

Addressing Disparities in Federal HIV/AIDS CARE Programs June 23, 2005

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MR. CHAIRMAN: So we don't delay our panelist and those testifying will start. Today's hearing will examine the financial status of the Ryan White Care Act, the nation's largest provider of AIDS specific services, which Congress is expected to re-authorize later this year. I have the privilege of authoring the 2000 re-authorization of this important law and as a practicing physician I have cared for numerous patients with HIV who relied upon the Care Act for their medical needs.

Twenty years ago I delivered a baby girl who would become the first child I ever delivered to die from AIDS. I discovered she was infected with HIV after I diagnosed her mother with full blown AIDS and full blown pneumocystis infection. The mother died two and half weeks after we learned she had the disease. Her daughter struggled through seven years of treatment of course she succumbed to the same fate as her mother. Back then much was still not known about HIV and AIDS. New medical therapies were available to treat the disease. The epidemic was believed to be almost centered in a few metropolitan areas among a very specific group of high-risk individuals. Even within the public health community, fear and a lack of knowledge about this new disease left many of those living with the virus unable to access what care that did exist and fear of stigmatization kept many others from even seeking testing or treatment. Today, HIV affects every state in our

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nation and the virus does not discriminate against any particular race, gender, age or sexual behavior. Medical breakthroughs however have dramatically transformed HIV infection for many into a chronic manageable disease and thereby delayed the onset of AIDS.

In 1990 Congress passed the Ryan White Care Act to provide for the unmet health needs of persons living with HIV disease. The Care Act was named after Ryan White, an Indiana teenager whose courageous struggle with HIV/AIDS and against AIDS related discrimination helped educate our nation.

While the face of AIDS has changed our federal response has been slow to adapt those changes. Funding for the Care Act has increased dramatically from 257 million dollars in 1991 to over 2 billion dollars in 2005. Yet thousands of Americans with HIV are on waiting list for access to life saving AIDS medications and many other face formulary restrictions. While patients in Kentucky and West Virginia have died while on waiting list for treatment provided by the AIDS Drug Assistance Program one of the metropolitan areas actually receiving Care Act Funds for the deceased.

Further tens of millions of Care Act dollars go unspent annually in some jurisdiction while other states find themselves faced with cutting patient's access to life saving AIDS drugs. These disparities have been created by a number of factors. First the Care Act continues to distribute federal funds based not upon the number of people with HIV but rather

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AIDS, the end stage of HIV infection. It often takes up to ten years to develop after HIV infection and now thankfully for the new innovations even later. Because AIDS cases comprise only a fraction of the total population of those living with HIV this misplaced emphasis as a bases for the Care Act funding ignores the vast majority with those of HIV. These affected communities are being ignored and not receiving a fair share of federal support. Studies have shown those with HIV but not AIDS are much more likely to be woman, Africa-American, Hispanic and those who live in rural areas. Incorporating HIV data into funding formulas and prevention strategies will ensure that we stay in front of the disease and that resources are directed toward where the disease is headed rather than where it was a decade ago.

In 2000 Congress sought to eliminate these disparities and treat all people with HIV/AIDS equally under the Care Act by incorporating all those living with HIV rather than just those diagnosed with AIDS and funding for it. The law requires that beginning no later than fiscal year 2007, cases of HIV disease reported to and confirmed by the Director of the Center of Disease Control and Prevention as sufficient and accurate and reliable will be the bases for Care Act funding priorities and formulas. Funding disparities have also been created by a Hold Harmless Provision in Title One of the Care Act. This Hold Harmless was intended to ensure that no metropolitan area suffered from dramatic funding decreases from one year to the

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next. While well intentioned this Hold Harmless has ironically caused harm in many areas and all but one of the 51 EMAs would fair better if the Hold Harmless were eliminated all together. Last year the San Francisco EMA received 92% of all Hold Harmless funding. As a result San Francisco receives twice the amount per AIDS cases as every other EMA and actually receives funding for AIDS patients that have long since passed away. The city finds itself in a unique position where it must find ways to spend excess money on non-essential services while its reported AIDS cases continue to drop. In sharp contrast the largest AIDS service provider, in the country, in Washington, D.C., the D.C. EMA is faced with dire financial problems that have forced the closing of several offices, massive staff layoffs despite a growing population affected by HIV/AIDS.

In addition some states benefit from double counting where AIDS cases are actually counted twice, once for funding under Title I and again under Title II. States that receive Title I funding receive 38% more per AIDS case than states without an EMA. Beyond simply addressing the formulas to ensure funding equity services provided by the Care Act must also be updated. When it became law fifteen years ago, few medical therapies existed and the Care Act primarily provided social services and end of life care for those with HIV/AIDS. What a wonderful progress we've made. Since that time medical breakthroughs have contributed to a great transformation in the lives of those with HIV. AIDS deaths have dropped

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significantly and for many HIV has become a chronic rather than a terminal disease. As a result, more Americans are living with HIV than ever before and the cost of life saving drugs is considerable. A drug combination including Fusion for example can cost between thirty and thirty five thousand dollars a year to treat a single patient. This incredible cost to provide essential treatment underscores the need to prioritize core medical services and effective prevention. Let me say that again, prioritize core medical services and effective prevention. US Federal government is expected to spend nearly 20 billion dollars on HIV/AIDS related programs this year alone and we as a nation have committed ourselves to provide billions of dollars worth of medication and care services for those living with HIV in Africa and elsewhere. Clearly there is no acceptable reason why such a large financial investment that any American living with HIV cannot access medically necessary care.

I look forward to hearing from our witnesses today to include Dr. Marcia Crosse, Director of the Government Accountabilities Office on Public Health and Military Healthcare issues. Dr. Deborah Hobson, Associated Administrator of the Health Resources and Services Administration HIV/AIDS Bureau, Dr. Robert Janssen, The Divisions of HIV/AIDS Prevention of the National Center of HIV, STD and TB Prevention at The Centers for Disease Control and Prevention, and Dr.

Michael Montgomery, Chief of the Office of AIDS for California

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Department of Health Services. Senator Lautenberg.

SENATOR LAUTENBERG: Pardon me. Thanks Mr. Chairman and I note I would respect your background and your interest and your view on things but I do appreciate your willingness by Congress in 1990 and as most know it was named after Ryan White, the young Indiana person whose brave struggle against related discrimination helped to educate our nation. The good news is and we heard it from Senator Colburn that in the years since this legislation was passed we've seen dramatic breakthroughs in treatments. Today a diagnosis of AIDS is no longer a death sentence. The bad news is that it is still a very serious problem and it continues to spread. Now more than 30 thousand people in my home state of New Jersey are living with HIV or AIDS. The number increased 3.5% over a six-month period last year. Of those 30 thousand New Jersians with HIV and AIDS more than one-third are women. New Jersey ranks first in the percentage of woman diagnosed with AIDS within the United States and third in the number of pediatric AIDS cases. I once visited a ward in Jersey City that where pediatric AIDS victims were housed and it was a tragic site to witness. Today, Ryan White Care reaches more than an half of a million Americans every year and it's our nation's largest program specifically targeted to help people living with HIV disease. The Care Act was amended and re-authorized in 1996 and once again in 2000. It is due for another re-authorization by September 30th of this year.

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When the Care Act was authorized by the Senate in 1990 no funds were appropriated in the original Labor HHS budget that year. I worked hard along with Senator Byrd from West Virginia to find funding for the original Care Act. I also worked to ensure that smaller cities which had a high per captia rates of AIDS were included in the Title I funding formula. By way of example I worked to include Jersey City as one of the special targeted recipients of aid along with the newer metropolitan area. Over all New Jersey has six areas that are eligible to receive funds under Title I of the Care Act and I hope this committee will support the re-authorization of this important program. I also urge my colleagues to oppose any effort to shift funding from areas with the high concentrations of HIV and AIDS cases. Mr. Chairman I believe that while the cost I think then the funds have effectively been put to good use. I think you have to have some kind of structure to get things to the patients and the people who ought to be cautious about the fact that AIDS is transmittable and a violent outcome. So, I thank you very much and look forward to hearing from our witnesses.

