COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Recommendations of

Communities Advocating Emergency AIDS Relief (CAEAR) Coalition

Patricia Bass, Chair

on the

Ryan White HIV/AIDS Treatment Modernization Act of 2006

Presented to

the House Committee on Energy and Commerce

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Communities Advocating Emergency AIDS Relief (CAEAR) Coalition appreciates the significant work of the Energy and Commerce Committee and your Senate partners in the Health, Education, Labor and Pensions (HELP) Committee toward developing a Ryan White CARE Act reauthorization proposal that strengthens the program's ability to respond to the HIV/AIDS epidemic in communities across the country.

The attached document outlines a limited number of recommended language changes and/or clarifications important to our shared goal of further enhancing the CARE Act's ability to best serve people living with HIV/AIDS without destabilizing existing systems of care.

Key Provisions in Draft Strengthen the CARE Act

We do wish to acknowledge a number of key provisions in the current draft that reflect significant progress in strengthening the program:

*Maintaining the Title structure and allowing Title II Emerging Communities to become Title I jurisdictions;

*Moving to living HIV/AIDS cases for formula distributions;

*Retaining the Planning Council requirements for existing Title I EMAs that transition to Tier II;

*Continuing to provide partial credit in Title II formula awards for cases in Title I EMAs;

*Providing resources to develop a national, unduplicated client data system;

*Requiring ADAP drug rebates to go back into the program;

*Increasing the ADAP set-aside in Title II from 3% to 5%;

*Requiring documented community input in Title III;

*Requiring strong coordination among Public Health Service agencies and other relevant federal departments, including the Department of Veterans Affairs and the Centers for Medicare and Medicaid Services, and mandating reporting requirements to Congress to guarantee such coordination;

*Maintaining current eligibility criteria for grantees in the dental reimbursement program; and

*Including the CARE Act component of the Minority AIDS Initiative within the authorization.

Changes Required Prior to Final Passage

There are some other areas where significant modifications are still required, including but not limited to:

*The FY2007 authorized appropriations for Title I must be increased so that the total, including the authorized MAI appropriations, matches the FY 2006 funding level of $604 million. The subsequent 3.7% annual increases must be built on this base figure and not the $590.7 (including MAI) in the current draft.

*The eligibility criteria for Title I jurisdictions should move from a 5-year case count to living HIV/AIDS cases, once a national HIV/AIDS data set is certified;

*The Title I hold harmless provision must apply to FY 2006 as if the 66% formula/33% supplemental shift had been in place. We also continue to recommend extension for a fourth-year of protections for those jurisdictions eligible in FY 2007;

*The core services definition should include “Case management to support access to and retention in health care and improved medical outcomes.” Health professionals in the field continue to believe that the “treatment adherence” language will not be sufficient to cover critically important case management services linked to medical outcomes; and

*The existence, authority and membership requirements of planning councils should be mandated for all existing Title I EMAs along with a mechanism in other Title I jurisdictions (planning council or other) for stakeholder input that requires consultation by the grantee in formulating the overall plan for priority setting and allocating funding.

Finally, there are still unresolved issues related to the HIV case proxy that must be addressed satisfactorily prior to final passage. We urge the committees to work together to resolve this issue as fairly and expeditiously as possible.

Recommendations of the Communities Advocating Emergency AIDS Relief (CAEAR) Coalition on the Ryan White HIV/AIDS Treatment Modernization Act of 2006

Following are CAEAR Coalition's recommendations with respect to the reauthorization language passed by the Senate HELP Committee. For those provisions/sections not mentioned below, CAEAR Coalition either supports or has no position on the proposal.

Issue	**RWHATMA as passed by the HELP Committee (5/17/2006)**	**CAEAR Coalition Position**	**Necessary Language Changes**
Title I			
Eligibility Criteria	Maintains 5-year cumulative AIDS case count as basis for Title I eligibility.	It is misguided to continue the five-year cumulative case count to determine Title I eligibility without any mechanism for moving to eligibility criteria based on living HIV/AIDS cases. Five-year case counts are not an accurate barometer of the current HIV/AIDS burden in a community and should not be used over the course of the authorization to determine Title I eligibility. This number continues to count people who have been diagnosed and died within the past five years and excludes those diagnosed more than five years ago but still alive. CAEAR Coalition continues to urge that living HIV/AIDS cases be used to determine eligibility once an accurate	Page 2, Line 13: SEC. 102. LIVING CASES OF HIV/AIDS (a) IN GENERAL Strike: Line 13 and Insert: "(a)(1) IN GENERAL.—Section 2601(a) of the Public" Page 2, Line 19: Strike: Lines 19 and 20 Insert: "2,000 cases of AIDS for the most recent period of 5 calendar years for which such data are available (or as determined by the Secretary pursuant to subsection (4))". Insert at the end of Line 20: "(2) Not later than September 30, 2010**,** the Secretary shall certify data on cases of HIV disease from all eligible areas (reported to and confirmed by the Director of the Centers for Disease Control and Prevention) sufficiently accurate and reliable for use for purposes of this section. In making such

