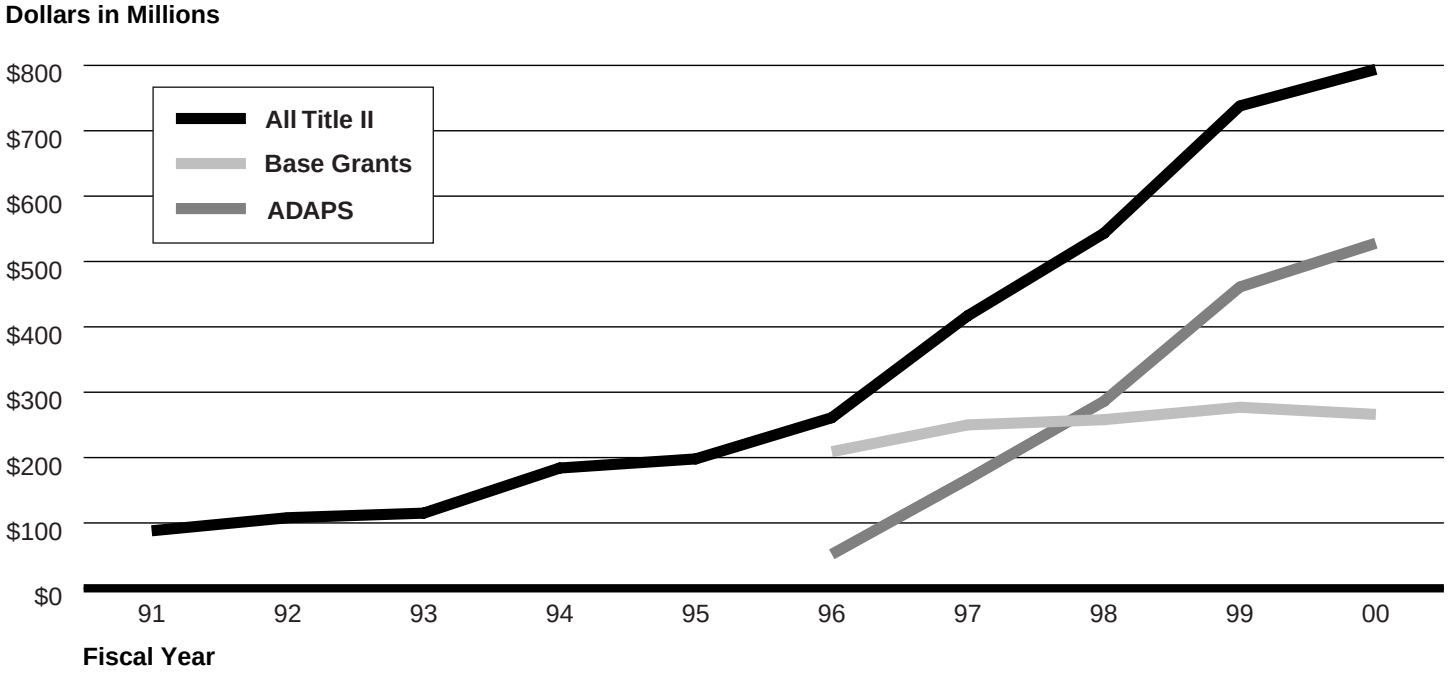
Since the first cases were identified in 1981, more than 700,000 persons in the United States have been diagnosed with AIDS. Recent developments in medical and pharmacological therapies have improved the survival of persons with AIDS and have slowed the progression from HIV to AIDS. At the end of 1999, an estimated 300,000 persons were living with AIDS. It is also estimated that an additional 500,000 to 600,000 people are infected with HIV that has not progressed to AIDS. The composition of the AIDS population has also changed over time, with minorities and women representing a larger portion of all cases.

Federal efforts to provide health and support services involve a wide variety of programs and activities. In addition to Ryan White grants, federal funding is provided through CDC, the Department of Housing and Urban Development, Medicare, Medicaid, Social Security Disability Insurance, and the Supplemental Security Income program, among others.

