

CARE Act Reauthorization Watch

Volume 2, July 28, 2005

The Reauthorization Watch, produced by NASTAD, provides periodic updates on activities related to the reauthorization of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. Please see NASTAD's Reauthorization Resources [webpage](#) for more information.

Administration Activities

On July 27, Department of Health and Human Services (HHS) Secretary Mike Leavitt [announced](#) the Administration's [recommendations](#) for reauthorization. The recommendations are principles, and not a detailed legislative proposal. The Secretary stated that HHS would be working with key Members of Congress to refine the principles in legislation. Leavitt also indicated that reauthorization is a high priority for the Administration and the Department. The recommendations include:

- Eliminate the hold harmless provisions in Title I and II to ensure that funding is directed to "areas with newer epidemics."
- Eliminate the ability of both states and Emerging Metropolitan Areas (EMAs) to receive funding for cases in EMAs or "double counting."
- Develop a "severity of need" for core services index (SNCSI). SNCSI would be used to fund core medical services and would include such factors as: HIV incidence; poverty levels; and availability of other resources including local, state and federal programs and support and private resources.
- Establish and maintain a list of ADAP core medications. The medications on the list would be based upon *U.S. Department of Health and Human Service's Public Health Service HIV/AIDS Clinical Practice Guidelines for use of HIV/AIDS Drugs* and should be prioritized for federal funding.
- Require that 75 percent of funding for Titles I-IV is directed to essential core medical services.
- Allow Title I planning councils to be structured at the discretion of the mayor, not have conflicts of interest and no longer be required to set priorities for spending.
- Include HIV data in distribution formulas by the start of FY2007, as is set in current law.
- Require states to implement routine voluntary HIV testing in public facilities. States will also be encouraged to adopt various HIV prevention strategies, such as routine opt-out HIV testing, contact tracing and the recommendations of the CDC Advancing HIV

Prevention Initiative.

Senator Tom Coburn (R-OK) released a [press release](#) applauding the Administration's principles, specifically their emphasis on primary care and treatment.

Congressional Activities

U.S. Senate

The Senate Subcommittee on Federal Financial Management, Government Information, and International Security of the Homeland Security and Government Affairs Committee, chaired by Senator Tom Coburn (R-OK) held an oversight hearing, "Addressing Disparities in Federal HIV/AIDS CARE Programs," on June 23. Panelists included Robert Janssen, Director, Division of HIV/AIDS Prevention, National Center for HIV, STD, and TB Prevention, Coordinating Center for Infectious Diseases, Centers for Disease Control and Prevention (CDC); Deborah Parham Hopson, Associate Administrator for HIV/AIDS, Health Resources and Services Administration (HRSA); Michael Montgomery, Chief, Office of AIDS, State of California; and Marcia Crosse, Director, Public Health and Military Health Care Issues, Government Accountability Office (GAO). In addition to Senator Coburn, the hearing was attended by Senator Frank Lautenberg (D-NJ) and Thomas Carper (D-DE).

In his [opening statement](#), Senator Coburn discussed the CARE Act funds going unspent as people are on waiting lists to receive their medications. Senator Coburn also highlighted several "funding inequities" that exist, including: continuing to use only AIDS cases, and not HIV, in funding formulas; the Title I hold harmless provision; and the use of Emerging Metropolitan Area (EMA) cases, in part or in whole, in both the Title I and II formulas. Referring to the use of EMA cases in both formulas Senator Coburn noted, "[s]tates that receive Title I funding receive 38% more per AIDS case than states without an EMA."

Dr. Janssen [testified](#) that CDC now estimates over 1 million Americans are living with HIV/AIDS, with HIV diagnoses among African American females being 18 times higher than white females. Janssen stated that "cultural, socioeconomic, and health-related factors" are increasing the numbers in minority communities. Janssen cited the reduction in mother to child HIV transmission as "one of the great success stories of HIV prevention." Dr. Janssen provided an overview of HIV surveillance programs and the limitations of the current HIV data system. Twelve states, the District of Columbia, and the city of Philadelphia use code-based reporting for their HIV disease surveillance. Janssen announced that CDC is moving from "advising" to "recommending" that jurisdictions use name-based HIV reporting. He cited the Institute of Medicine study, "[Measuring what Matters: Allocation, Planning, and Quality Assessment for the Ryan White CARE Act](#)," called for in the last CARE Act reauthorization, and the goal of reaching nationwide, high-quality HIV data, as reasons for this move.

Dr. Hopson [testified](#) about the successes and challenges of the CARE Act. As successes, Hopson cited the provision of "antiretroviral treatment, primary care and support services to over half a million people annually" in the U.S. and the targeting of services to those that

are in greatest need. As challenges for the upcoming reauthorization, Hopson highlighted the consistent presence of waiting lists for ADAP and directing funds to minority populations that are "increasingly and disproportionately impacted by HIV/AIDS." When looking at the allocation of funds during reauthorization, Hopson cited the need to be aware of a few mechanisms that need to be reengineered: "hold harmless" provisions, formulas based on AIDS rather than HIV cases, and allowing funds that have not been put to work in a timely manner to "roll over" or revert to the Treasury, rather than giving the Department of Health and Human Services the necessary flexibility and authority to reprogram resources to communities in need.