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Eligibility Criteria (cont.)		national HIV data set is certified. It will be entirely feasible to use living HIV/AIDS cases with different, but equivalent, thresholds and still maintain a 3-tier structure. Living HIV/AIDS counts provide the most accurate measure in a community and it would be most logical to base both formula funding and eligibility on this measure.	certification, the Secretary shall take into consideration the findings of the study under section 501(b) of the Ryan White CARE Act Amendments of 2000 (relating to the relationship between epidemiological measures and health care for certain individuals with HIV disease). "(3) Following the certification required by subparagraph (2) any grants provided pursuant to Sections 2601(a), 2609(a)(1)(A), and 2609(a)(1)(B) shall be derived from data on living cases of HIV/AIDS disease in an eligible area. "(4) Following the certification required by subparagraph (2) the Secretary shall announce the number of living cases of HIV/AIDS disease which make an eligible area eligible for grants under Sections 2601(a), 2609(a)(1)(A), and 2609(a)(1)(B), respectively. In determining the levels of living cases of HIV/AIDS disease, the Secretary shall take account of, and maintain to the extent practicable, the distribution levels of funds under each section." Page 16, Line 21 SEC 110 TRANSITIONAL GRANTS FOR OTHER AREAS Subpart II—Transitional

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Eligibility Criteria (cont.)			Grants SEC. 2609 ESTABLISHMENT (a) Eligible Areas (1) In General (A) Strike: Line 21 Insert: "years for which such data are available (or as determined by the Secretary pursuant to Section 2601(a)(4)); and" Page 17, Line 2 SEC 110 TRANSITIONAL GRANTS FOR OTHER AREAS Subpart II—Transitional Grants SEC. 2609 ESTABLISHMENT (a) Eligible Areas (1) In General (B) Strike: Line 2 Insert: "for which such data are available (or as determined by the Secretary pursuant to Section 2601(a)(4))."
Hold Harmless	Limits hold harmless to 3-years at the rate of 90, 85, 80 percent	The hold harmless provision needs to be maintained for four years at the percentages of 90, 85, 80, and 75 to ensure the stability of existing systems of care during the transition to the new funding criteria. In addition, the FY 2006 base year figures must be calculated based on what the FY 2006 formula appropriations would have been had the 66 2/3% formula provision been in place at that time.	Page 9 Line 3 SEC. 103. TYPE AND DISTRIBUTION OF GRANTS (c) HOLD HARMLESS (4) INREASES IN GRANT (A) IN GENERAL Insert: (iv) for fiscal year 2010, the grant is not less than 75 percent of the amount of the base year grant. Page 9 Line 4 Strike: Lines 4-6 Insert: "(B) BASE YEAR.—With respect to grants made pursuant to paragraph (2) for an eligible area, the Base Year shall be equal to the amount of funding provided in

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Hold Harmless (cont.)			fiscal year 2006 if the change made in subsection (a) had been in effect."
Planning Councils	Planning councils voluntary for Tier 2 and Tier 3 starting in 2010.	Existing Title I EMAs that will become Tier 2 EMAs under the proposal have existing planning councils that play a central role in the priority-setting and funding allocation in their jurisdictions. Those councils should be maintained in all of those jurisdictions. There should also be a requirement that new Title I jurisdictions have a mechanism for significant, meaningful stakeholder input into the priority setting and funding allocation process, including people living with HIV/AIDS that use CARE Act services, but with flexibility to convene planning council or another mechanism. Language should indicate that the voluntary planning council be consulted in formulating the overall plan for priority setting and allocating funding.	Page 17 Line 22 Subpart II-Transitional Grants SEC. 2609A. APPLICATION OF OTHER PROVISIONS (a) ADMINISTRATION (1) IN GENERAL Insert: after "except that": "with respect to metropolitan areas not previously funded under Section 2601" Page 18, Line 2 Strike: "the design and implementation of activities related to such grant." and Insert: "formulating the overall plan for priority setting and allocating funding provided under the grant."