Seventy percent of Ryan White funds are distributed by formula under titles I and II of the act, while titles III and IV provide discretionary grants for a variety of support services. Title I has provided $527 million in assistance in fiscal year 2000 to consortia of local service providers in EMAs. To be eligible, a metropolitan area must have a population of at least 500,000 and must have had a cumulative total of more than 2,000 reported AIDS cases in the past 5 years. There were 16 EMAs when the program began in 1991, and the number has grown to 51 today.

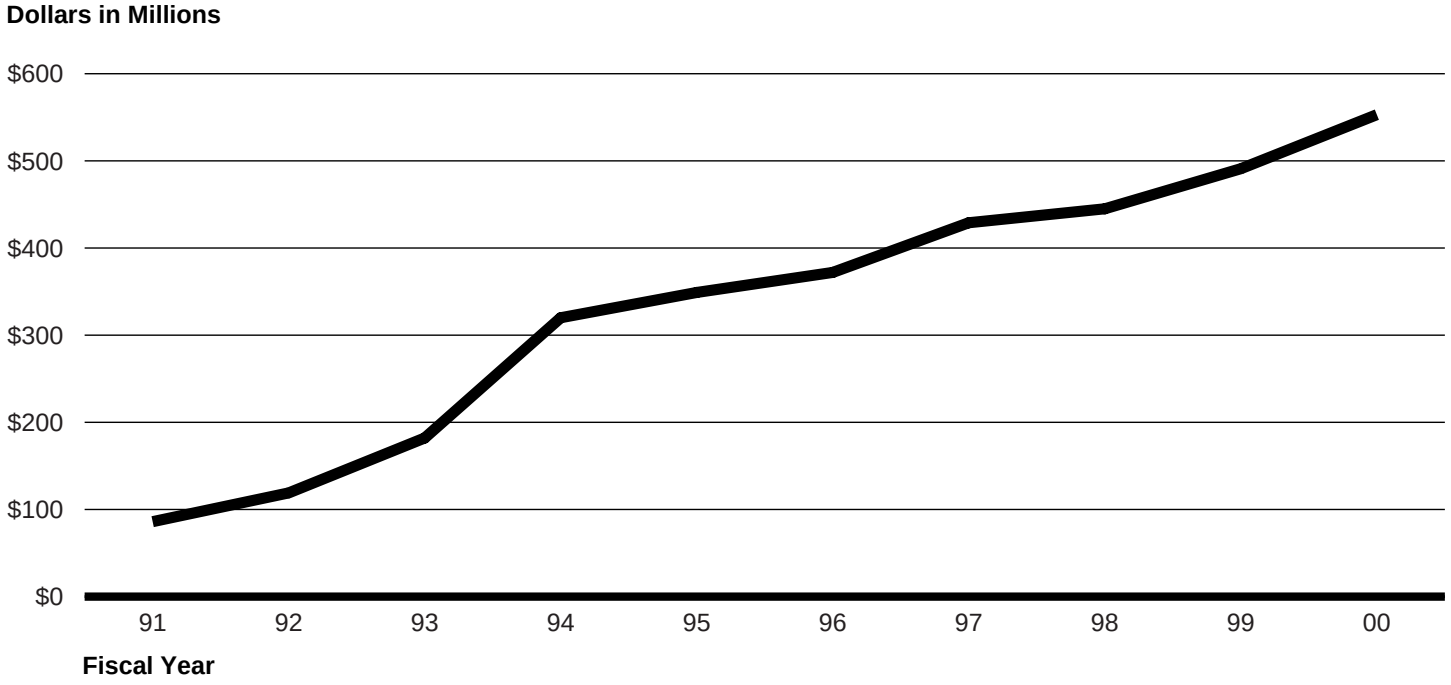
Title I funding has increased at an average annual rate of 24 percent since 1991. (See fig. 1.) Half of these funds is distributed by formula on the basis of estimated living AIDS cases in each EMA. HRSA distributes the remainder of title I funds among EMAs on a discretionary basis in response to proposals EMAs submit. Historically, the distribution of discretionary grants has generally mirrored the pattern of the formula grants.

