

# **Ryan White Care Act Reauthorization of 2005 Recommendations**

**By the**

**CDC/HRSA Advisory Committee on  
HIV and STD Prevention and Treatment**

Adopted  
November 20, 2003

## Introduction

Since 1990, the Ryan White CARE Act has been central to the effort to provide access to health care, treatment and support services for people living with HIV and AIDS. The Act was originally enacted to improve the quality and availability of care and services for low-income individuals and families affected by HIV disease. As stated at the beginning of the CARE Act, its purpose was "to provide emergency assistance to localities that are disproportionately affected by the Human Immunodeficiency Virus epidemic and to make financial assistance available to States and other public or private nonprofit entities to provide for the development, organization, coordination and operation of more effective and cost efficient systems for the delivery of essential services to individuals and families with HIV disease." With the CARE Act, Congress acknowledged the enormous impact of AIDS.

The CARE Act was designed to fill the gaps in health care and services that prevented so many people living with HIV and AIDS from accessing adequate care. It was designed to address the disproportionate impact of AIDS on the poorest and most disenfranchised Americans. It was intended to help remedy the overwhelming strain on local health and social service resources by promoting the creation of more affordable and responsive AIDS care options.

Since 1990, there have been significant advances in treatment of HIV disease, helping many to maintain health and live longer. These developments have shifted the emphasis of the CARE Act to helping people, particularly those in underserved populations, access health care, medications and essential support services as early as possible in the course of the disease.

### **CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment**

In November 2002, in order to promote better coordination of prevention and care resources, the Health Resources Services Administration AIDS Advisory Committee (HAAC) and the Centers for Disease Control and Prevention Advisory Committee on HIV and STD Prevention (ACHSP) were combined into one entity.

The resulting body, the CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment (CHAC), held its first meeting on May 15-16, 2003. The CHAC is charged with helping to shape the future direction of HIV and AIDS and STD prevention and care programs. CHAC advises the CDC, HRSA, and the Secretary of Health and Human Services on

- activities related to prevention and control of HIV and AIDS and other STDs,
- support of health care services to persons living with HIV and AIDS, and
- education of health professionals and the public about HIV and AIDS and other STDs.

The Committee helps CDC, HRSA, and HHS determine how best to identify and respond to the prevention and health care service needs of communities and individuals affected by HIV and AIDS and other STDs. CHAC offers recommendations on strategic, programmatic, and policy issues, and provides general support to the agencies as they respond to emerging HIV or STD-related health needs.

Members of CHAC include physicians, nurses, public health officials, administrators, professors, people living with HIV and AIDS, social workers, epidemiologists, researchers, and members of the general public. Up to 26 CHAC members, nominated by the Secretary of HHS, serve terms of up to four years. The Committee meets twice each year, in meetings open to the public.

The AIDS epidemic has disproportionately affected people who have traditionally been marginalized by society: the poor, communities of color, women, men who have sex with men, substance users, and people with mental health problems. As a result, CARE Act clients are increasingly people who do not have the insurance or financial means to afford all of their health care. Many also lack a social support system to help them manage the complex task of living with HIV disease.

Increasingly, CARE Act clients come from communities of color. The percentage of CARE Act clients who are women has also increased. More CARE Act clients are poor and struggling with other illnesses, such as hepatitis C, mental illness, and substance abuse. The average age of CARE Act clients is rising, with an increase in associated age- or treatment-related ailments, such as heart disease and hypertension. Rural CARE Act clients are often isolated from providers familiar with treating HIV disease. People living with HIV and AIDS still must deal with stigma surrounding the disease. For all of these clients, the CARE Act is a vital safety net, providing access to care and services that they would not otherwise have.

Treatment breakthroughs, which have offered hope of prolonged health and life for people living with HIV and AIDS, have sparked an effort for earlier testing, diagnosis, and intervention with people who are at high risk of contracting HIV. The success of new medications has meant that more people are living longer with HIV disease, thus creating an increased and sustained demand for the care and services provided by the CARE Act.