MR. CHAIRMAN: I am going to ask the witnesses to limit their testimony to ten minutes and I am also going to make a comment about availability of your testimony. And this is directed towards the Administration and not the individuals sitting here because I know the betting process under which your testimony goes. Three hours before this committee hearing

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we got testament that is totally unacceptable. For us to discuss a subject as serious as this and the Administration prove itself in capable or incompetent to bring forth testimony on a hearing that they have been aware of two weeks. So I would hope that you would take that message back so that in fact we can do the job and without timely availability of testimony, which I understand either Dr. Jansen or Dr. Hobson is your fault. The fact is the timeliness and availability that testimony allows us to do a better job here and ultimately fund this program better. I want to recognize Dr. Robert Jansen, M.D., Director of the HIV Prevention National Center for Infectious Disease to go first and Dr. Hobson, Associated Administrator for HIV Health Resources Services and Department of Human Services to go second and Dr. Michael Montgomery, Chief of Office of AIDS, Department of Health and Human Services in Sacramento California, followed by Dr. Gross, Director of Public Health and Military Care Issues. Dr. Jansen.

ROBERT S. JANSSEN, M.D.: Thank you Mr. Chairman. Thank you Senator Lautenberg. Thank you for the opportunity to discuss trends in HIV and AIDS in the United States and the status of HIV surveillance systems. At the National HIV Prevention Conference held in Atlanta last week, CDC announced there is now an estimated one million thirty nine thousand, one million one hundred eight five thousand Americans living with HIV or AIDS. This is an increase from the 850,000 to 950,000

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reported five years ago.

Due to more effective treatment people are living longer and healthier lives after diagnosis of HIV. Despite the growing pool of persons capable of transmitting the virus we estimate the number of person becoming newly infected each year have remained constant over the last ten years. At approximately 40,000 new infections per year as you can see in this figure. CDC analysis of trends in HIV diagnoses include all new HIV diagnoses with or without an AIDS diagnosis in the 32 states that have conducted confidential named bases HIV/AIDS case reporting for at least four years. Between 2000 and 2003 one hundred twenty five thousand eight hundred people were diagnosed with HIV infection in these 32 states. During 2000 to 2003 the overall rate of HIV diagnoses that is the number of diagnoses per one hundred thousand people remained stable. It was 19.5 in 2000 and 19.7 in 2003, however sharp racial disparities continue to exist. Rates of HIV diagnoses among African Americans are significantly higher than among other racial and ethnic groups. Looking at trends by risks, the annual diagnoses among men who have sex with men or MSM increased 11% during this four-year period. MSM accounted for 44% of cases in this time period. The annual number of diagnosis associated with high-risk heterosexual contact remained roughly stable from 2000 to 2003 while new diagnoses associated with injection drug use declined slightly. In 2003 the highest rate of HIV diagnoses were among African American

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males, 103 per hundred thousand population. That is a rate that is nearly three times the rate among Hispanic males and seven times the rate among white males. The rate of HIV diagnoses among American females in 2003 was 53 per hundred thousand. That is almost five times higher than Hispanic females and more than 18 times that among white females. Among American Indians, Alaskan Natives the rate of HIV diagnoses among males was slightly higher than the rate among white males and the rate among females was twice that among that of white females. The lowest rates by gender are among Asian and Pacific Islander males and females.

AIDS cases and deaths reported from all U.S. states and territories continue to provide a valuable measure of the impact of the disease. Data on the number of new AIDS cases provide us with measures of late stage disease that are not reflective of the entire epidemic. HIV progresses to AIDS in an untreated person in approximately 8 to 10 years and even longer for persons receiving treatment. The number of persons diagnosed with and dying with AIDS after the introduction of highly active antiretroviral therapy dropped dramatically until 1998 and since then has remained relatively constant. African Americans continue to be most severely affected by AIDS. In 2003 rates of AIDS cases were highest among African Americans, next highest among Hispanics then American Indian and Alaskan natives and then whites and lowest among Asian and Pacific Islanders. From the end of 1999 to the end of 2003 the number

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of persons in the United States living with AIDS increased 30% from a little over 311,000 to nearly 406,000.

CDC is responsible for ensuring the integrity of the National HIV Surveillance System to accurately monitor the epidemic in the United States. CDC also provides funding, technical assistance in coordinates activities with states to aggregate data that comprises this national system. As with other diseases, individual state governments have statutory and regulatory authority for HIV/AIDS reporting and data protection including the decisions as to what methods will be used for disease reporting such as name based or code based. Except for HIV all other reported infectious diseases including AIDS are routinely reported to states using named bases reporting systems. The states then remove names before submitting the data to CDC. Since the beginning of the epidemic AIDS Surveillance has been the cornerstone of national, state and local efforts to monitor the scope and the impact of the HIV epidemic. AID surveillance data however no longer accurately describe the full extent of the epidemic as effective therapy slow the progression of HIV disease. It is more accurately described the epidemic in 1999 CDC recommended that all states implement reporting of HIV diagnoses and advised that cases be reported to local and state health departments by name.

To reach the goal of nationwide high quality HIV data as of today CDC is now moving from advising to recommending jurisdictions use named based HIV reporting using the same

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named bases approach that is currently used for AIDS surveillance nationwide. Currently 38 states and five territories have adopted Name Based HIV Reporting. Seven states and the city of Philadelphia and the District of Columbia have Code Based Reporting in which a code is reported to the Health Department. Five states have Name to Code Reporting in which a name is reported to the Health Department and the Health Department creates a code. Implementation of HIV infection, second slide yeah. There are fourteen areas that use codes and in those areas thirteen different codes are used.

All states do not use a uniform name bases approach to reporting. There are limitations to the current National HIV Reporting Database. These limitations include national data on HIV diagnoses are not representative of some high morbidity areas for example, California whose data are not included. Despite a growing number of states with quality systems the staggered implementation of HIV reporting means HIV data at the national level are currently less accurate than AIDS data at the national level.

In 1999 CDC published a set of Performance Standards for HIV Reporting Systems. CDC reports HIV infection data only from areas conducting confidential Named Based Reporting because this reporting has been shown to routinely achieve high levels of accuracy and reliability. Confidential Named Based Surveillance Systems have been shown to meet the necessary

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performance standards. Studies have also shown that implementing Code Bases and Name to Code Systems are more expensive to implement than confidential Name Based Systems. Currently only confidential Named Based HIV Reporting integrated with AID Surveillance data can be used by states to identify and remove cases that are counted in more than one state a process we call E-Duplication before they can be incorporated into the CDC National Surveillance Database.

The last Ryan White Care Act re-authorization called for the Institutes of Medicines study of states HIV Surveillance Systems and their adequacy and reliability for the purpose of using such data for the basis for Care Act Formula Grant allocation. Re-authorization also called for the Secretary of Department of Health and Human Services to make a determination regarding the use of HIV data for Care Act formulas. The Institute of Medicine issued a report. Measuring What Matters, on allocation, planning and quality assessment for the Care Act. Based on the report findings in June 2004 the Secretary determined that HIV data not be used for purposes of making formula grants under Title I and II of the Ryan White Care Act and that estimated living AIDS cases continue to be utilized until such time high quality HIV data are available nationwide.

We continue to work closely with the states to help them adopt and implement high quality HIV surveillance systems.

Having all states collect HIV information in the same matter

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will ensure that the nation has reliable and valid data to monitor and describe the scope of the epidemic to ensure equitable distribution of resources to those with greatest need and to plan for and evaluate prevention, care and treatment programs. A uniform system is needed for measuring HIV incidences. It is also needed for evaluating HIV and AIDS care in the United States. We have recently launched the Morbidity Monitoring Project which is a study which when fully funded will allow nationwide estimates of the quality of HIV and AIDS care. Also reasons why people are not receiving care and information on sexual and drug use risk behavior. Again I want to thank you Mr. Chairman and the committee for this opportunity to talk about HIV and AIDS trends in the United States and HIV Surveillance Systems. Thank you.

MR. CHAIRMAN: Dr. Hobson.

DEBORAH P. HOPSON, PH.D.: Good afternoon. Mr. Chairman, members of the sub-committee thank you for the opportunity to meet with you today on behalf of the Health Resources and Services Administration to discuss the programs of the Ryan White Comprehensive AIDS Resources Emergency Act also known as the Care Act. We certainly appreciate Dr. Colburn your continuing support that you and your colleagues have for the Care Act Programs. Your interest in the Care Act services is certainly welcome given the state of today's epidemic as just described by the CDC.

