



THE AIDS INSTITUTE

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***The Next Wave in AIDS Care:
Reauthorization of the Ryan White CARE Act 2005-2010
Recommendations***

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The Next Wave of AIDS Care: Reauthorization of the Ryan White CARE Act 2005-2010

Moving Forward - Points to Consider

The following points to consider are made as critical discussion items in the national conversation about addressing the domestic HIV/AIDS epidemic in the long and short-term. While it is recognized that the possibilities and options for change in the system of care may be limited in the CARE Act reauthorization process, it is also necessary to identify longer-term issues. The AIDS Institute paper, "The Next Wave of AIDS Care: Reauthorization of the Ryan White Care Act 2005-2010", of which this document is only a section, attempts to identify such issues.

General Statement

The recommendations of the IOM report, *Public Financing of HIV/AIDS Care: Securing the Legacy of Ryan White* (2004) are supported by The AIDS Institute (TAI). The IOM committee that worked on this report provides a model of care designed to resolve many of the issues associated with the current system of care. While creating a new program focused on primary medical care and treatment, the committee recommends the continuation of a reformatted CARE Act to provide for a range of important support services and to ensure the coverage of all populations. The components of these recommendations are supported by TAI as the framework to reform the overall system of care in the long-term, over the next decade. Additionally, TAI encourages that a close look be taken at the medical models of care created by Title III programs of the CARE Act and the overall family and community focused models created by Title IV of the CARE Act. The comprehensive nature of Titles III and IV models may serve as important underlying foundations to any approach to improve the system of care in the long-term. In the short-term, for the 2005 CARE Act reauthorization, TAI believes the IOM report confirms the need for the points listed below to be addressed. This reauthorization should make significant movement forward toward an improved system of care.

In addition to the points made below about the 2005 reauthorization of the CARE act, *TAI strongly supports congressional passage of the Early Treatment for HIV/AIDS Act (ETHA)*. Modeled after the Breast and Cervical Cancer Act, ETHA would afford states the option of providing Medicaid to HIV positive people prior to an AIDS diagnosis and development of disability. In jurisdictions adopting such an option, the lives of low-income people living with HIV would improve due to early and consistent medical treatment to prevent the onset of AIDS and related disability.

The following recommendations in regard to the 2005 CARE Act reauthorization are made with the above General Statement in mind. Several points are offered for consideration, grouped by category. The overall intent of these recommendations is to expand and improve access to HIV/AIDS services under the CARE Act.

RWCA Services

1. A set of minimum services should be available through the CARE Act to all persons eligible for CARE Act services regardless of where they live. TAI is in general agreement with recommendations made by the American Academy of HIV Medicine (AAHIVM) and the HIV Medicine Association (HIVMA), as well as the IOM report, that such services should focus on medical care. Given advances in medical care, this *minimum set of services includes: primary medical care, medications, laboratory services, oral health services, mental health services, substance abuse treatment, case management, hospice, and such medical setting counseling as adherence, nutritional, prevention, and wellness counseling. Primary medical care must include access to such specialties as pediatrics, obstetric and gynecological care.*

The *medications formulary, at a minimum, should include the drug therapies recommended by the U.S. Department of Health and Human Services for antiretroviral agents and the prevention and treatment of opportunistic infections in HIV positive adults, adolescents, and children.* While this set of services would need to be achieved through Titles I and II of the CARE Act, jurisdictions with Title III and IV programs should play a supporting role in achieving them. These services need to be funded as priorities in each jurisdiction.

In regard to the AIDS Drug Assistance Program (ADAP), TAI recommends that patients at 350% of the Federal Poverty Level (FPL) and below be eligible for ADAP in all jurisdictions. Flexibility should be permitted for jurisdictions that demonstrate that this minimum set of services is provided through funding sources other than the CARE Act, both public and private. Additionally, in order for this goal to be achieved, increased collaboration and cooperation between Titles I and II, and the other titles, as well, will be required in each state.

In addition to these minimum services, *TAI views a number of essential support services as crucial to the adherence of medical care, including: transportation, housing assistance, food, child care, and legal assistance.* Funding for these services should continue to be based on the needs of jurisdictions and take into account how the minimum requirements stated above are funded by sources other than the CARE Act.

Funding

2. It has become clear that the success of the CARE Act currently, and after the 2005 reauthorization, depends on maintaining and expanding funding. There are three aspects to this point of consideration. *The first, and most obvious, is the need for increased congressional appropriations for the CARE Act.* Most of the CARE Act has been flat funded for several years, except for minor increases in ADAP. This is occurring at a time when people are living longer with HIV/AIDS and case loads continue to climb, as does the cost of healthcare.