**The CHAC Ryan White CARE Act Reauthorization Workgroup  
and Public Meetings on CARE Act Reauthorization**

Within the CDC/HRSA Advisory Committee, the Ryan White CARE Act Reauthorization Workgroup is charged with recommending proposals to the CHAC for improving the CARE Act for the upcoming Congressional reauthorization of the Act. When these recommendations are finalized, CHAC then presents them to HRSA and the Secretary of HHS. The Workgroup carefully examines all aspects of the CARE Act to assess how well the Act is fulfilling its purpose of providing quality health care, treatment, and essential support services to the most vulnerable people living with HIV and AIDS.

The Reauthorization Workgroup considers emerging trends and changes in the HIV and AIDS epidemic, care and treatment developments, technological advancements, and other factors in evaluating the CARE Act. Recommendations for change focus on making the CARE Act more responsive, flexible, and effective in meeting the needs of clients. The Workgroup's recommendations encompass many areas of the Act, including the structure of the Act itself, resource distribution, funding priorities, and program management.

Reauthorization Workgroup members themselves have considerable expertise in HIV care programs and policy, but in keeping with the collaborative spirit of the CARE Act, the Workgroup also seeks input from others in making its recommendations. In 2003, the Workgroup held three public meetings, in Washington, D.C. (September 12), Miami (September 25), and Los Angeles (October 3), to solicit comments on what works and what does not about the current CARE Act, and to gather suggestions about future directions in HIV and AIDS care and treatment programs. More than 430 people attended the public meetings, and 105 people provided oral testimony. Testifiers included public health officials, program administrators, physicians, and CARE Act clients. More than 80 written testimonies were submitted. The Workgroup carefully considers all public testimony, identifies recurring themes and issues, and often incorporates these comments into its recommendations.

The CARE Act serves more than 533,000 individuals each year. It is certainly central, but not exclusive, to meeting the care and service needs of people living with HIV and AIDS. Simply put, the CARE Act cannot do it all. It is designed to serve as a safety net, providing emergency care and support services not available through other programs. The CARE Act is supposed to be the “payer of last resort.”

It is essential that the government increase coordination among all the federal agencies, and the critical programs they are implementing, which serve people living with HIV and AIDS,<sup>1</sup> and that these entities work together in a way that maximizes effectiveness and efficiency, and decreases duplication. For example, while numerous federal HIV/AIDS programs have emphasized improved access to testing and early intervention, Medicaid (the largest provider of health coverage for poor and low-income people in the US) generally does not provide access to care until HIV has progressed so much that a person becomes disabled by AIDS. This undermines the principle that the CARE Act is supposed to be the “payer of last resort,” filling gaps not covered by other programs and resources.

The CARE Act has created an impressive system of care and support services. Funding for the CARE Act must be increased to preserve this critical “infrastructure” and to meet the growing needs for treatment and services. CARE Act clients and providers around the country emphasize the importance of supportive services in helping people living with HIV and AIDS access and maintain demanding care and treatment regimens. It is impossible to get quality health care if you have no way to get to the doctor. The success of complex treatment protocols often relies on access to case management services, substance abuse treatment, and mental health programs. The CARE Act must continue to recognize provision of supportive services as a key part of its mission.

One of the hallmarks of the CARE Act has been fostering collaboration among the federal, state, local, and private sectors. These partnerships, and the flexibility afforded local entities by the Act, have been critical to the successful creation and maintenance of the continuum of care and the system of support for people living with HIV and AIDS. The CARE Act needs to sustain its commitment to providing a continuum of care and health-related support services, while continually improving coordination with other federal programs.

Over the past 13 years, the CARE Act has offered care, support, and hope to hundreds of thousands of people living with HIV and AIDS. It remains a cornerstone of the federal effort to fight this epidemic in the United States, and a critical safety net for the vulnerable clients it serves. With more people than ever living with HIV disease, the need for the CARE Act has only increased, and it must be reauthorized and adequately funded.