Figure I: Title I Funding, Fiscal Years 1991-2000



Title II provides funding for state agencies. In fiscal year 2000, 96 percent of funds was distributed by formula, $528 million for the AIDS Drug Assistance Program (ADAPS) and $266 million to provide health and support services to persons not living in an EMA and for other activities. Title II funds have grown at an average annual rate of 29 percent. Almost all this growth has resulted from increased funding in the ADAPS program. (See fig. 2.)

Figure 2: Title II Funding, Fiscal Years 1991-2000



In our previous report on the CARE Act funding formulas, we recommended to the Congress that the funding formulas be modified so that

- comparable medical services funding be made available regardless of where people with AIDS live and
- an indicator be added to the formulas that reflect relative differences across states and EMAs in the cost of serving people with AIDS. [2]

As I will discuss in more detail, these recommendations continue to be applicable today.

[2] *Ryan White CARE Act OF 1990: Opportunities to Enhance Funding Equity* (GAO/HEHS-96-26, Nov. 13,1996).

State HIV Reporting Is Improving but Is Still Incomplete

Because the Ryan White program serves persons who have been diagnosed with HIV that has not progressed to AIDS as well as those for whom it has, it would be reasonable to distribute funds on the basis of the total number persons living with HIV. However, while all states report AIDS cases, many do not report the number of persons with HIV that has not progressed to AIDS. Therefore, for purposes of distributing formula funds equitably, the total number of AIDS cases continues to be the best available indicator of need.

CDC indicates that 21 states, with 58 percent of all AIDS cases, do not report HIV cases, report only some cases, or are awaiting CDC approval of their reporting systems. Most notable among these are New York and California which together have 31 percent of all AIDS cases. New York's legislature recently authorized HIV reporting to CDC but has not yet begun implementation, and California has yet to authorize HIV reporting. Table l lists the states with CDC-approved reporting systems and those not yet approved.

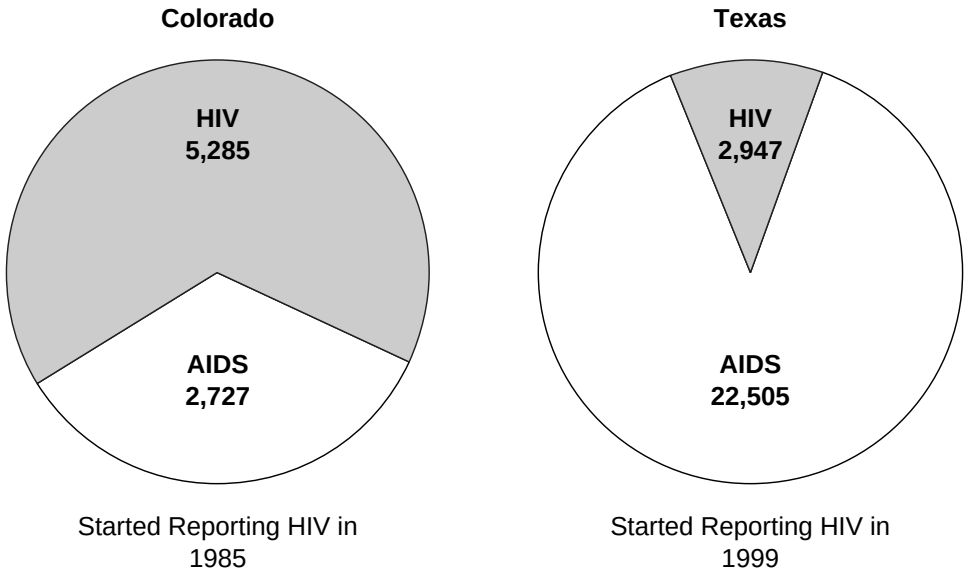
Table 1: States and Their HIV Reporting Status

CDC-approved		Not approved	
Alabama	New Jersey	California	Montana
Alaska	New Mexico	Connecticut	New Hampshire
Arizona	North Carolina	Delaware	New York
Arkansas	North Dakota	District of Columbia	Oregon
Colorado	Ohio	Georgia	Pennsylvania
Florida	Oklahoma	Guam	Puerto Rico
Idaho	South Carolina	Hawaii	Rhode Island
Indiana	South Dakota	Illinois	Vermont
Iowa	Tennessee	Kentucky	Washington
Kansas	Texas	Maine	
Louisiana	Utah	Maryland	
Michigan	Virgin Islands	Massachusetts	
Minnesota	Virginia		
Mississippi	West Virginia		
Missouri	Wisconsin		
Nebraska	Wyoming		
Nevada			