The second is to ensure that other major programs that fund HIV/AIDS services, such as Medicaid, Medicare, Housing Opportunities for People with AIDS (HOPWA), and the Minority HIV/AIDS Initiative (MHAI), are not destabilized due to structural and/or funding changes. Destabilization in services paid for by other funding sources negatively impacts the CARE Act by placing more clients on its caseload, over burdening a program that in some jurisdictions already has waiting lists for ADAP and other services. The third area of concern has to do with looking into new ways to maximize CARE Act funding, with a focus on ADAP. TAI encourages the DHHS Secretary to review insurance continuation programs used in several states for HIV/AIDS services. By paying insurance company premiums of people living with HIV/AIDS, financial savings can be achieved for the CARE Act which can be used for additional CARE Act services. In particular, the DHHS Secretary is encouraged to review the program in Florida, the state with the largest AIDS insurance continuation program in the nation.

RWCA Titles I and II

3. Requirements for community planning processes in Titles I and II should be simplified and made less costly. *TAI proposes that a maximum of four percent of Title I and II CARE Act funds be devoted to the planning process. Focus should be on the meaningful participation of consumers of CARE Act services and health planning experts. Funds saved from this measure should be directed to the flexible fund to be used at the discretion of the DHHS Secretary as described in number seven below. TAI supports requirements to ensure greater coordination in the planning and delivery of services between the Titles, particularly in those states that have Title I metropolitan areas.*

4. TAI supports the recommendation, made by several bodies, and included in the previous reauthorization, to move toward the use of HIV data as the basis for formula distributions under the CARE Act. *TAI encourages the DHHS to devote the necessary resources to the states so that this can occur as soon as possible.*

5. TAI has long supported an increase in the formula portion of Title I in order to stabilize the Title I base and minimize major changes in the funding of Title I jurisdictions that are not based on epidemiological data and projections. *HRSA/CDC Advisory Committee (CHAC) has recommended that the formula proportion of Title I be increased from 50% to 75%, leaving 25% for the supplemental portion, a change TAI supports. TAI further supports that recommendations contained in the IOM Report “Measuring What Matters”, regarding the need for more quantitative data measures, be considered in distributing the non-formula awards.*

6. TAI believes that the hold harmless provisions in Titles I and II contribute to the types of funding inequities for emerging crisis areas as discussed in the IOM report and in this paper. *While at the same time it is understood that too rapid of a change in the Titles I and II hold harmless rates could seriously destabilize some jurisdictions that are heavily impacted by the epidemic. Therefore, TAI supports*

a progressive reduction of the hold harmless provisions over time. For Title I, the Communities Advocating Emergency AIDS Relief (CAEAR) Coalition/AIDS Action recommendation is supported which discusses moving from the current 15% to 21%. For Title II, the position of the National Alliance of State and Territorial AIDS Directors (NASTAD) is supported. This framework moves the Title II hold harmless from one percent per year over five years (total of 5%) to 1.5% per year over five years (total of 7.5%).

7. President Bush outlined reauthorization principles in a June 2004 speech given in Philadelphia. These included issues of: flexibility, accountability, and community participation.

In regard to flexibility, TAI is concerned about the continuous emergence of such crisis situations as ADAP waiting lists, other cost containment measures, and waiting lists for other critical services. To partially address these issues, it is recommended that five percent of Title I and non-ADAP Title II funds be set aside each year to be used for such emergencies at the discretion of the DHHS Secretary.

AIDS Drug Assistance Program

8. TAI concurs with a recommendation made by the HRSA/CDC Advisory Committee (CHAC) regarding the AIDS Drug Assistance Program (ADAP) supplemental funding. This recommendation specifies that: *HRSA should be authorized to develop a mechanism to temporarily remove the state match requirements for state's eligibility to supplemental funding when the Chief Elected Official (CEO) of the state has a valid financial reason to remove the match.* The removal of the state match would only last one year and any further match removal request would have to be reapplied. *TAI supports the continuation of the current state match requirements for ADAP funding distributed through formula.*

9. TAI supports a system of CARE Act medication pricing that is consistent across all CARE Act funded programs that purchase drugs and across all jurisdictions. DHHS needs to ensure that the lowest possible prices paid by the federal government are utilized by all CARE Act programs purchasing drugs.

10. In order to help alleviate the funding crisis in the ADAP program, when the new Medicare Part D Drug benefit begins, TAI supports that contributions from the ADAP program should be able to wrap around the Medicare drug benefit and count as true out of pocket expenses. Further, *TAI recommends that DHHS commission an independent study of the first year of the new Medicare drug benefit's impact on ADAP.*

11. TAI concurs with NASTAD that any unexpected funds from all Titles of the CARE Act from all years be redirected to ADAP. The previous two grant periods would be exempted from this redirection. That is in year 16, utilize all unexpected funds from year 13 and prior.