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<sup>1</sup> These agencies and programs include Medicaid, Medicare, Substance Abuse and Mental Health Services Administration, the Centers for Disease Control and Prevention, the Veterans Administration, the Social Security Administration, the Minority AIDS Initiative, the Indian Health Service, and the Department of Housing and Urban Development.

## DRAFT

### The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act: Legislative History

*"This legislation is about care, it is about options, and it is about a tradition of caring for those who are sick with dignity... we are acting in the best interests of the Nation--by fighting AIDS and not people with AIDS."*—Senator Edward Kennedy, May 16, 1990

*"This is a landmark piece of legislation. This legislation is public health legislation of the highest sort. Its purpose is to alleviate pain and suffering, to find ways of ending this pain and suffering and the difficulties that AIDS has brought throughout this country."*—Senator Orrin Hatch, May 16, 1990

The CARE Act is named for Ryan White, an Indiana teenager whose courageous public battle against AIDS and AIDS-related discrimination raised national awareness about AIDS in the early years of the epidemic. Ryan White lost his battle with AIDS in April 1990, at age 18; the Act bearing his name was signed into law in August 1990.

#### Enactment (1990)—101<sup>st</sup> Congress

- March 16, 1990—CARE Act introduced in the U.S. Senate by Sen. Edward Kennedy (D-MA), with 66 co-sponsors.
- April 4, 1990—CARE Act originally introduced in the U.S. House of Representatives by Rep. Henry Waxman (D-CA), with 4 co-sponsors.
- May 16, 1990—CARE Act passes Senate, 95-4.
- June 13, 1990—CARE Act passes House, 408-14.
- August 18, 1990—CARE Act signed into law by President George H.W. Bush, becomes Public Law 101-381.

#### 1<sup>st</sup> Reauthorization (1995-1996)—104<sup>th</sup> Congress

- January 4, 1995—CARE Act Reauthorization originally introduced in House of Representatives by Rep. Henry Waxman (D-CA), with 38 co-sponsors.
- March 28, 1995—CARE Act Reauthorization introduced in Senate by Sen. Nancy Kassebaum (R-KS), with 65 co-sponsors.
- June 16, 1995—substitute House bill introduced by Rep. Michael Bilirakis (R-FL), with 90 co-sponsors.
- July 27, 1995—Reauthorization passes Senate, 97-3.
- September 18, 1995—Reauthorization passes House in voice vote.
- May 1, 1996—House passes Reauthorization Conference Committee Report, 402-4.
- May 2, 1996—Senate passes Reauthorization Conference Committee Report by unanimous consent.
- May 20, 1996—CARE Act Reauthorization signed into law by President Bill Clinton, becomes Public Law 104-146.

#### 2<sup>nd</sup> Reauthorization (2000)—106<sup>th</sup> Congress

- March 29, 2000—CARE Act Reauthorization introduced in Senate by Sen. James Jeffords (R-VT), with 51 co-sponsors.
- June 6, 2000—Reauthorization passes Senate by unanimous consent.
- June 29, 2000—CARE Act Reauthorization introduced in House of Representatives by Rep. Tom Coburn (R-OK), with 253 co-sponsors.
- October 5, 2000—Reauthorization passes House, 411-0.
- October 20, 2000—CARE Act Reauthorization signed into law by President Bill Clinton, becomes Public Law 106-345.

# CARE ACT REAUTHORIZATION, STRUCTURE AND APPROPRIATIONS

## 1. Reauthorization of the CARE Act

### Recommendation:

- The Ryan White CARE Act should be reauthorized.

### Rationale/Background:

- The CARE Act provides critical health care and support services to people living with HIV and AIDS—without it, many would have no access to life-saving and life-sustaining treatment.
- Access to care, treatment, and services through the CARE Act has empowered people living with HIV and AIDS, and enabled many to do more than just survive. People living with HIV and AIDS have returned to work, becoming taxpayers and decreasing dependence on government programs.
- The urgent need for the CARE Act remains, especially as the ongoing epidemic disproportionately burdens disadvantaged communities.

## 2. Structure of the CARE Act

### Recommendation:

- Retain the current title structure in a reauthorized CARE Act.

