

To: HIV Planning Council

From: Policy Committee

**U.S. Senate Committee on Homeland Security and Government Affairs
Subcommittee on Federal Financial Management, Government Information, and
International Security**

Title: Addressing Disparities in Federal HIV/AIDS CARE Programs

Date: June 23, 2005

Place: Dirksen Senate Office Building, Room 562

Senator Coburn (R-OK):

Senator Coburn opened the hearing with his personal experience of treating a patient who was born with HIV and died 7 years later. He talked about the changing HIV/AIDS medical landscape and stated that while face of AIDS has changed, federal response to HIV/AIDS has not changed much. He stated that while thousands of people living with HIV/AIDS on waiting lists for ADAP (KY and WV people dying) “tens of millions” CARE Act funds go unused.

Disparity of distribution of funds:

- CARE Act distribution of funds based on AIDS, not HIV
 - AIDS cases comprises only a small percentage of the total population with HIV, the CARE Act funding does not serve the vast majority of those with HIV.
 - Effected communities not receiving fair share of support.
 - CARE Act states that Secretary should transfer to HIV data if sufficient.
- The “hold harmless” provision resulted in inequitable distribution of funds.
 - All but one EMA (San Francisco, CA) would benefit from elimination of hold harmless - SF uses 92% of “hold harmless” funds for “non essential” services.
- Inequities between states with Title I vs. those without
 - Those states with Title I and Title II are “double counting,” in which AIDS cases are counted twice

He stated that we need to prioritize funds for “core medical services” and effective prevention.

Senator Lautenberg (D-NJ):

He urged the Committee to oppose shifting funding away from areas with high concentration of HIV/AIDS cases.

Dr. Robert Janssen, CDC:

In his testimony, Dr. Janssen stated that the CDC estimates over 1 million Americans now have HIV/AIDS. Number of persons becoming newly infected has stayed constant at 40,000 per year. (this data come from 32 states with name-based HIV reporting.)

Dr. Janssen mentioned that most other communicable diseases are name based systems (currently, 38 states and 5 territories have adopted name based reporting), and due to a lack of a uniformed, name-based HIV reporting, the national HIV reporting data is less accurate than AIDS data at the national level and does not represent some of high morbidity areas, such as CA, whose data are not included in the national data set.

He advocated strongly for name based systems in lieu of code based systems and cited the Institute of Medicine report, *Measuring What Matters*, on viability of using HIV data for determination of Title I and II funds – based on that report, HHS Secretary has determined that HIV data not be used for making formulate grants under Title I and II and that estimated living AIDS continue to be used until high quality HIV data are available nationwide. Dr. Janssen concluded his testimony by stating that a “uniform” system is important to tracking the epidemic nationally.

Dr. Deborah Hopson, HRSA

Dr. Hopson gave an overview of the Ryan White CARE Act and described persons served and types of services provided by RWCA. She talked about RWCA being an “imperfect instrument” needing some improvements to help identify the epidemic at earlier stages very important, and cited the three principles of RWCA Reauthorization outlined by the President: (1) Life extending “core” medical care services; (2) Greater flexibility to target CARE Act to areas of greatest needs; and (3) Improved accountability

She talked about the importance of each segment of the CARE Act: ADAP has helped people living with HIV/AIDS to live longer and healthier lives and Title IV prevents perinatal transmission. Through the successes of HIV/AIDS service programs, the epidemiology and treatment of HIV has shifted to a more chronic disease model, resulting in changes to continuum of care and types of treatment offered.

Dr. Hopson stated that the challenge going ahead is to treat persons unconnected to care: outreach to persons not in care and without access to services. These include minorities, rural areas, complex co-morbid conditions, uninsured and underinsured. She explained that mechanisms to allocate funds must be recognizant of changes to epidemic, “hold harmless” provision must be amended to meet emerging needs, and HRSA must be given authority to reallocate funds in lieu of funds going back to U.S. Treasury.

Mr. Michael Montgomery, Chief, Office of AIDS, California Department of Health Services, and Chair, NASTAD

Mr. Montgomery stated that ADAP which serves 30% of people living with HIV/AIDS nationally, works closely with states to provide services and to be the payer of last resort. He talked about NASTAD’s ADAP Crisis Task Force that negotiates with the

pharmaceutical industry on behalf of all ADAPs to get the lower prices on drugs (in fiscal year 2004, the Task Force achieved an estimated \$90M in savings.)

He stated while the current structure of the Ryan White CARE Act is a contributing factor to funding disparities that affects availability, accessibility and quality of services and alternative proposals for saving people living with HIV/AIDS developed by others, including IOM, should be reviewed, state AIDS directors recommend retaining the current structure of the CARE Act with the following two goals:

- Enhance ADAP resources – a minimum increase of \$60M to be provided annually to support ADAPs.
 - Redirect any unexpended funds from all titles of the CARE Act from all years with the exception of the previous two grant periods.
 - Redirect any unexpended funds that exceed HRSA’s approved percentage of any CARE Act grantee’s award amount from all titles of the CARE Act.
 - Institute an equal percentage tap on all CARE Act titles, excluding ADAP.
- Strengthening the emerging communities mechanism – provide additional resources to states chronically insufficient Title II based funds through the Emerging Communities mechanism.
 - Title II Emerging Communities (EC) supplemental grants sought to address the challenges faced by areas with a significant burden of AIDS cases but that lacked the density of cases to be a Title I EMA and the goal was to provide resources to smaller communities to enhance local health care infrastructure to provide HIV care services. Since its creation in 2000, ECs faced significant funding fluctuations because ECs do not permanently being eligible once they begin receiving funds. In the past four years, 14 ECs have been eliminated completely.