The Ryan White Care Act is the centerpiece of our

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domestic response to care and treatment needs of low-income people living with HIV and AIDS. Currently funded at 2.1 billion dollars it provides primary healthcare, life saving medications and support services to individuals who lack health insurance and financial resources to provide for themselves. On two occasions including his most recent State of the Union Address, President Bush has addressed the importance of this program and has called for the timely re-authorization of the Ryan White Care Act. Since its last re-authorization we have been able to provide antiretroviral treatment, primary care and support services to over a half million people annually in the United States, Puerto Rico, the Virgin Islands and Pacific Basin. Fifty percent of these individuals live below the federal poverty level. Less than 10% had any private health insurance and less than 30% were enrolled in Medicaid. In 2003 over half of the Ryan White clients were African-American. The Ryan White Care Act programs have provided important benefits to these populations. Overall AIDS mortality is down and lives have been extended with HIV/AIDS medications purchased through the AIDS Drug Assistance Program also known as ADAP. Pregnant women have been provided with care that has allowed them to give birth to children free from HIV infection and thousands have received support services that have allowed them to access and remain in healthcare. Although we are making progress in providing services to people living with HIV and AIDS, the epidemic is not over and will be in need of our continuing

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attention for some time to come. The president and the secretary understand the dynamics and the severity of the epidemic and they are committed to ensuring that the departments, HIV/AIDS Programs are as effective as possible in preventing infection and treating those who become infected. During the past five years we have recognized that, as an essential as the Care Act has been to serve Americans living with HIV and AIDS it is an imperfect instrument in need of revitalization. Despite record levels of funding we continue to face waiting list for life saving drugs through the ADAP and there are marked disparities in access to quality medical treatment across the country. As minority populations are increasingly and disproportionately impacted by HIV/AIDS changes to existing systems of care designed for an earlier epidemic are increasingly urgent. We are challenged as never before to make sure that federal funds are directed where they are most needed and used for the most vital purposes.

President Bush has laid out three principals for the re-authorization of the Care Act. First, that we should focus federal resources on life extending medical care such as antiretroviral drugs, doctor visits and lab test. Core services that are critical to maintain the health and well being of people living with HIV and AIDS. Second, that we provide greater flexibility so that Care Act resources can be targeted to areas of greatest need and third, that we ensure accountability in all that we do. Based on the new CDC data it

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is estimated as Dr. Jansen has just said that there are between 1 and 1.2 million people living with HIV/AIDS disease in the United States. Approximately 40,000 new HIV infections and over 18,000 AIDS related deaths occur per year. Of those living with HIV disease 74% are male, 47% are African-Americans while 34% are white and 17% are Hispanic. In addition to challenges related to poverty and lack of adequate health insurance individuals living with HIV disease commonly face other problems. About 22% of those with HIV/AIDS were infected through injection drug use and an estimated 20 to 50% of people living with HIV/AIDS suffer from mental illness both related and unrelated to their infection and co-infection with Hepatitis B and C is an increasing problem.

As I stated earlier each year the Care Act programs primarily through grants to states, metropolitan areas, providers and educators reach more than a half-million underserved persons more than half of those living with HIV/AIDS in the United States. Since AIDS was first recognized the pattern and the treatment of HIV disease has shifted. Now we can strive to manage HIV/AIDS as a chronic disease. More than 2,700 providers funded by the Care Act programs are providing primary care and treatment and are building networks with other public and private providers to expand the response to the epidemic. Innovative outreach programs and community based points of entry such as public health, social service and substance abuse treatment organizations help to extend the Care

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Act services to hard to reach and at-risk populations. Since the initiation of the Care Act programs in 1990 perinatal transmission of HIV has declined dramatically. Less than 2% of all Care Act HIV positive clients are children under 12 or younger due in large part to the advances and prevention of perinatal transmission. The CDC reports that in twenty-five states with long standing confidential Named Based HIV reporting cases of HIV/AIDS in infants born to HIV infected mothers declined 74% over the ten year period from 1994 until 2003. Access to antiretroviral therapy for the Care Act population has been expanded through cost mechanisms used by individual state aid ADAPs and other discount programs. Antiretroviral therapy has lead to longer, healthier lives for individuals living with HIV and AIDS. As a result, almost one-third of the Care Act population is age forty-five or older. ADAP which provides funds to states to purchase live saving medications is the single largest Care Act program because of the high cost of medications and the growing number of people living with HIV and AIDS. In fiscal year 2005, HERSHA distributed 787.5 million dollars in ADAP funds to states. In the fiscal year 2006 President's budget request includes a ten million dollar increase for ADAP. The ADAP program reaches approximately 90,000 people every month. This program is state defined and thus differs in eligibility criteria and formularies from state to state.

The Epidemiology and treatment of HIV has shifted in

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recent years to a more chronic disease model requiring a changing continuum of services to support this model. This shift and the success of new treatments has resulted in longer life spans and an overall increase in the demand for care and related treatments. Going forward the greatest challenge is reaching people who have nowhere else to turn especially HIV/AIDS prevalence, healthcare cost, and the burden of HIV among the uninsured and the underinsured increases. Resources are likely to become more and more strained as the Care Act's outreach efforts coupled with CDC's prevention initiatives continue to successfully identify individuals living with HIV disease. These newly infected individuals are more likely to be low-income, to be minority and to have complex co-morbidities as I mentioned before. Many will live in rural areas. Strengthening healthcare and community organizations capable of serving these populations will be an increasingly important role in the Care Act's next decade. Mechanisms to allocate funds must be cognizant of these changes. Hold Harmless provisions, formulas based on AIDS rather than HIV, and allowing funds that have not been put to work in a timely manner to roll over or revert to their treasury rather than giving DHHS the necessary flexibility and authority to reprogram resources to the communities in need must be re-engineered.

We take great pride in the advances and the care and the support for people living with HIV/AIDS that have been made

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by the Care Act program over these last fifteen years. We are thankful to you for your help and that of the dedicated providers and communities all over the country. However, we are humbled by the significant challenges that remain to reach people living with HIV/AIDS who have no where else to go for care in an age of increasing HIV/AIDS prevalence, increasing healthcare cost and a growing burden of HIV among the uninsured and underinsured. We will soon be releasing an expanded set of policy points based upon the President's principals. We intend these to serve guidepost for discussion and deliberation on the very tough issues we must face together. How we ensure that the most vulnerable and needy in this country receive life saving treatment. How to work more effectively with state and local governments and communities impacted with HIV. How to hold ourselves and our partners more accountable for the use of federal tax dollars and importantly how to advance HIV prevention in this nation. We look forward to working with you to revitalize the Care Act. Thank you.

MR. CHAIRMAN: Thank you Dr. Hobson. Dr. Montgomery.

MICHAEL MONTGOMERY: Good afternoon Mr. Chairman and distinguished members of the committee. My name is Michael Montgomery, Chief of the Office Of AIDS for the California Department of Health Services. I am also the Chair of the National Alliance State and Territorial AIDS Directors or NASTAD. I want to thank you for inviting me to speak with you today to discuss the importance of the Ryan White Care Act in

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helping states to provide comprehensive care and treatment services to persons living with HIV and AIDS. State AIDS Directors appreciate the long-standing support of the United States Senate for the Ryan White Care Act program. Assuring that all people with HIV and AIDS regardless of geographic location have equal access to appropriate and high quality HIV and AIDS services is our highest priority.

I would like to share with you some of the views of my fellow State Aids Directors in addition of those in the State of California. I have limited my comments to those that address the disparities in the Care Act where our issues covered the ongoing GAO investigation. California Office of AIDS administers California's HIV/AIDS Prevention and Care programs, which are funded by federal and state funds including Care Act Title II funds. HIV infections have penetrated nearly every metropolitan and rural communities in our state. California remains an epicenter of the AIDS epidemic with 137,213 accumulative cases and 57,308 individuals living with AIDS as of May 31, 2005. To date California has 37,531 reported HIV non-AIDS cases. In federal fiscal year 2005 California received 221 million dollars in Ryan White funding for Titles I and II including 31 million dollars for Title II based, 90 million dollars for ADAP, and 169,000 for a single emergent community, Bakersfield. California has nine Title I eligible metropolitan areas that are funded at 99 million dollars.