### Rationale/Background:

- Changing the CARE Act structure would disrupt well-established care and service systems, to the detriment of people living with HIV and AIDS.
- The current structure allows for local flexibility and responsiveness in meeting diverse needs in different regions. The current structure also fosters collaboration and shared responsibility among public and private entities to create a continuum of care for people living with HIV and AIDS.
- The current structure of the CARE Act gives the federal government the ability to ensure and support localized effort.

## 3. Adequate Funding of the CARE Act

### Recommendation:

- The CARE Act should have authorization levels and be funded commensurate with the care, treatment and service needs of those living with HIV and AIDS.
- Each year, either the Congressional Budget Office (CBO) or Health and Human Services (HHS) should provide Congress with a comprehensive analysis of identified HIV and AIDS needs and with the actual total resources required to meet those needs.

### Rationale/Background:

- The CARE Act is chronically underfunded, undermining the goal of providing access to care, treatment, and support services to low-income people living with HIV and AIDS. With no decrease in HIV incidence, and people living longer with HIV disease, there is growing demand for services, and increasingly fewer resources to meet that demand.
- While access to care, treatment and support services is expensive, it is also cost-effective, since it helps maintain health and avoid more costly medical interventions. Through CARE Act services, many people living with HIV and AIDS become healthy enough to return to work and thus reduce dependence on government assistance.
- If we are successful in reaching the estimated 180,000 to 280,000 HIV positive Americans who are currently unaware of their HIV status, funding of the CARE Act must be increased to meet the demand for care, treatment and services that will be created. To be effective, initiatives, such as the new CDC Advancing HIV Prevention initiative, must be coordinated with the CARE Act to ensure that those newly identified as living with HIV have access to care, treatment and essential support services, including positive prevention.

## **ADMINISTRATION/MANAGEMENT OF THE CARE ACT**

### **4. Funding/Resources for CARE Act Administration**

#### Recommendation:

- HRSA AIDS Bureau and other parts of HRSA working on CARE Act activities should be given increased financial and human resources to fulfill their administrative and oversight responsibilities under the CARE Act.

#### Rationale/Background:

- Administrative oversight, management, and technical assistance responsibilities for the CARE Act have increased. HRSA needs additional financial and human resources to meet these demands.

### **5. Increasing Length of Grant Periods**

#### Recommendation:

- Any grant period in a CARE Act title, whether formula, supplemental or discretionary, that is currently a one-year cycle should be increased to two years.

#### Rationale/Background:

- A one-year grant period is unduly administratively burdensome and potentially destabilizing and disruptive to care and service provision. The course of the epidemic does not generally change significantly in the course of one year. Changing to a two-year award would reduce administrative burdens and allow more resources to go towards care and services. (This recommendation does not address current one-year budget award cycles, which should remain unchanged.)

### **6. Administrative Caps/Program Evaluation**

#### Recommendation:

- For those directly providing CARE Act services under a 10% administrative cap, the administrative cap level should be increased to 20%.

#### Rationale/Background:

- The current 10% cap on administrative costs is inadequate to meet the enormously complex administrative demands facing many direct providers of CARE Act services. Administrative costs include reporting requirements, fiscal accounting, day-to-day operations, and management of staff. Experience has shown that actual administrative costs are well over 30%.
- Under the current 10% administrative cap many small community-based organizations (including many run by and serving minorities) find that they cannot serve as CARE Act providers. Other agencies choose not to receive CARE Act funds due to the administrative requirements, leading to a lack of services in some jurisdictions.
- This recommendation does not increase the amount allowed for planning and evaluation, as we believe that current percentages allocated in these areas remain adequate.

### **7. Statewide Coordinated Statement of Need**

#### Recommendation

- The Statewide Coordinated Statement of Need (SCSN) process should be administratively strengthened so as to better assure equitable service access, integration and coordination. Consistently strong language within each title should require that all grantees participate in the development of the SCSN.
- A legislative mandate should require that relevant federal agencies providing direct services in a state (e.g., the Veterans and Social Security Administrations) and state agencies receiving federal funds (e.g., state agencies receiving funds from CMS and SAMHSA) participate in the development of the SCSN.