Mr. Montgomery stated while he supports the use of HIV data in addition to AIDS cases to allocate the CARE Act funds, state AIDS directors agree that Title II funds should not be withheld in order to force states to switch from a code or name-to-code HIV reporting system to a name-based HIV reporting system. He urged CDC to work with the states that do not have name based reporting to develop a methodology to estimate HIV cases for these states in order to incorporate HIV data in fiscal year 2007

Lastly, he stated that the unspent funds should not be returned to the Treasury but give HRSA authority to move CARE Act funds to states with chronic shortages from states with unspent funds, and talked about the importance of “hold harmless” including 30 states benefiting from hold harmless.

Dr. Marcia Crosse, Government Accountability Office (GAO)

Dr. Crosse talked about history of the “hold harmless” provision of Title I and II and the grandfather clause of Title I EMAs.

She presented some of the preliminary findings of GAO study, including:

- Distribution of funds varies greatly in funding per case between cities and states. “Double counting” for states with Title I and Title II - States with EMAs generally received 38% more per person than states without EMAs.
- San Francisco is getting 90% of hold harmless funding - SF is the only EMA with hold harmless lasting since mid-1990s. Dr. Crosse argued that SF is essentially counting people who are now dead, as it uses funding base back from when cumulative AIDS cases (not estimated living AIDS cases as now does) was used to allocate Title I formula funds.
- Recommends transitioning to HIV cases, even with current limitations posed by code based systems. Dr. Crosse talked about comparisons of Title II awards among states if HIV reporting was used and with or without hold harmless. Southern states would benefit the most from this transition to HIV data.

Senator Carper (D-DE-Committee Ranking)

Senator Carper stated that it is imperative that everyone with HIV/AIDS gets the highest quality of care no matter where they live, and suggested the following ideas: 1) RWCA is on the whole working; 2) we need to look at the whole picture. Is funding per case fair? Should we look at RWCA funding in role of the bigger picture, such as Medicaid, percent of people enrolled in Medicaid & private insurance and the role of RW in whole picture; and 3) If there are inequities, we need to be careful not to jeopardize those states that have developed good health care infrastructure. He ended his comment by stating that the Ryan White CARE Act has been a bipartisan bill and he hopes it will remain that way.

Questions from Coburn:

- 1) What is impact of CDC changing from recommending to advising transition to name based reporting?

Janssen – a strong recommendation from CDC would give states the strength to push their legislators to transition to name based HIV reporting. HIV should be like other infectious diseases – name based reporting and given voluntarily by the states to CDC.

Montgomery – a code based HIV reporting system is very accurate, is cumbersome but is also only been in operation for three years. CA has named based reporting system for AIDS, but code based reporting system for HIV.

- 2) What percentage of Title I funding goes to PC support?

Hopson - \$30.3M for FY2003 for Title I PC support, \$48.7M for Title II planning consortia.

- 3) Should unspent CARE Act funds be reallocated to areas of greatest needs?

Hopson – That is the primary objective of the President to give HRSA resources to allocate funds to areas of greatest need.

Crosse –Minimum grant provisions may be important for some states to ensure minimum amount to maintain a program, but has concerns for “hold harmless” funding, which primarily benefits one EMA.

Jansen – CDC is addressing 250,000 U.S. citizens who don't know their status by expanding counseling and testing opportunities, including new April 2003 “Advancing HIV Prevention” initiative to expand testing. CDC is not certain how many states have adopted this strategy, but CDC Prevention PPG groups must adopt some of these measures. Some clinics have developed an “opt out” approach to HIV testing (e.g., STD clinics in Texas have developed an opt-out approach to HIV testing.)

Montgomery – Encourage other creative measure to resolve issues of inequities in funding, such as was developed for Title III new clinics in non-EMA areas.

Coburn – Way to stop HIV infection is test everyone: (1) Get them into treatment (2) so HIV infected persons don't infect anyone else. “Lets do the right thing. Lets test.” He informed the panelists will be receiving written questions and would like to see responses within two weeks.

Q&A from Senator Carper (D-DE):

Senator Carper stated that he is concerned about states such as his (Delaware) that use code based reporting systems. He cited the IOM study that CDC accept data from all states including those using code based systems, that IOM study stated that there are ways around this issue.

1) Should I be worried that in 2007 CDC will not accept my states data and others?

Janssen – CDC conducted a pilot evaluation of the effectiveness of code based systems and it showed mixed results. A bigger concern is de-duplication across systems and across states/cities – duplication is normally 4% AIDS and 9% for HIV nationwide but in some areas such as Washington DC duplication it is 20% duplication of reporting. He listed problems with code based systems even within the same state, as many labs tests will be resulted many times to State health department, and with even slight variation in the data can result in numerous duplications of same person.