Governor Schwarzenegger and the California legislature have

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demonstrated their commitment to HIV/AIDS care and treatment by providing 111 million dollars in state general funds despite California's continuing budget deficit. For people with HIV the Care Act is the safety net under which other public programs are the safety net under public programs such as Medicaid and Medicare. The Ryan White programs must adapt to fill the gaps particular to each state. ADAPs work closely with their state Medicaid programs to ensure that ADAPs remain the last resort. In particular, state ADAPs will be working to fill gaps in coverage for those enrolled in the new Medicare Prescription Drug Plans and those who have incomes over 150% of the federal poverty level. As the payer mixes in cost of delivery of care vary across the country it makes the exercise of comparing Care Act programs from one state to another exceedingly challenging. Annually ADAP serve approximately 136 thousand clients or about 30% of the people with HIV and AIDS estimated to be receiving care nationally. In conjunction with my colleagues from New York I helped to establish NASTAD's ADAPs crisis task force to negotiate with the pharmaceutical industry on behalf of all ADAPs. Although the large states have the bargaining power we feel it is critical that all ADAPs large and small have access to the same prices and discounts. The task force began negotiations in March of 2003 with AIDS manufacturers of AIDS drugs. As a result of this highly successful public/private partnership we achieved supplemental discounts, rebates and price freezes that achieved 90 million

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dollars in savings during fiscal year of 2004. ADAPS received the lowest available prices in the country for Antiretroviral therapies. Understanding that there are disparities between states and what they are able to offer in terms of services State AIDS Directors recommend keeping the Title II based formula as is. Equity among the states cannot be achieved simply by rearranging the 334 million dollars in the Title II base and the problem and geographic disparities cannot be solved in the back of Title II alone. The entire Care Act must have responsibility to achieve equity for persons living with HIV and AIDS. In looking at per AIDS case funding disparities from state to state one needs to take in consideration Title III, Title IV and Part F in addition to Title I and II. In the re-authorization of the Care Act in 2000 language was included which directed HERSHA to prioritize Title III funding and non-title areas. This has been notably successful in moving towards geographic equity in funding and any analysis of per AIDS expenditures while looking at Titles I and II alone distorts the equation.

Disparities in the availability of resources affect the accessibility in equality of HIV services both within and between states. State AIDS Directors recognize that the multi-titles structure of the Ryan White Care Act contributes to the challenges faced by some states ineffectively addressing the needs of persons living with HIV and AIDS. In many states the current structure is a contributing factor to funding

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disparities that effects availability, accessibility and quality of services both within and between states as well as the coordination of HIV care and efficient delivery of essential services. While the Ryan White Care Act cannot be viewed as the sole mechanism for equalizing these inherent differences the current structure of the Care Act leaves many states struggling with the care and delivery of the coordination of HIV services while trying to meet the legislative mandates to provide for the public health of its citizens.

In recommending retaining the current structure of the Care Act State AIDS Directors do so while establishing the following two goals, which are reflective of our vision for improved HIV, care services in the nation. One, to enhance the availability of ADAP resources and services for persons living with HIV and AIDS and need in all areas of the nation and two to provide additional resources to states with chronically insufficient Title II base funds by strengthening the emergent community's mechanism. Time does not permit for me to describe the details of these proposals, which are outlined in my submitted testimony, and NASTAD's recommendation is to guide the 2005 re-authorization of the Ryan White Care Act.

State AIDS Directors believe the current emergents communities vision should be modified to address the needs of states with a sever lack of Title II base resources that fund critical primary care and support services. Authorized in

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2000, the Title II emergents Community Supplemental Grant sought to address the challenges faced by areas with a significant burden of AIDS cases but lacked the destiny of cases to be a Title I EMA. Since its creation the emergent communities have been subject to significant funding fluctuations due in large part to emergent communities not permanently being eligible once they begin receiving funds. The number of areas eligible for these supplemental grants has continued to diminish over the five-year re-authorization period because of reductions in the number of AIDS cases. In the past four years fourteen emergent communities have been eliminated all together. We strongly support incorporation of HIV data and Care Act distribution formulas. We believe the use of HIV cases in addition to AIDS cases in more closely reflects the epidemic than living AIDS cases. Forty-three jurisdictions have Named Based HIV Reporting, the remaining thirteen jurisdictions utilizing a name or a Name to Code System for Reporting HIV cases. Several jurisdictions have only recently implemented HIV reporting both Code and Name based and therefore their HIV data is not yet considered mature enough to use in funding formulas. To incorporate HIV data in fiscal year 2007 CDC will need to develop methodology to estimate HIV cases for these states. State AIDS Directors urge that the CDC be required to work the states in developing this methodology. California is the only state among the five largest that uses a HIV reporting system different from its AIDS Reporting System.

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The Schwarzenegger Administration is concerned by not converting into a Named Based Reporting System California risk losing its fair share of Carrot Funds when the funding formula changes. While legislative attempts were unsuccessful this year to change from a Code to Named Based Reporting a spirited dialogue in California continues. Having said that, State AIDS Directors unanimously agree that our federal funds should not be withheld in order to force states to which reporting systems. We believe that surveillance is within the domain of the states. States should determine what methodology best serves the needs of their citizens.

State AIDS Directors unanimously agree that expiring un-extended funds must be put back into the Care Act rather than return to the treasury as is the currently the case. Our ADAP proposal would redistribute un-obligated and expiring funds from all titles back into the ADAP program. Unspent funds typically result from delays and notice of grant awards from federal government, from timing issues related to sub-contracting of services, payroll savings due to state hiring delays or freezes, expenditure of other funds for similar services or unanticipated fluctuations in spending at the state level. California currently has 5,319 dollars in carryover.

States with excessive and chronic amounts of un-obligated funds need immediate technical assistance from HERSHA to address issues that are hindering a state from spending their award. We support HERSHA providing HERSHA with the

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authority to move un-obligated funds from states with identified need lower than federal funds appropriated to states with chronic shortages. State AIDS Directors support the continuation of the Hold Harmless provision for Title II base at a reduce rate of loss. From California's perspective the Hold Harmless is necessary to protect California from under funding resulting from the estimated living AIDS cases formula, which under estimates California's actual living AIDS cases by 30%. A twenty million dollars lost to the state in current years Title II funding. Experience shows that after the last re-authorization due to the unattended consequences of changes in the law 30 states were held harmless from significant and funding losses. With limited funding as well as three consecutive years to cuts to the Title II base these disparities cannot be corrected be a major shifts in Title II resources without impacting critical existing services and jurisdictions that would lose funding. However, we support the removal of the second Hold Harmless Provision of the overall Title II award that has resulted in the unattended effect of reducing the amount of money available for the ADAP Supplemental Allocation due to significant fluctuations in the emergent communities funding.

I hope my remarks have illustrated the critical and importance to the Ryan White Care Act to California and the complexities of addressing disparities and that you will consider the recommendations I have outlined. Thank you for the

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opportunity to speak to you today. I look forward to answering any questions that you may have.

MR. CHAIRMAN: Thank you Dr. Montgomery. Dr. Cross.

MARCIA G. CROSSE, Ph.D.: Yes. Mr. Chairman and members of the Sub-committee I'm pleased to be here today to discuss the Ryan White Care Act. As we have heard the Care Act makes funds available to states and localities to provide healthcare, medications, and support services to individuals and families affected by HIV and AIDS. In fiscal year 2004 over 2 billion dollars in funding was provided through the Care Act. The majority of which was distributed through Title I grants to eligible metropolitan areas or EMAs and Title II grants to states, the District of Columbia and territories. Metropolitan areas qualify as EMAs if they have a total of 2,000 reported AIDS cases in the previous five years. Titles I and II use formulas to distribute grants according to a jurisdiction's reported counts of AIDS cases. The Care Act re-authorizations in 1996 and 2000 modified the original funding formulas. Prior to 1996 the Care Act measured a jurisdiction's caseload by its cumulative count of AIDS cases. Which is the number of AIDS cases both living and deceased recorded since reporting began in 1981. The 1996 re-authorization changed the measurement to an estimation of the number of living AIDS cases. This switch would have resulted in shifts of funding away from jurisdictions with a longer history of the disease and a higher proportion of deceased cases. To ease these