#### Rationale/Background:

- Currently, different titles of the CARE Act have different requirements for participation in planning coordination. Language about cross-title participation must be consistent across all titles of the Act. While some titles say that grantees “shall” or “will” coordinate with other providers, others say only that grant applicants should “make reasonable efforts.” Consistently strong language within each title will help clarify the coordination requirement.
- The development of a successful SCSN demands the participation of all public agencies providing care, treatment and prevention services to people living with HIV and AIDS. Without a mandate requiring such participation it is unfair to expect that the public health agency administering the grant for each state can develop an adequate SCSN.

### **8. Increased Service Delivery Coordination Between Titles**

#### Recommendation

- A reauthorized CARE Act should require that service delivery be coordinated among the different titles of the Act.

- As a condition of funding, CARE Act grantees and sub-grantees must document efforts and outcomes for the coordination of service delivery.
- Integration of service delivery must be a requirement of Title I and II planning activities and documented in their comprehensive plans.

#### Rationale/Background

- Increased service delivery coordination between the various titles of the CARE Act will help to maximize the effective use of limited CARE Act resources.
- Increased service delivery coordination will help to reinforce the goal of a seamless delivery system of care and services to people living with HIV and AIDS within and across titles of the CARE Act.

### **9. Establishment of Consumer Grievance Procedures**

#### Recommendation

- All grantees and sub-grantees in all titles providing direct services to consumers should be required to have a grievance process through which consumers can address service concerns.
- Grantees and sub-grantees providing direct services should be required to present a written notice of the grievance policy to all of the consumers receiving their services.
- HRSA should provide to all grantees recommended guidelines for the implementation of consumer grievance procedures.

#### Rationale/Background

- This grievance process will provide a formal mechanism for ensuring that consumers have the ability to address concerns directly to the providers of CARE Act services as well as to grantees.

### **10. Title I Planning Councils**

#### Recommendation:

- Maintain the requirement that 33% of planning council members be people living with HIV and AIDS and consumers of Title I services, but modify the “non-aligned” requirement, so that if a consumer is designated “non-aligned” at the time of joining the planning council, that designation is maintained until expiration of the consumer’s term.
- Allow honoraria for consumers of CARE Act services to support participation in planning council activities.

#### Rationale/Background:

- The requirement that 1/3 of planning council members be non-aligned consumers has increased participation of people living with HIV and AIDS in Title I priority setting and decision making, which is commendable. However, the non-alignment requirement has caused destabilizing turnover on planning councils, requiring planning councils to continually have to recruit, train and orient new members. Additionally, many of the most active consumer members increasingly seek and obtain employment, often with Title I organizations. This forces them to leave the planning council or be reassigned to an aligned seat. The non-alignment requirement makes it very difficult to meet the 33%

consumer membership standard. Basing the 33% non-aligned requirement on an individual's status at the time of appointment would alleviate this problem. This recommendation does not affect current conflict of interest requirements, which should be maintained.

- Many consumers do not have the resources to actively participate in time-consuming and demanding planning council activities without financial assistance. Providing funds to support consumer participation, in addition to current provisions allowing for reimbursement of expenses, will help ensure that the planning council process is equally open to all.

## 11. Title II—Participatory Planning

### Recommendation:

- Title II of the CARE Act should include a legislative mandate for a public advisory planning process that includes people living with HIV and AIDS and a range of representatives from affected communities and service providers.
- States receiving Title II funds must be required to demonstrate that such a participatory process exists and that participants are consulted in decisions about needs assessment and priority setting for Title II funds.
- Consortia funded through Title II must be required to demonstrate that their membership includes representation reflecting the epidemiology of HIV and AIDS in their geographic area and includes people living with HIV and AIDS as well as providers of services to impacted populations. Consortia should be required to conduct open nomination processes and to conduct open business meetings.