CDC officials told us that they expect all states to be reporting newly diagnosed HIV cases by 2003 and that an additional 1 to 3 years may be needed to get all HIV cases entered into a new reporting system. The potential for lags in reporting the older cases was clear when we

compared the experience of states that had been reporting HIV cases for different lengths of time. States with long reporting histories had many more HIV cases compared with their number of AIDS cases than did newly reporting states. This is illustrated by comparing Texas and Colorado. Texas just began reporting HIV cases in 1999 but Colorado has been reporting since 1985. Reported HIV cases in Texas are about one-eighth the number of AIDS cases. In Colorado, with a much longer reporting history, the number of reported HIV cases exceeds reported AIDS cases by a factor of about 2 to 1. (See fig. 3.) The extent to which states can identify preexisting cases once they begin HIV reporting is not known. Some of the discrepancy, illustrated by the Colorado and Texas comparison, could be reduced as Texas identifies more preexisting cases. States that begin reporting more recently may continue for some time into the future to have a larger proportion of previously diagnosed but not reported cases.

Figure 3: HIV Reporting Not Comparable Across States



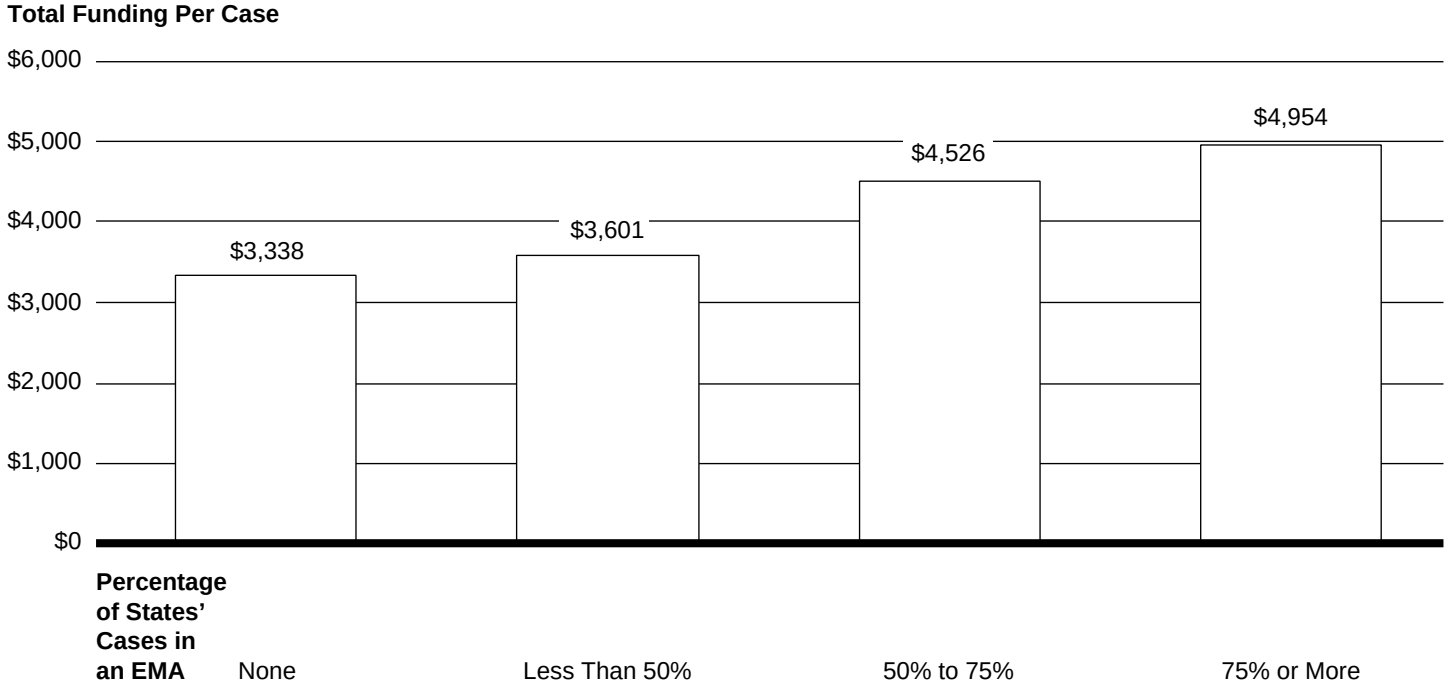
The cost of serving persons who have HIV disease can vary substantially, depending on the stage of their disease. Persons whose disease has progressed to AIDS often require more expensive drug therapies and more intensive care. If HIV data were integrated into the funding formulas, greater weight could be assigned to persons whose need for therapy are in the more expensive stages of the disease. Doing so would better ensure that the distribution of funds is commensurate with the cost of care. Information on such cost differences and how to estimate the number of persons in different stages of the disease would need to be addressed before this type of adjustment could be incorporated.