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funding shifts the Care Act includes Hold Harmless Provisions under Title I and Title II that protect grantees from decreases in funding from one year to the next. Title I of the Care Act also includes a grandfather clause for EMAs that guarantees that once a metropolitan area has become an EMA it will continue to receive funding under Title I even if its caseload drops below the threshold for eligibility. The most recent re-authorization of the Care Act in 2000 maintained these modifications and it further specified that HIV cases should be used in funding formulas no later than 2007 as we have heard. HIV case counts have not been used to date to distribute funding under the Care Act. To assist the Sub-committee in its consideration of the Care Act my testimony provides our preliminary findings on some of the issues that we are reviewing for the Chairman and other requestors. My remarks today will focus on selective provisions of the Care Act; specifically I will discuss the impact of Care Act Provisions on the distribution of funds that is based upon the number of AIDS cases in metropolitan areas. The impact of the Care Act Hold Harmless provisions and a grandfather clause on the distribution of funds and the potential shifts in funding among grantees if HIV case counts had been incorporated in fiscal year 2004 funding formulas. Our analysis shows that certain Care Act Title I and Title II provisions related to the distribution of funds in metropolitan areas result in variability between the amounts of funding per case among

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grantees. As you will see in the figure states that have EMAs within their borders receive more funding per estimated living AIDS case than those without EMAs because cases within EMAs are counted twice. Once to determine Title I funding to EMAs and once again to determine a state's Title II grant. For example, states with no AIDS cases in EMAs receive about 36 hundred dollars per AIDS case. States with 75% or more of their cases in EMAs received about five thousand dollars per AIDS case or as the Chairman noted 38% more funding than states with no EMA. If the total Title I and Title II funding had been distributed equally per AIDS case among all grantees each state would have received about forty-eight hundred dollars per AIDS case.

Metropolitan areas that have been affected by the epidemic but do not have the necessary numbers of AIDS cases to become EMAs may qualify for funding as emerging communities under Title II. As the figures show the allocation of these grants is made by separating eligible jurisdictions into two tiers based on the reported numbers of AIDS cases. Because one half of the total emerging communities grant award is allocated to each tier regardless of how many cases are in each tier. In fiscal year 2004 jurisdictions in one tier with a total of 15,994 cases receive three hundred and thirteen dollars per case while jurisdictions in the other tier with a total of 4,754 cases received one thousand and fifty two dollars per case. The Hold Harmless provisions under Titles I and II and the grandfather clause for EMAs under Title I sustain the funding and

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eligibility of Care Act grantees. By guaranteeing either a certain percentage of previous years funding amounts or a EMAs eligibility to receive funding these provisions make it more difficult for Care Act funding to track the most current distribution of the epidemic. As this figure shows Title I Hold Harmless Provisions for EMAs has primarily benefited the San Francisco EMA, which received over 90% of the fiscal year 2004 Title I Hold Harmless Funding. San Francisco is the only EMA that has disease cases factored into its allocation. Because it is the only EMA with Hold Harmless Funding that dates back to the mid 1990s when funding was based on the accumulative account of AIDS cases living and dead. In essences deceased cases are still being used to determine funding for San Francisco with the result of the cities funding is equivalent to what an EMA with 84% more living cases would have received. As you can see in the next figure the grandfather clause in Title I maintained the funding for 29 of the 51 EMAs that became eligible for Title I based grants in the past. These EMAs however would not have qualified for Title I based grants in fiscal year 2004 based upon their case counts which were below the eligibility threshold of 2000 reported AIDS cases in the last five calendar years. Four of these EMAs had fewer reported cases than any of the cities receiving emerging community funding. All states have established HIV case reporting systems in the 200 re-authorization of the Care Act required that HIV cases be used

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in determining formula funding no later than fiscal year 2007. However, CDC as we have heard currently only accepts Name Based Case Counts. The states shown in our figure here in blue therefore, state reported HIV cases that use codes rather than names would not be counted and allocating Care Act funds if HIV case counts were used in funding formulas. As shown in the figure in orange twelve states, the District of Columbia and Philadelphia, Pennsylvania have some form of a Code Based System rather than a Named Based System. CDC does not accept the Code Base principally because methods have not been developed to make certain that a Code Reporting HIV case does not represent an individual already counted in another jurisdiction. While we are aware of some of the limitations of HIV data as an example of what might occur we use two approaches to examine the potential impact of using HIV cases in addition to AIDS cases on fiscal year 2004 Title II Base Grant distributions. The first approach reflects the data that would be used if funding allocations were based on the HIV and AIDS case counts currently received by CDC. Under the second approach we use the same HIV and AIDS case counts as our first approach for the jurisdictions for CDC accepts HIV data but supplemented these data with the HIV case counts collected by the other states in the District of Columbia from which CDC did not accept HIV data. As shown in this figure for each approach we estimated the impact if funding was distributed equally per case both without Hold Harmless or minimal grant provisions

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shown in the two figures on the left and with such provisions shown on the right. Our analysis indicate that under either approach to including HIV cases at most 14% of Care Act Title II base funding would have shifted. With southern states being the primary beneficiaries. Some states however could have seen large increases or decreases. Changes in funding would be largely offset at least initially if the funding formulas included Hold Harmless and minimal grant provisions.

In conclusion the services provided under the Care Act have filled important gaps in communities throughout the country but as Congress reviews this Act we believe it is important to understand how variable this funding can be. Today I have highlighted a few of the issues that are relevant to this review. For each of these issues we found that the provisions of the Care Act have impacted the extent to which funds have been distributed in proportion to the incidence of HIV and AIDS. It is clear that the level of funding available per case is quite variable depending on where an individual lives. The way cases from EMAs are counted twice. The tiered allocation of funds to emerging communities, the Hold Harmless provisions and the grand fathering of the EMAs have all resulted in considerably more funding going to some communities than others with equivalent numbers of cases. The inclusion of HIV cases in the funding formulas would also result in variable funding depending in part upon the type of reporting system used in each state.

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Mr. Chairman this completes my prepared statement. I would be happy to respond to any questions you or other members of the sub-committee may have at this time.

MR. CHAIRMAN: Thank you Dr. Cross. I am going to recognize my ranking member and good friend and for an opening statement and then we will take up the questioning.

SENATOR CARPER: I appreciate the opportunity to first of all welcome our witnesses. I apologize for being delayed and missing at least the very beginning of some of the opening statements. Please that I had a chance to hear from each of you. I think Senator Colburn physicians have forgotten more about these issues than I know and so I come to this hearing really as an opportunity to learn. I understand that the Ryan White Care Act was first enacted what in 1990 and Senator Lautenberg was there as a Page [laughter]. And he is still with us today. It is named after a very courageous teenager who struggled not only with AIDS but also the discrimination as well. I will recall his fear and prejudice as well. These days I think we've made a whole lot of progress. We've lived to see it both in terms of combating this stigma and combating the disease itself. I think we all can agree that we have a good long ways to go. The Care Act nonetheless has been one of the Chief Federal Programs in this fight against HIV and AIDS. I think we can all agree that our goal in examining the Ryan White Care Act today is to ensure that Americans living with HIV/AIDS can get needed care and services. The Ryan White

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Program serves and estimated I'm told 533,000 people each year and it provides not only vital prescription drugs but needed support services to help patients stay on those drugs and to adhere to a complex drug regiment. My own state of Delaware we've done a good job of providing needed health services to those with HIV and AIDS. We've made the quality healthcare a priority and fortunate to be able to offer a generous Medicaid program. A very generous AIDS drug Program and a high quality Ryan White services. Our witnesses that we've heard from today have been discussing a number of different issues largely focusing on the funding of Ryan White. Since I believe this is a jurisdiction of this sub-committee and several of these issues that deal with variations and the level of funding and care around our country. We've been hearing and we're going to hear some more about the states getting more funding than others, about some states having ADAP waiting list while others are able to serve everyone and so forth. I think it is imperative that we ensure that any living person with HIV or AIDS receives a high standard of care no matter where he or she lives whether it is New Jersey, Delaware, or Oklahoma.