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Authorization of Appropriations	Authorizes appropriations at levels below FY 2006	The authorized amounts for Tier I and Tier II essentially follow the allocations to Title I cities in FY 2006, but they do not take into account the administrative costs and taps taken by HRSA and HHS prior to the allocations, leading to a discrepancy between the FY 2006 appropriation and the proposed FY 2007 authorized appropriation. In FY 2006, Title I received $604m. The authorized FY 2007 amount for Title I (including the MIA funds in Sec. 2693) adds up to only $590.7m. The authorizing levels for Tier I and Tier II must be raised to account for the administrative costs and shaves taken by HHS and HRSA prior to formula and supplemental grants to the EMAs.	Page 19, Line 22 Subpart II – Transitional Grants SEC. 2609B. AUTHORIZATION OF APPROPRIATIONS Strike: Page 19, Line 22-Page 20, Line 2 and Insert: (1) with respect to areas described in section 2609(a)(1)(A), $127,500,000 for fiscal year 2007, $131,000,000 for fiscal year 2008, $135,900,000 for fiscal year 2009, $140,900,000 for fiscal year 2010, and 146,100,000 for fiscal year 2011; and Page 20, Line 14 Subpart III-General Provisions SEC. 2606 AUTHORIZATION OF APPROPRIATIONS Strike: Lines 14-18 Insert: For the purpose of carrying out this subpart, there are authorized to be appropriated $432,700,000 for fiscal year 2007, $444,800,000 for fiscal year 2008, $461,100,000 for fiscal year 2009, $478,200,000 for fiscal year 2010, and 495,900,000 for fiscal year 2011.

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Title I and Title II			
HIV Case Proxy	Calls for a proxy for HIV cases to be available to states that have HIV reporting or that have agreed to begin HIV reporting by 10/1/06 but that do not have established surveillance systems. The proxy is the lesser of .9 of living AIDS cases or 110 percent of the previous year's funding.	It appears that the proxy will not be available to many states in which case the proxy disadvantages the state. For example, states in which the HIV to AIDS ratio is lower than .9. Persons with AIDS are living longer, and the number of deaths due to AIDS has fallen. In addition, most states have not captured all prevalent HIV cases. Make the proxy available to states with HIV to AIDS ratios that are below .9.	Page 4, Line 20 SEC. 102. LIVING CASES OF HIV/AIDS (b) DISTRIBUTION BASED ON LIVING CASE OF HIV/AIDS (C) LIVING CASES OF HIV/AIDS(ii) FISCAL YEARS 2007 THROUGH 2010 Insert: "or" at the end of paragraph (III) and a new paragraph (IV), "the State's current ratio of HIV to AIDS cases is below .9." Page 24, Line 8 SEC. 201 LIVING CASES OF HIV/AIDS (c) DISTRIBUTION FUNDS (2) (F) LIVIJNG CASES OF HIV/AIDS (ii) FISCAL YEARS 2007 THROUGH 2010 Insert: "or" at the end of paragraph (III) and a new paragraph (IV), "the State's current ratio of HIV to AIDS cases is below .9."
Title II			
Severity of Need Index	SONI-based allocations for all funds in FY2011	It is appropriate for Title II funds to be based on a severity of need index if such an index truly represents objective, comparable, measurable and weighted indexes. The SONI must not punish local and state governments that have prioritized	Page 31, line 14 SEC. 204. DISTRIBUTION FACTORS (4) (E) SEVERITY OF NEED (i) FISCAL YEARS BEGINNING WITH 2011 Insert: after "clause (v)," "and the Secretary has made the determination under subparagraph ____ of this title."

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Severity of Need Index (cont.)		their tax levy resources to support HIV/AIDS care and reward localities and states that have not made HIV/AIDS care a priority. Federal funding levels must also not be tied to the amount of private resources that have been donated by citizens or foundations to support HIV/AIDS care locally. Any indicators used to distribute resources nationally must be standardized and comparable between all EMAs and states. In attempting to identify appropriate indices for funding distribution, the confounding differences in data collection from state to state and locality to locality must be addressed. Indices should not be subject to factors with high levels of fluctuation such as the amount of private resources donated by individuals to HIV/AIDS efforts in a community or state. In 2000, Congress recognized that the mechanism for distribution of funds is only as good as the underlying data. That is why provisions were written into the statute to ensure that states had surveillance systems that were	Insert: "(__) DETERMINATION OF SECRETARY REGARDING CLIENT LEVEL DATA-Not later than July 1, 2009, the Secretary shall determine whether there is client level data from all eligible areas (reported to and confirmed by the Administrator of HRSA) sufficiently complete, accurate and reliable for use for purposes of the severity of need index in subparagraph (E)(i)." "(__) EFFECT OF ADVERSE DETERMINATION-If under clause (i) the Secretary determines that data on client level data is not sufficiently complete, accurate and reliable for use for purposes of subparagraph (E)(i), then notwithstanding such subparagraph, for any fiscal year prior to fiscal year 2013 the references in such subparagraph to severity of need index do not have any legal effect. Page 34, line 6 insert SEC. 204. DISTRIBUTION FACTORS (4) (E) SEVERITY OF NEED (v) REQUIREMENTS FOR SECRETARIAL NOTIFICATION (v) ANNUAL REPORTS Insert: “(V) The completeness, accuracy and