Mr. Montgomery, who is also the chair of the National Alliance of State and Territorial AIDS Directors (NASTAD), [highlighted](#) California's CARE Act programs, as well as the disparities in the CARE Act from the perspective of state AIDS directors. Montgomery cited the work of the ADAP Crisis Task Force in realizing \$90 million in savings for strained ADAPs during FY2004. AIDS directors have concluded that although the multi-title structure of the CARE Act contributes to challenges and funding disparities for states, they recommend retaining the current structure. Montgomery detailed two of NASTAD's [proposals for reauthorization](#) designed to improve HIV care services in this nation: enhancing the availability of ADAP services and strengthening the Emerging Communities provision of the CARE Act. Montgomery also spoke to the importance of the incorporation of HIV cases into CARE Act distribution formulas as well as redistribution of expiring unobligated funds.

Marcia Crosse's [testimony](#) included preliminary findings of an ongoing GAO investigation, "Ryan White CARE Act: Factors that Impact HIV and AIDS Funding and Client Coverage." The findings include:

- **Variability of funding -**
 - States with EMAs receive a greater amount per AIDS case than states without an EMA.
 - Within Title I, one EMA (San Francisco) receives 90% of hold harmless funds.
 - 29 currently funded EMAs received funding due to the 1996 grandfather clause, even though they were below the eligibility threshold in FY2004. It was noted that many of these EMAs have case numbers lower than many Title II Emerging Communities.
 - The separation of Emerging Communities into two eligibility categories adds to unequal funds for states.
 - Counting AIDS cases in EMAs in both the Title I and II formulas results in more funding for states with EMAs.
- **Use of HIV cases in formula -**
 - If HIV case counts had been used with estimated living AIDS cases in FY2004 funding allocations, about half of the states would have received increased funding, with the other half realizing less funding.
 - 11 of the states receiving increased funding were located in the South.
 - The maturity of HIV case data would greatly affect the funding for jurisdictions because an immature system might not capture an accurate count of a state's HIV cases.
- **Variation among ADAPs -**

- ADAPs have wide variability among formula, eligibility criteria, and funding from sources other than the Title II ADAP award.
- No relationship was found between any one factor (i.e. a type of additional funding beyond the federal ADAP award, income eligibility criteria) and the presence of a waiting list.

The GAO testimony contains detailed graphs and charts relating to the above findings.

Senators Lautenberg, Jon Corzine (D-NJ), Hillary Clinton (D-NY), Chuck Schumer (D-NY), Barbara Boxer (D-CA), and Dianne Feinstein (D-CA) sent a [letter](#) to the GAO expressing their concern with several of the preliminary findings of the report. The letter specifically asks that GAO consider the following issues for their final report: what barriers could arise in EMAs if the grandfather clause was eliminated; using the cost of providing services and the level of services provided when discussing a per capita funding level; and what would happen the ability of states to provide services if the funding formula was changed to eliminate cases within EMAs.

During the question and answer session, Senator Coburn asked Dr. Hopson how much of Title I and Title II funds went towards Planning Council support. She answered that for fiscal years 2003 and 2004, Title I spent \$30.3 million on planning council support and Title II spent \$48.7 million for consortia support and planning and evaluation activities. Senator Carper expressed concern that even though the IOM study recommended that the CDC accept HIV data from code-based states, in 2007 when the CARE Act incorporates HIV data into the formulas, his state's HIV data will not be accepted. Dr. Janssen replied that the CDC recently concluded a pilot evaluation of the effectiveness of code-based data, yielding mixed results. He said the biggest barrier to the acceptance of HIV data from code-based systems is the duplication of cases across systems, states and cities.

The [CAEAR Coalition](#) also issued a [press release](#) in response to the hearing, as well as submitted written [testimony](#) for the record. CQ HealthBeat wrote an [article](#) on the hearing.

U.S. House of Representatives

The Federal AIDS Policy Partnership's (FAPP) Reauthorization Work Group recently met with staff from the Congressional Hispanic Caucus and the Congressional Black Caucus to discuss the reauthorization of the CARE Act. The tri-caucuses (including the Asian/Pacific Islander Caucus) expect to be very involved in the discussion of reauthorization on the House side. Staff of Caucus Members are currently working on a statement of reauthorization principles.

Stakeholder Recommendations

Two additional AIDS organizations have issued position papers providing recommendations for changing the law. Released positions are:

- The [National Minority AIDS Council \(NMAC\)](#) details reauthorization priorities in their [Public Policy Agenda for 2005](#).
- The [National Association of People with AIDS](#) (NAPWA) released [principles](#) for

reauthorization.

For a complete list of stakeholder positions please visit NASTAD's [Reauthorization webpage](#).

Community Activities

The FAPP Reauthorization Work Group has sent [letters](#) to lead staff in both the House Energy and Commerce Committee and the Senate Health, Education, Labor and Pensions Committee asking for a meeting to discuss the status of the reauthorization process. The group is concerned that there is little more than two months before the CARE Act expires.

Please forward the *Reauthorization Watch* to interested colleagues. Please email [Ann Lefert](#) to be added or removed from our email distribution list.

National Alliance of State and Territorial AIDS Directors
444 N. Capitol St, NW, Suite 339 • Washington, DC 20001
Phone: 202.434.8090 • Fax: 202.434.8092 • Website: www.nastad.org