However, I think it is important that we keep in mind several issues when considering the data that we are hearing today. Let me mention a couple of those. First, the Ryan White Care Act on the whole is working. We've lengthened the time from HIV infection to the onset of AIDS. People are living longer and they are living healthier. We can always strengthen

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the program but I think we are doing a fair job so far. Second, as we consider whether we are appropriately distributing funding I think we should ensure that we are looking at the whole picture. GAO has presented some various data today on the per case funding around the country and on ADAP waiting list. However, we should consider a few issues. Namely whether per case funding is the best way to exam Ryan White funding distribution and whether we can look at Ryan White funding in a vacuum. In every single state the burden placed on Ryan White depends on what percentage of the HIV/AIDS population is enrolled in Medicaid and how generous that state's Medicaid program is. It depends on what percent of people with HIV/AIDS are enrolled in Medicare and what percent have private insurance. So the needs of different areas of the country, both in terms of funding and need services are going to vary and I think it is important that we consider this whole picture finally. If we determine that there are inequities then we ought to seek to address them but we should keep in mind that many of our cities where over 70% of people with HIV/AIDS still do reside have built up a successful public health infrastructures to combat this disease and we want to be careful not to jeopardize or dismantle those. I hope that the issues that are brought up here today can inform not only me but the upcoming debate on re-authorization. The Ryan White has always been a bipartisan issue and I hope that this

Congress this year will continue that tradition and we can work

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together with our friends in the House of Representatives to produce a bipartisan re-authorization package. And again to our witnesses thanks for coming and Mr. Chairman thanks for letting me give this belated opening statement.

MR. CHAIRMAN: We have a vote on and I think I will recess the committee so that we can go vote and come back. It will take us about maybe ten minutes hopefully. The committee stands in recess.

SENATOR LAUTENBERG: Mr. Chairman may I ask before we go to adjournment to be able to submit some questions to the witnesses.

MR. CHAIRMAN: Absolutely.

SENATOR LAUTENBERG: In writing and to include a letter written by myself and several other Senators in California and New York to Mr. Walker, who is the Controller General of the United States regarding the JAL studies.

MR. CHAIRMAN: Without objection.

SENATOR LAUTENBERG: Thank you. Thank you very much.

MR. CHAIRMAN: And we will stand in recess til we get back from the vote. The record questions that Senator Lautenberg wanted to have asked. Dr. Jansen in your testimony CDC is moving from advising to recommending jurisdictions use Name Base Reporting. What is the practical impact of that change in terminology number one, number two is will CDC withhold financial support for example if the jurisdiction does not follow CDC's recommendations?

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ROBERT S. JANSSEN, M.D.: First we've heard from a number of jurisdictions about CDC recommendations. Jurisdictions that would like to move from Code Base to Name Base Systems and they felt a stronger recommendation from CDC would help them be able to move through their state legislatures and through their regulatory processes to change their systems.

MR. CHAIRMAN: So that might mean if they heard from Congress about that to that might be beneficial?

ROBERT S. JANSSEN, M.D.: Um, I can only speak from a CDC prospective about that but at least that is what we've told by health departments so it is a stronger recommendation than we made in 1999. Um the reason for it is really several fold as many people have mentioned already. We do not currently include Code Base data. The reason is that we have not completely even developed methods for evaluating Code Base data even within a state. So not even within the state or between states. We have completed and just completed at the end of last year a pilot evaluation of several Code Base Systems that gave us mixed results. Based on that we are attempting to develop a full evaluation system of those Code Based.

MR. CHAIRMAN: Tell what mixed results means.

ROBERT S. JANSSEN, M.D.: Uh some states found that they were having trouble meeting the Standards we published in 1999 and at least in one case they did meet the Standards at least in the pilot. Uh, in addition which we think that CDC

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works with the counsel, state and territorial Epidemiologist who develop a list of reportable diseases and we felt that HIV should be like other infectious diseases reported by name and reported voluntarily by the states. We do not intend to withhold funds from states that continue to collect data by Codes even though we do note that in many cases this seems to be a cumbersome process. It is also more expensive and at this point there are no data to suggest that Code Based Data Collection Systems are better than Named Based Systems. The reasons for Code Based Systems originally were based on very valid concerns for members of affected communities about potential discrimination and about potential -.

MR. CHAIRMAN: I understand that. I understand the background on it. Well given the fact that the law says Named Based Reporting and they have about 18 months to do it why would we not send the stronger signal to say, you need to be moving here?

ROBERT S. JANSSEN, M.D.: I think the shift from an advisory condition to a recommendation is actually a very large move on the basis for CDC and for the department and I think that does signify a major shift and I think there are a number of jurisdictions right now who are right now looking at how difficult it is to use Code Based Systems and concerned as Mr. Montgomery noted about the concerned about potentially losing Ryan White funds because of the use of Code Based Systems.

MR. CHAIRMAN: That is my whole point. If in fact that

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the law says you will use HIV Named Reporting and in fact in his testimony Mr. Montgomery said that the CDC will need to develop a methodology to establish estimates of HIV cases for these states. That is not what the law says and I'm not sure that the CDC has the authorization under the Ryan White Care Act to do that because of what the law states as the primary author of that Bill in the year 2000. Do you understand that the law does not allow for that and only counted cases of HIV diseases reported to and confirmed by that's what the law says, CDC will be acceptable for Federal funding. So is it clear to CDC that that is what the law says?

ROBERT S. JANSSEN, M.D.: Absolutely what we are doing is working and we feel very strongly that the best data are reported cases. In some or for some purposes we have to use model estimates for data but for this case we feel very strongly that the best data are case counts of reports.

MR. CHAIRMAN: And we know that because that is a public health strategy that has worked in numerous other diseases, correct?

ROBERT S. JANSSEN, M.D.: Including AIDS.

MR. CHAIRMAN: Right. Let me refer to something that I keep wanting to call you Dr. Palmer. I'm sorry Dr. Hobson. Uh, talked about the decline in perinatal transmission of HIV. Why did that come about?

ROBERT S. JANSSEN, M.D.: It has come about because of the effectiveness of Antiretrovirals for preventing mother to

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child transmission. From the old 076 trial and now what is happening recently is that mothers are on HRT and that worked even more effectively reduces transmission. AZT by itself cut it in half. HRT now reduces it to less than 2%.

MR. CHAIRMAN: What about the effect that mothers who are pregnant are tested for HIV so we know their status?

ROBERT S. JANSSEN, M.D.: Right that, that's also part of it. The first thing we have to have is the intervention and then once we have that we need to identify the people who benefit from that intervention. In fact, as you pointed out that's what getting people tested has done.

MR. CHAIRMAN: Actually I would pretend to use it as reverse. You need to identify because what we did know before we had the 076 study and before we had HRT therapy that in fact if we eliminated breast-feeding that transmitted it we knew what the percentage was of transmittable disease in terms of pregnancy. And in fact if we eliminated the breast-feeding and if we did Cesarean Section and we did some of the other things that we lessened the disease. So I would, that is one of the things that kind of troubles me about this knowing the vectors and treating them with respect but also knowing where the risk factors are have to become a complete part of our model. The other thing that I wanted to talk with you on Name Based Reporting if states are going to be compliant for 07' funding that would mean that they would need to start next month. Is that right?

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ROBERT S. JANSSEN, M.D.: They would need to start as soon as possible.

MR. CHAIRMAN: Well how will they meet the requirements under the 2000 Care Act if they haven't started in July?

ROBERT S. JANSSEN, M.D.: We have been working with and continue to work with health departments and provide as much support as we possibly can to enable them to meet the obligations that they have.

MR. CHAIRMAN: Is that something different than you told me before in terms of HIV Name Reporting under the law?

ROBERT S. JANSSEN, M.D.: No I, I think what we're doing is we're making a recommendation for Name Base Reporting and we have been and we will continue to work with states to develop the best systems that they can use.

MR. CHAIRMAN: Okay. Uh, Mr. Montgomery has California conducted any evaluation of its HIV reporting system for accuracy and reliability?

MICHAEL MONTGOMERY: We have had insufficient funding to do a complete study of it. We have studied how closely we are adhering to CDC's Standards and most of the measures that we are except for the percentage that report Social Security Numbers. We believe our system is very accurate. It is also as Dr. Jansen implied very cumbersome and it's been in operation nearly three years and we're only two-thirds of the prevalent cases reported. So it obviously has some challenges.

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MR. CHAIRMAN: California Performance Review recently found the state risk loss of 50 million annually in Ryan White Care Act funds that the CDC does not confirm. California's reported HIV cases for fiscal year 2007 noting that California can prevent this loss if it conforms to its HIV reporting system to Named Based AIDS Reporting System. You have a Named Based Age Reporting System correct?

MICHAEL MONTGOMERY: We do.

MR. CHAIRMAN: And are there difficulties with that reporting system?

MICHAEL MONTGOMERY: There are not.

MR. CHAIRMAN: Dr. Hobson, Mr. Montgomery and NASTAD have proposed require un-obligated funds be redistributed back into the ADAP fund. This could result in 30 million more for ADAP next year and most likely much smaller amounts in the years that follow. Could you comment on his proposal?