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Severity of Need Index (cont.) .		able to provide accurate and reliable HIV counts before HRSA began distributing funds on the basis of HIV counts. However, in the current draft of the bill there are no provisions that ensure that the client-level data which will be used to distribute funds in accordance with the severity of need index will be accurate and reliable. Language is needed to ensure that before HRSA implements a Severity of Need Index, accurate and reliable client level data is available for the purposes of accurately distributing funds on the basis of need.	reliability of each state's client level data system reported by each measure included in the severity of need index."
Title III			
Underserved Populations	Singles out individuals co-infected with HIV and hepatitis B or C among all individuals with co-morbidities	There are a number of co-morbidities associated with HIV/AIDS, including hepatitis B and C, substance abuse and mental illness and people living with HIV/AIDS with these co-morbidities should be reflected in any definition of underserved populations. CAEAR Coalition believes that the language must be broader to reflect who is being served and who should be served by Title III clinics.	Page 48, Line 10 SEC. 301. CATEGORICAL GRANTS (b) MINIMUM QUALIFICATIONS OF GRANTEES (a) ELIGIBLE ENTITIES (2) UNDERSERVED POPULATIONS Strike: "individuals co-infected with and Hepatitis B or C," Insert "individuals with co-morbidities, including Hepatitis B or C, mental illness or substance abuse."

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Authorization of Appropriations	The appropriations increase each year except FY 2010, in which there is a decrease. [Likely a drafting error.]	CAEAR Coalition supports the increased authorized appropriations for Title III with the exception of FY 2010, which we believe to be a drafting/transposition error.	Page 49, Line 19 SEC. 301. CATEGORICAL GRANTS (e)AUTHORIZATION OF APPROPRIATIONS Strike: "$234,800,000" Insert: "$243,800,000"
Title I, Title II, Title III			
Core Medical Services	Makes core services requirement in Title I, Title II and Title III. Mandates that support services can be provided only with the Secretary's approval.	CAEAR Coalition strongly supports continued jurisdictional level flexibility and accountability to determine the appropriate mix of HIV health care and supportive services, taking into account the local assessment of unmet and continuing needs and the availability of other resources. If a core services requirement is included, the definition of "case management" can not be limited to medical case management so as to ensure that people living with HIV/AIDS have the support they need to access care and services. In addition, it is crucial that substance abuse treatment not be limited to outpatient treatment, as inpatient	Page 10, Line 21 SEC 104. CORE MEDICAL SERVICES (h) REQUIRED FUNDING FOR CORE MEDICAL SERVICES (2) CORE MEDICAL SERVICES (K) Strike: "outpatient" Page 10, Line 22 Strike: "(L) Medical case management, including treatment adherence services" Insert: "(L) Case management to support access to and retention in health care and improved medical outcomes." Page 39, Line 25 SEC. 205. CORE MEDICAL SERVICES (e) REQUIRED FUNDING FOR CORE MEDICAL SERVICES (2) CORE MEDICAL SERVICES (K) Strike: "outpatient"

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Core Medical Services (cont.)		treatment is by far the best and most effective treatment modality for many substance abusers with HIV/AIDS.	Page 40, Line 1 Strike: "(L) Medical case management, including treatment adherence services" Insert: "(L) Case management to support access to and retention in health care and improved medical outcomes." Page 53, Line 5 SEC. 2688. REQUIRED FUNDING FOR CORE MEDICAL SERVICES (b) CORE MEDICAL SERVICES (11) Strike: "outpatient" Page 53.Line 6 Strike: "(12) Medical case management, including treatment adherence services" Insert: "(12) Case management to support access to and retention in health care and improved medical outcomes."
Secretary's waiver of the 75% requirement		CAEAR Coalition believes that it is the intent of this provision to grant the waiver taking into consideration all available funding sources for services, but that needs to be clarified in report language.	Report Language to Provide Guidance to the Secretary Regarding the Waivers Contained in SEC. 104; SEC. 205., SEC. 303.: The Committee notes the Ryan White Care Act was created as a payer-of-last-resort for services provided to individuals with HIV/AIDS and nothing in this legislation changes this payer-of-last-resort status. The Committee believes, therefore, the Secretary should take note of all available sources of

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Secretary's waiver of the 75% requirement (cont.)			medical services – whether provided through another government program or through a private source – when granting waivers of the core medical service mandates contained in Section 2604(h).