### Rationale/Background:

- Given their responsibilities for sub-contracting and overseeing significant federal funds, Title II grantees, state governments and consortia must include community and consumer representation in their governance and decision-making process. While this recommendation does not suggest mandating the same kind of intensive participatory planning process used in Title I of the CARE Act, it confirms the principle that there is value in consumer participation and a public planning process.

## 12. Grievance Process for Title I and Title II Grantees

### Recommendation:

- A reauthorized CARE Act should assure the authority of HRSA to investigate and assess deficiencies of Title I and II grantees and sub-grantees fund management and service delivery. If such deficiencies are upheld, HRSA can employ interventions including HRSA/HHS Secretary taking over the grant.
- HRSA should establish processes by which consumers, sub-grantees and the public can request investigations.

### Rationale/Background:

- This grievance process will provide a check on Title I and Title II grantees, and will enhance accountability and the ways in which HRSA can address the concerns of consumers and sub-grantees/subcontractors who observe serious and ongoing mismanagement of a grant.

### 13. Price of Pharmaceuticals

#### Recommendation:

- A reauthorized CARE Act should ensure that all drug assistance programs, including the Title II AIDS Drug Assistance Programs, receive the lowest price for pharmaceuticals available to the federal government, unless otherwise individually negotiated at a lower rate.

#### Rationale/Background:

- Medications for HIV- and AIDS-related illnesses comprise a significant part of CARE Act resources and the largest part of Title II spending. Federal involvement can help stretch limited CARE Act resources by ensuring that the lowest price currently paid by the federal government for a medication is also the price paid by CARE Act-funded programs (e.g., Veterans Administration drug pricing).

### 14. Title III—Consumer Participation

#### Recommendation:

- As a condition of funding, Title III grantees must be required to demonstrate that they have a mechanism for meaningful consumer input into grantees' Title III programs (e.g., a consumer advisory board).

#### Rationale/Background:

- There is currently no requirement for any consumer participation in Title III programs. Consumers bring different and valuable perspectives, as recognized by the CARE Act in other titles. Consumer participation will enhance the provision of Title III services, and help promote accountability on the part of grantees.

## **DISTRIBUTION OF RESOURCES**

Several significant distribution of resources issues are not addressed in this document, including:

- the use of HIV case reporting and service utilization data to determine eligibility under Title I and funding under Titles I and II of the CARE Act;
- changes to the existing Title I and II hold harmless provisions;
- changes in the percentages of the Title I grant awarded by formula and competitively;
- changes in the percentages of the Title II AIDS Drug Assistance Program (ADAP) distributed by formula and supplemental awards; and
- comparability and portability of the ADAP.

While we recognize that these are critical issues, at the present time we do not have enough information on which to make formal recommendations. The Institute of Medicine report on HIV case reporting was released on November 7, 2003. The workgroup did not have enough time to review this report and make recommendations before the November 20<sup>th</sup> meeting of the CHAC. The information contained in this report will be thoroughly reviewed and may have a significant impact on a recommendation regarding the use of HIV case data. In addition, we have requested data from HRSA and others, on the impact of changes to both the hold harmless provisions and the current formula structure. Our plan is to review all of this additional data as soon as possible and determine and issue separately any recommendations regarding these issues.

## **HEALTH CARE SERVICES**

### **15. Public Health Service Guidelines as Priority for CARE Act Services**

#### Recommendation:

- All grantees under all titles of the CARE Act must be required, as a condition of award, to document the specific steps they are taking to ensure that people living with HIV and AIDS in their area of service are offered services that meet or exceed all Public Health Service (PHS) guidelines and joint CDC/HRSA recommendations for HIV-related treatment, care and prevention.

#### Rationale/Background:

- The PHS guidelines (e.g., for HIV, STD and TB) and joint CDC/HRSA recommendations provide an objective effort to measure a basic standard of treatment, care and prevention. All Ryan White CARE Act grantees must make meeting or exceeding these guidelines and recommendations a service priority.