DEBORAH P. HOPSON, PH.D.: I haven't seen the NASTAD proposal so no I cannot comment at this time.

MR. CHAIRMAN: Can you provide for us the total amount spent by the Care Act on planning activities for the past two years?

DEBORAH P. HOPSON, PH.D.: That I can provide.

MR. CHAIRMAN: Okay.

DEBORAH P. HOPSON, PH.D.: For the years in question 2003 and 2004 in the Title I program we spent 30.3 million for planning counsel support. This represents 2.4% of the Title I

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appropriations for those years. In Title II the consortia spent 48.7 million dollars on grantee planning and evaluation and consortia needs assessment planning and evaluation activities and that represented 2.3% of the Title II appropriation for those years. And in the Title III program we have a planning grant program. We did not fund any planning grants in 2004 but we did fund five planning grants in 2003 and the amount was for two hundred ninety nine thousand and fifty-eight dollars, which is .07% of the Title III appropriation for those years.

MR. CHAIRMAN: Okay thank you. Do you believe that the priority of the Care Act should first and format must be to provide direct medical care and medication to Americans living with HIV/AIDS regardless of geography and only after that should other non-essential funds be used?

DEBORAH P. HOPSON, PH.D.: Yes I do and certainly the first principal that President Bush outlined was that we should focus the federal resources meaning the Ryan White Care Act resources on life extending medical care such as Antiretroviral therapy, doctor visits and lab test and so forth. These are the core services that many are talking about in terms of the Care Act so yes that is the first principal that the President has outlined. I think we should look at prioritizing how we fund grantees in the Ryan White Care Act.

MR. CHAIRMAN: So should unspent Care Act funds then be redistributed to where there is a need?

DEBORAH P. HOPSON, PH.D.: That is another one of the

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President's principals that he has outlined that we have flexibility so that the Secretary of HHS would have flexibility to redistribute funds to the areas of greatest need or to target those funds.

MR. CHAIRMAN: Dr. Crosse based on the charts that you put up there in terms of the disproportion and I know there are some question about whether that accurately reflects care given with all the other models of care and organizations that have been there. Is there any recommendations that you can make to us that would help us redistribute fairly under Title I, Title II, Title III and Title IV a system that would recognize, not give the least harm to those in place organizations that are offering services but yet create a fair and more equitable distribution of funds based on care and outcome?

MARCIA G. CROSSE, Ph.D.: Well I don't think we could give you a simple recommendation on what to do. Among all of things that we have examined for this testimony we found all these provisions that are leading to variability and the funding and that are not necessarily counter balanced by other provisions that we have not discussed today. Clearly some of the provisions I think are more distorting of the funding than others. Things such as minimum grant provisions maybe necessary for example for states with vary small number of cases in order to maintain any sort of program at all but we certainly have some concerns about some of the Hold Harmless funding whether that should be maintained with as gradual a decline as it has

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been in the previous re-authorizations or whether it is essential in all of these programs at all. As you correctly pointed out the Hold Harmless Funding for the EMAs primarily benefit one if that Hold Harmless provision were eliminated depending upon the assumptions you make at most we believe three EMAs might lose some money. The other forty-eight of the fifty-one EMAs would gain money including 18 of the 21 that are receiving Hold Harmless funding. So there clearly are some distortions in the way that the current bill has played out. It does not take into account necessarily the variability in need across states which is a much more complex question but clearly the funding is provided by the federal government through this program is not in proportion to the prevalence of the disease as it currently stands.

MR. CHAIRMAN: Okay would you put that uh over. Dr. Jansen by associated million base data a couple of questions that I have for you. One is number one of that number what percentage are unaware of their HIV status?

ROBERT S. JANSSEN, M.D.: We estimate that about 25% of people living with HIV are unaware of their HIV status.

MR. CHAIRMAN: So about 250,000 people in this country are unaware of their HIV status. Which means they are going to rapidly progress over the next 8 to 10 years. They are also going to infect and what is the CDC's position on how we approach that 250,000 people?

ROBERT S. JANSSEN, M.D.: In April 2003 we launched

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advanced HIV prevention a large part of that is focusing on increasing testing, availability of testing and recommending and testing. The first part of that is routine offering in medical care settings. We will be coming out with new guidelines at the end of this year. Based on making recommendations about more routine testing and screening in healthcare settings. They should be available by September or October of this year. We also have been encouraging and stimulating the use of rapid testing for outreach purposes. We have an article that will be published tomorrow in Morbidity and Mortality Weekly Report on a model that we are calling Social Networks where people who are living with HIV recruit friends, sex partners, drug using network partners to come in and get testing. People who they think maybe infected who don't know if they are infected and we are reporting those data tomorrow which showed that about 5.7% of people recruited in nine demonstration projects that we funded turned out to be new HIV diagnoses. That is about two and half times what we routinely get out of our Counseling Testing System.

MR. CHAIRMAN: Are there any concern on your part that this level incidence of HIV maybe getting ready to bump up from 40,000 cases?

ROBERT S. JANSSEN, M.D.: I think that as we look at a variety of different pieces of data to get to triangulate on what that real number is I think my major concern is that number is not going down. The increase we are seeing in HIV

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reports among men who have sex with men are a concern. What we don't know is whether they reflect new infections or whether we are seeing more testing. Because of the advance in HIV prevention I am anticipating that we may see a bump in HIV reports because the increases in diagnoses. So that is going to be confusing. Our HIV Surveillance incidence surveillance system is being implemented right now. We anticipate at having our first national HIV incidence ready by fall of 2006.

MR. CHAIRMAN: I want to look at this chart. We drew this chart up just so you could see the disparity that is happening through the Ryan White funding now. I think there are six other EMAs in California that suffer directly because of the excess protections that are afforded San Francisco. That is all the EMAs in the country and if you look at that what you can see is a significant disproportion so it is pretty hard to defend even though there are wonderful programs in the San Francisco EMA. It is pretty hard to defend that kind of funding and disproportion, as ideally we would like to see it higher for everybody. But the point is, is that the Act is going to have to be changed to straighten it out and to do that in a gentle way that does not disrupt the institutional structures that are there. Uh, in 2003 you launched the new initiative Dr. Janssen advancing HIV prevention with four key strategies that emphasize routine HIV testing. How many states have adopted those strategies?

ROBERT S. JANSSEN, M.D.: We have not done a

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systematic assessment of the number of states that have adopted strategies however; in the new health department cooperative agreement which funding began January 2004 we did put some directives into the language in that announcement. First was that community planning groups would prioritize people living with HIV as the number one priority group for prevention interventions in their jurisdictions. In addition to which we encouraged use of changing testing and looking at where they are getting the higher yield to moving money from one place to another in terms of getting better yields in terms of testing. We have purchased over in 2003 and 2004 we purchased 700,000 Rapid Test for use in out of medical care settings. In 2005 we procured 2.3 or spent 2.3 million dollars on the Oral Fluid test again for increasing access to testing away from medical care settings, out in the community. In addition for community based organizations we have in the new program announcement that was funded June 1st of last year about 60% of the funds in that new program announcement that are directed towards advancing HIV prevention activities.

MR. CHAIRMAN: So you markedly increase the rapid testing. On the STD clinics that you find for prevention are these recommendations in terms of the advance in HIV prevention incorporated within those grants and that money? For the CDC funded STD clinics.

ROBERT S. JANSSEN, M.D.: For STD clinics, for HIV testing and activities in those STD clinics yes.

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MR. CHAIRMAN: So there are following this advancing program?

ROBERT S. JANSSEN, M.D.: They are and in what we are encouraging we will be encouraging more this year. Some clinics have developed an opt out approach to testing. There is an example in Texas actually where they have been doing this for a number of years. We are looking at other STD clinics as demonstration projects. Later this year to actually implement opt out testing in that state.

MR. CHAIRMAN: Mr. Montgomery I want to give you a chance to respond to anything that we might have said about this or any other area. I don't want you to feel cut off as you leave here and I do look forward in working with you to solve the problems in California because there is a concentration but just as important as solving the problems here in Washington, D.C. with the unmet need that is not being met and if you have anything that you would like to say I would love to hear it.