12. To address the unmet need for access to medications, TAI further concurs with NASTAD to redirect to the ADAP earmark any unexpended funds that exceed HRSA's approved percentage of any CARE Act grantee's award amount (using the FSR submitted 90 days following the conclusion

of each grant award) from all Titles of the CARE Act. Grantees would be able to spend up to the approved amount of their previous year's award for use during the next grant cycle. The remaining amount of unexpected funds for each grantee for that year would be reserved for the award cycle for ADAP grants.

RWCA Titles III and IV

13. TAI encourages the establishment of new Title III and IV programs with the use of any new Title III and IV funds to be focused on America's poorest counties, including rural areas. Rural America, in particular, is lacking many of the resources necessary to deliver HIV/AIDS services. President George W. Bush noted the general problem of healthcare in America's poorest counties in his 2005 State of the Union Address. *Additionally, it is recommended that DHHS ensures that at least five percent of all existing Title IV services and funds be targeted to the nation's poorest counties, including rural areas.* In a related matter, *TAI supports the recommendation of the Communities Advocating Emergency AIDS Relief (CAEAR) Coalition to establish a formal plan to ensure that HIV/AIDS care is identified as a core component of healthcare services to be provided by 330 Clinics and other Federally Qualified Health Centers.* This will require increased collaboration between the Bureaus of HIV/AIDS and Primary Health Care at the Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS).

RWCA AIDS Education and Training Centers

14. TAI recommends that changes be made to the AIDS Education and Training Centers (AETC) program through reauthorization to address concerns about the shortage of medical providers who are HIV specialists, a trend that is expected to continue. Said changes would include permitting AETC funds to be used for training programs for new clinicians who want to enter the HIV field; healthcare education loan forgiveness programs for providing service in HIV public health settings; and other incentives.

Accountability

15. TAI supports accountability in CARE Act programs. As summarized in this paper, the IOM report found a number of problems with the type of data collected regarding the CARE Act. *It is recommended that HRSA conduct a comprehensive review to reform program reporting and account for unduplicated case counts, as well as clear and standard health and social outcome measures.* In addition, outcome measures for programmatic coordination and collaboration between RWCA Titles and other federal government programs need to be developed. *It is further recommended that the administrative burden to CARE Act grantees and sub grantees be evaluated by HRSA and recommendations for streamlining and simplifying them, and an assessment of the cost effectiveness of current and proposed data requirements, be made.*

Community Participation

16. Community participation in the provision of services is an important part of the CARE Act. *TAI concurs that the competitive process for awarding contracts to sub-grantees should be focused on the delivery of high quality services to consumers and continuity of care and services. Community and faith based organizations that can demonstrate the capacity to deliver appropriate, high quality services should be encouraged to compete for CARE Act funds. Title I and II awardees should be required to competitively bid all grant awards, rather than retain funds at their level without competition.*

Medical Co-Morbidities

17. A number of co-morbidities are associated with HIV/AIDS. Over the past several years there have been improvements made in linking HIV/AIDS services to those related to other Sexually Transmitted Infections and Tuberculosis. More recently, concerns have focused on hepatitis, primarily hepatitis C, but also hepatitis B. *Based on TAI policy research, the agency is convinced that improvement is needed in the collaboration between HIV/AIDS and hepatitis services in the public health sector. We encourage CARE Act funded medical settings, with funding from either the CARE Act or other public or private funding sources, make hepatitis prevention (e.g., hepatitis A and B vaccinations) and treatment (in particular for hepatitis C) an area of attention.*

Return To Work Issues

18. As treatment for HIV/AIDS has improved the length and quality of life for many individuals, some people are able to return to work on either a part-time or full-time basis. It is an important goal of any AIDS related care program to return people to work. One barrier for return to work programs for people with chronic diseases, and, in particular in HIV/AIDS, has been the potential loss of medical benefits. *TAI recommends that DHHS study this issue and develop a framework that allows individuals to return to work without necessarily losing CARE Act benefits. This framework would, of course, need to look at issues such as eligibility, progressive transfer of benefits from public to private workplace sources, and the ability to return fully to CARE Act services in the event of employment disruption.*

Portability of Services

19. TAI recognizes that part of the problem of service equity in the CARE Act involves situations when a person relocates from one jurisdiction to another and the matrix of services is different. Recommendation number one above will help to address these situations, but not necessarily in a complete way. Some advocates have suggested that CARE Act services should be “portable”. This has mostly been suggested in the area of ADAP. While there are attractive elements to portability, especially for ADAP, there are also a number of logistical and practical limitations to such a system.

Thus, TAI recommends that DHHS commission an independent study of the options associated with ADAP portability and develop a set of guidelines for possible implementation.

Coordination Between Federal Government Agencies and Programs

20. In order to gain efficiencies, improve coordination of various federal funding services, and to ensure that the CARE Act acts as the payer of the last resort, TAI supports additional requirements that make sure all pertinent federal programs work closely together in the planning and providing of services.