States With No EMA Are Disadvantaged Under the Current Formula Structure

Whether states have an EMA or not, they have the same service delivery responsibilities: to provide health care and support services to persons who have HIV disease. However, states with EMAs receive more funding per case because EMA AIDS cases are counted once in distributing title I funding and counted a second time in distributing title II funding. States without an EMA receive no funding under the title I distribution, and, thus, when total Ryan White resources are considered, some states receive considerably less than others per case. The magnitude of these funding differences is illustrated in figure 4. In fiscal year 2000, states that have no EMA have received approximately $3,340 per case. States with less than 50

percent of their cases within an EMA have received $3,600 per case. States with more than 75 percent of their cases within an EMA have received nearly 50 percent greater funding than states with no EMA, or $4,954 per case.

Figure 4: States With No EMA Receive Less Funding



A comparison of Colorado and Indiana provides a clear example of these funding disparities because both states have roughly 2,300 living AIDS cases. Colorado has an EMA because most of its cases are concentrated in the Denver metropolitan area. Indiana's cases are more dispersed. As a consequence, Indiana does not have an EMA and receives no title I funding. The effect is that Indiana receives $3.3 million less to help it serve the same number of cases as Colorado.

The Hold-Harmless Provision Currently Benefits a Single EMA

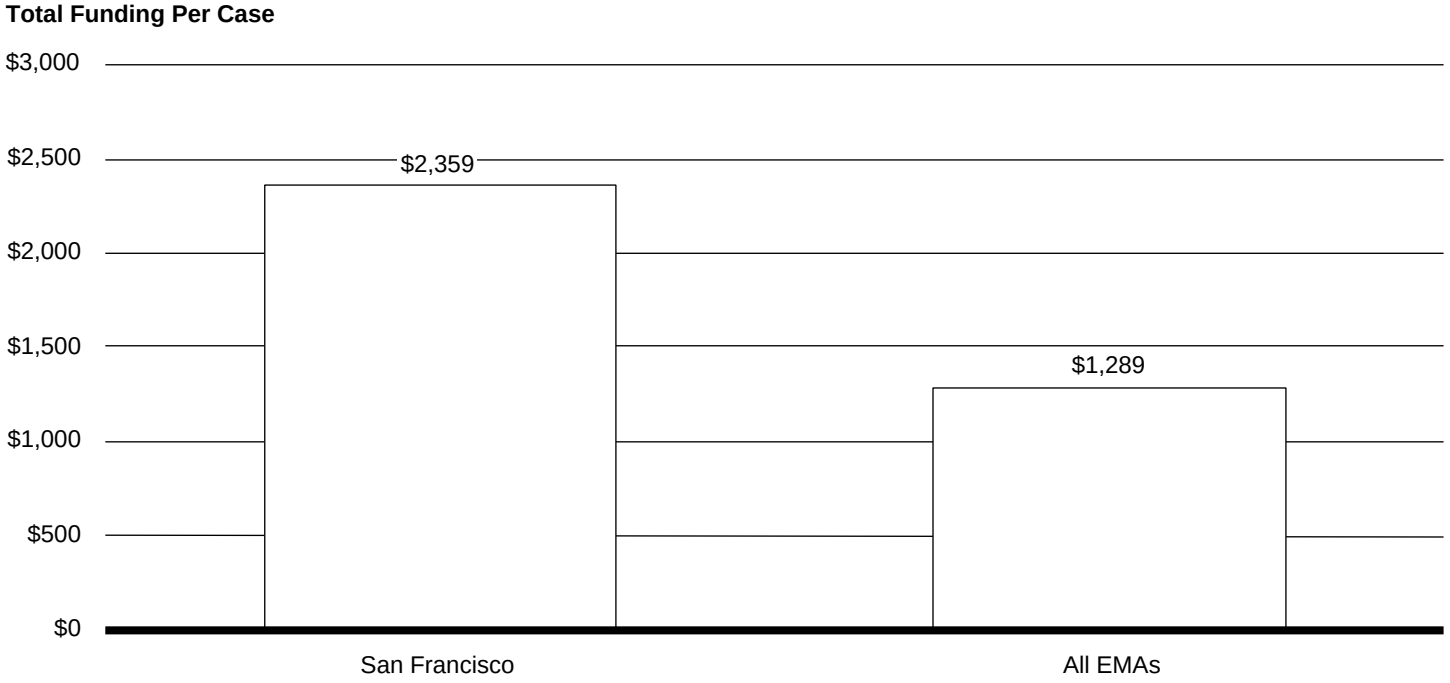
Finally, I would like to discuss the hold-harmless provision added to title I in the 1996 reauthorization. Before the 1996 reauthorization, funding was distributed among EMAs on the basis of the cumulative count of diagnosed AIDS cases. By 1996, many persons diagnosed with the disease in the 1980s had died, yet they were still counted for purposes of distributing funding to EMAs. The areas of the country with the longest experience with the disease had the most deceased cases and benefited the most from using cumulative case counts in the formula.

The 1996 Ryan White reauthorization changed this practice by replacing cumulative case counts with estimates of living AIDS cases. The effect of the change was to shift funding away from EMAs with high proportions of deceased cases and toward those with higher proportions of newly diagnosed cases.

Because these shifts would have been quite large, a hold-harmless provision was added so that the EMAs that were affected would gradually make a transition to an allocation based on living AIDS cases. Under the transition rules adopted at that time, EMAs that would otherwise have lost funding were guaranteed to receive in fiscal year 1996 the same funding they received in 1995, 99 percent in 1997, 98 percent in 1998, 96.5 percent in 1999, and 95 percent in 2000.