MICHAEL MONTGOMERY: Thank you for the opportunity. Yeah I have a couple of things I would like say. One is that I want to clarify the earlier discussion about the need for estimated cases to incorporate HIV data in 2007. I was talking about both Name Base and Code Base Reporting but the systems that is what I was really addressing. The one comment that I would like to make is I would like to go back to my testimony and say that I think at the discussion of using AIDS cases as a measure of equity is a very complicated issue and I appreciate

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in your question GAO you included Title III and Title IV and Part F in that formula and I would really encourage you to ask GAO to look at all titles and how that affects the per AIDS case formula. In California's case if you use Title I and Title II California is above average for the per AIDS case venture. If you add in Title III and IV and Part F California is below average in terms of the average per expenditure per case.

MR. CHAIRMAN: That is a great challenge. We will ask it.

MICHAEL MONTGOMERY: I think that is a measure of the re-authorization in 2000 that you worked so hard on was that there was language that was put in there to encourage HERSHA to direct Title III funds to non-EMA areas and that has had an impact and I congratulate you on putting that in the language. And I would also encourage you to discuss with JLA looking at the effect of using an estimated living AIDS case formula, which is inherently under estimates in some jurisdictions the impact of the epidemic. And for California it under estimates our epidemic significantly and under estimates our living AIDS cases by 30%.

MR. CHAIRMAN: That's where we find ourselves in trouble and we're afraid to go out and test. Look this is a treatable controllable epidemic. It is controllable if we will all get tested and all get treated we can make this break the back that you wanted to do Dr. Janssen. But the fact is nobody has the courage to stand up and say we need to treat this. We

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need to go after those people who are going to discriminate on the basis of this disease and we need as a nation to stop this. The best HIV prevention is to test everybody and know where they are so that they first of all can be treated early with life saving drugs so they don't progress and number two so they don't infect anybody else. The model, just to get a little history when I was here in 1996 a Congress refused to recommend prenatal testing of pregnant women for HIV, refused adamantly. Well you can't treat pregnant women with HIV if you don't know their status. And now that we are following a public health strategy on HIV for pregnancy what have we seen? We've seen a 76% reduction in infection. That means people who are going to have to get treated. Whereas before that they would all be being treated and their life would be limited. So my caution is for us all to take our biases out of the room and say how do we treat this disease as a nation. We can make a big difference next year if we will all say let's do the right thing. Let's test. Let's go after this disease. Let's not let one innocent person, one individual in this country to get this disease. We could do that but it takes all of us walking from all strides of life, every angle, every philosophy working together and saying the enemy is not each other. The enemy is the disease and we need to go after the disease. Anybody else want to offer any comments? Dr. Crosse.

MARCIA G. CROSSE, Ph.D.: Yes I would just in response to Mr. Montgomery let him and the other requestor we are

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examining other portions of the Care Act.

MR. CHAIRMAN: Well I want to thank each of you. You will be receiving some extra questions from us in written form. We will love to have those back to us within two weeks and I will give Senator Carper an opportunity to ask questions because I was just about ready to dismiss the panel.

SENATOR CARPER: I'm glad you're still here. Uh, I just have one question. I think I am going to ask Dr. Janssen if you would to respond to this for me please. I think you spoke to this in your testimony but I want to come back and revisit it. It seems that most stakeholders' support distributing Ryan White funds based on the number of HIV cases in an area instead of the number of AIDS cases in a particular area or at least that is my sense. However, I am concerned that a number of states including my own state of Delaware maybe in danger of losing a large portion of our funding because CDC will not accept the type of HIV data that we collect and some other folks collect. I think your testimony notes that the Name Based Reporting has been shown and I think these maybe your words in your testimony achieve high levels of accuracy and reliability. But you don't seem to be saying that Code Base Reporting cannot be improved or made more accurate. In fact, I think the Institute of Medicine did a study and I think in you referenced in your testimony that CDC accept HIV data from all states including those that have Code Base Systems. The Institute of Medicine's also said that duplicate

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cases could be estimated and that the procedures could be developed through just for this. And what I would just ask is that CDC perusing this option and should I be worried that in 2007 CDC won't accept my state's data and maybe the data from some other states as well?

ROBERT S. JANSSEN, M.D.: In terms of Coded identifiers we have last year which ended early this year in which I was told that Senator Colburn that it showed mixed results in terms of how some of these codes worked. In some areas they worked and some not at least in the pilot. We are still in the process of developing a full evaluation of coded identifiers. So those even that effort has not been developed. It is possible to develop it and we are working on it. The bigger concern however is the D-duplication across jurisdictions from one state to another. In this area Maryland, Washington D.C. and Virginia 20% of cases reported for more than one jurisdiction so there is a lot of overlap. Nationwide I think it is about 2% I believe.

SENATOR CARPER: So you're going to have one person whose case is being reported in the District and the same person's case is reported say in Maryland.

ROBERT S. JANSSEN, M.D.: In Maryland, yeah.

SENATOR CARPER: So would you say that is unusual?

ROBERT S. JANSSEN, M.D.: That is unusual. It is more like 2% nationwide. I will have to check with Dr. McKenna who is our surveillance.

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SENATOR CARPER: Where is Dr. McKenna?

ROBERT S. JANSSEN, M.D.: Right here.

SENATOR CARPER: Dr. McKenna.

ROBERT S. JANSSEN, M.D.: So it's 4% for AIDS and 9% then for HIV. So 20% is pretty high. The problem is when you have different codes across those boundaries it is virtually impossible to D-duplicate cases. We've talked about this a fair amount and we believe from an academic perspective conceptually one might be able to develop such methods but practically we are not convinced it is possible. So that is probably for us and it was mentioned earlier the most difficult problem is trying to D-duplicate cases across state boundaries. There is also a problem within states with codes and we have not, it isn't proven it is a conceptual problem and that is that in jurisdictions it is not just the HIV test that is reported to the health department, CB counts are reported, viral loads are reported. So someone in care might be reported to the health department seven, eight, ten times a year over years they could be reported forty or fifty times to the health department. If they go to different providers and the code is changed in just one way they would be counted multiple times. So that becomes a problem where you have people in care reported multiple times and then you have somebody who is just diagnosed and not in care and so they end up not being represented equally with the people who are in care so that is a potential problem with codes even within a state. So your question was can codes made

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to work better than names or even as good as names. At this point we have evidence that codes are better than names. We have evidence as Mr. Montgomery mentioned that in California for example where actually the system is fairly cumbersome and difficult and expensive. So that's the reason or those are some of the reasons that we are recommending that states use Named Based Systems.

SENATOR CARPER: Anybody else on the panel want to take a shot at what I just asked? No, one last follow-up. Mr. Montgomery did you?

MICHAEL MONTGOMERY: No we now have three years of experience of operating a Code Based System and it is an extremely complicated system. We think it is very accurate but we think it has as Dr. Janssen said very expensive and has caused backlogs within the health department so we are concerned about our ability to carry out a Code Based System.

SENATOR CARPER: Okay. One quick follow up if I could Mr. Janssen. You mentioned pilot study that was conducted earlier, when was that, this year, last year?

ROBERT S. JANSSEN, M.D.: It was finished at the end of last year. In terms of data collection analysis was done this spring.

SENATOR CARPER: And you mentioned that there is a more comprehensive evaluation. Is it underway or planned?

ROBERT S. JANSSEN, M.D.: Being developed.

SENATOR CARPER: And when would you expect that to be

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done?

ROBERT S. JANSSEN, M.D.: At the end of next year.

SENATOR CARPER: The end of a calendar -.

ROBERT S. JANSSEN, M.D.: 2006.

SENATOR CARPER: 06' okay. Okay our thanks to each of you and thanks for joining us and I learned a new word today, D-duplicate [laughter]. And this is a good job we have we learn something everyday. That is my new word.

MR. CHAIRMAN: I would just like unanimous consent to enter this into the record. Los Angeles Times reported that county health officials are being aloud to peruse medical records in California complete with patient names to ensure that the cases are being reported. If it is true then that undermines the whole concept of a Code Based System and you know the fact is that California right now through your office is recommending that is going to have to spend 500,000 dollars, I believe that is to formally evaluate the system and to determine whether the system meets CDC minimal guidelines and so you know we are running short on time and we know what the law says and the message ought to be get a Named Based System since the Named Based System on AIDs is working and not being violated and we know it works. And we know we are going to have better success and you are going to save a lot of money. And the money that you save is going to treat a lot of folks. Thank you all each for being here.

[END RECORDING]

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