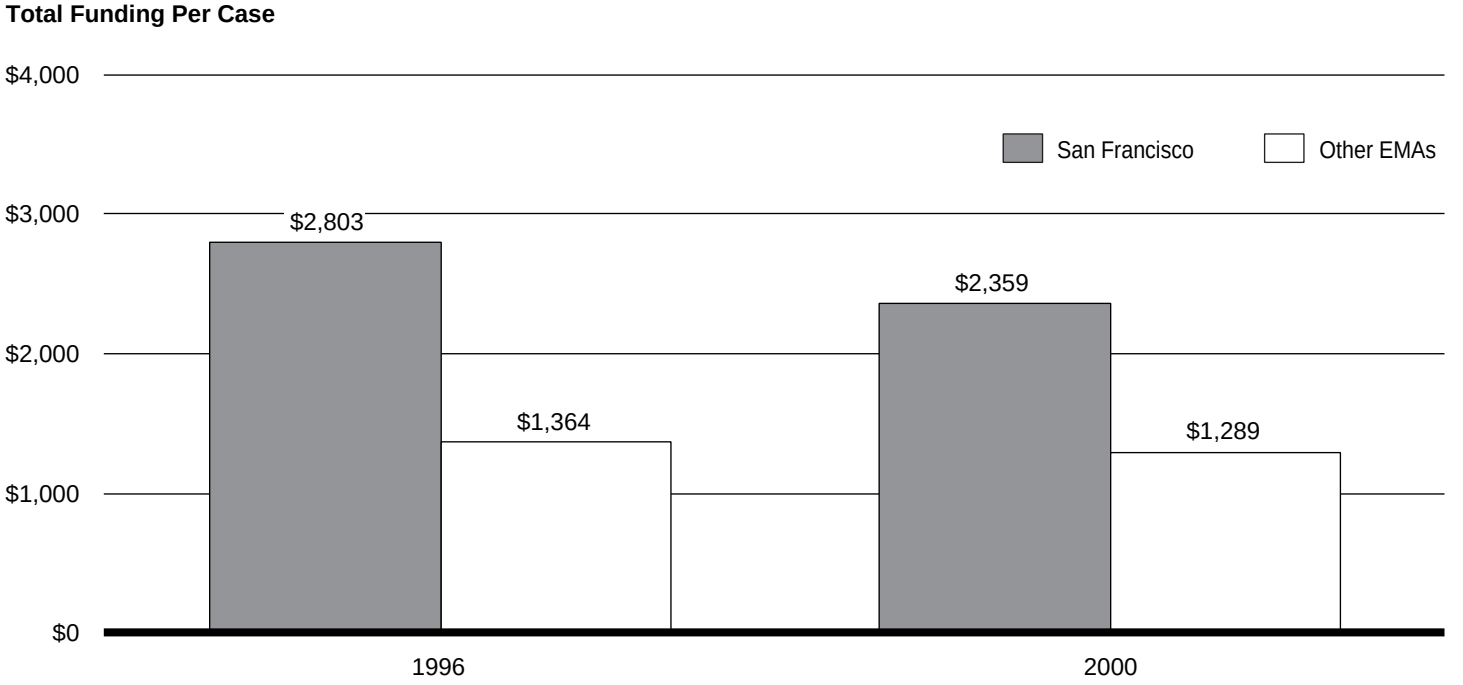
HRSA records show that four EMAs benefited from the hold-harmless provision in 1996: Houston, Jersey City, New York, and San Francisco. By 1999, San Francisco was the only EMA that continued to benefit from the provision for two reasons. First, it had benefited the most from using cumulative rather than live cases before fiscal year 1996 and second, it has had smaller increases in newly reported cases than other EMAs. It received 80 percent more title I funding than other EMAs: $2,360 per case compared with $1,290 in fiscal year 2000 (see fig. 5).

Figure 5: San Francisco Receives Substantially More Funding Than Other EMAs



The high grant that San Francisco derives from the hold-harmless provision has declined somewhat but continues to be sizable. Figure 6 shows that in fiscal year 1996 San Francisco's title I grant was more than twice the grant of other EMAs. In fiscal year 2000, it has been reduced to roughly 80 percent.

Figure 6: San Francisco's Funding Advantage Has Declined Modestly, Fiscal Years 1996-2000



As I noted earlier, roughly half of title I funding is distributed by formula, and half is distributed on a discretionary basis. Discretionary funding is awarded on the basis of the quality of proposals submitted to HRSA. The discretionary grants awarded to San Francisco appear to reflect the hold-harmless provision as well as those in need. For example, for fiscal year 2000 San Francisco's discretionary award per AIDS case was roughly twice as large as the average for the other EMAs.

In conclusion, Mr. Chairman, the HIV-AIDS epidemic continues to evolve and the location of the disease continues to change as well. As a consequence, it becomes increasingly important that federal resources match the distribution of persons who suffer from this dread disease. When data on all living HIV cases become available in the next few years, their inclusion in funding formulas will improve the ability of the Ryan White CARE Act to effectively deliver funding to persons in need. However, improvements in matching funding to persons in need of health and support services could also be achieved with this reauthorization if, as we have recommend, the double counting of EMA AIDS cases was phased out. We would be happy to work with subcommittee to achieve this.

Mr. Chairman, that concludes my prepared statement. I would be happy to answer any questions that you or other Members of the Subcommittee may have.

GAO Contacts And Acknowledgments

For future contacts regarding this testimony, please call William J. Scanlon at (202) 512-7118 or Jerry Fastrup at (202) 512-7211. Greg Dybalski and Michael Williams also made important contributions to this statement.

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