### **16. Priority to Core Services and Linkages to Health Care**

#### Recommendation:

- CARE Act grantees and planning bodies should develop strategies and implement programs to voluntarily connect into health care those not currently accessing it (while respecting client choice and autonomy around care decisions) through expanded outreach and voluntary counseling and testing services.
- The CARE Act must instruct grantees and planning bodies to give the highest priority, as appropriate to the needs of the locality, to the provision of health care services and medications.

#### Rationale/Background:

- Given that this recommendation instructs grantees to give the provision of health care the highest priority, it follows that healthcare services would be given the highest priority in resource allocations. In making resource allocation decisions, grantees must take into account all sources of funding for healthcare within their jurisdictions, including CARE Act funds.
- Support services play a significant role in ensuring and supporting access to health care and the successful use of therapeutics. CARE Act funds should not be restricted to a narrow range of directly medical services. This recommendation recognizes the necessity of ensuring access to health care and treatment, and also the importance of supportive services in enabling people living with HIV and AIDS to access care and treatment.

### **17. Integration of Care and HIV Prevention Services**

#### Recommendation:

- The CARE Act should promote integration of care and prevention services by encouraging the development of coordinated planning and service systems between HRSA and CDC-

funded programs. Grantees should recognize their responsibility to integrate prevention into the care of HIV-positive people.

Rationale/Background:

- CDC initiatives, especially the Advancing HIV Prevention initiative, include goals and priorities that are particularly relevant to the CARE Act. Issues of early referral to care and services for newly-diagnosed individuals, and “positive prevention” (e.g., helping people living with HIV learn strategies to prevent transmission of HIV) are already CARE Act goals. Increased coordination and collaboration, in care and prevention planning and service delivery, will help ensure that activities are not duplicated, and that the benefits of integrated care and prevention services are maximized.

## **18. Dental/Oral Health Care**

Recommendation:

- Support for dental school clinics should continue. In addition, funds should be made available, on a competitive basis, to support community-based clinics providing dental care for people with HIV, especially in communities without a participating dental school clinic or with high unmet oral health care needs.

Rationale/Background:

- The requirement that grants are limited to dental schools and those that partner or have an affiliation with them is overly restrictive. Community-based dental programs, that are not affiliated with dental schools, should be eligible to receive CARE Act funding to provide oral health care to patients with HIV disease in unserved areas.

## **REMOVING BARRIERS TO CARE**

### **19. Addressing Stigma, Cultural Competence and Discrimination**

Recommendation:

- CARE Act resources should be allowed to be used to address ongoing stigma and discrimination against people living with HIV and AIDS, and cultural competence, as these issues continue to represent significant obstacles to care, treatment and services. In addition, HRSA should consider prioritizing Special Projects of National Significance (SPNS) projects or creating specific set-asides for programs that focus on addressing and reducing stigma and discrimination and improving cultural competency.

Rationale/Background:

- More than two decades into the HIV and AIDS epidemic, there is still significant stigma associated with an HIV diagnosis. HIV-related stigma and a lack of culturally competent services all too often discourage people from testing, from learning their status, from accessing health care, from adhering to treatments, and from participating in care and prevention activities. This undermines the goals of the CARE Act, and can have potentially devastating consequences for the health of people living with HIV and AIDS. Resources

should be allocated to evaluate the consequences of discrimination and develop plans to reduce these effects.

## 20. AIDS Education and Training Centers

### Recommendation:

- The AIDS Education and Training Centers (AETCs) should continue to focus on providing training on HIV care for health care providers, but their mandate should be expanded to include the training of additional disciplines involved in the care, treatment and support of people living with HIV and AIDS.

### Rationale/Background:

- The AETCs can play a valuable role in ensuring that a broader range of professionals (e.g., case managers and nutritionists) has up-to-date knowledge of relevant health care and treatment issues. Training efforts should focus on building care and treatment capacity in the areas of greatest need, including among rural providers and providers serving minority communities and other underserved communities.
- A reauthorized CARE Act should ensure that the AETCs continue to provide state of the art training. Providers should be trained on new treatment technologies, including rapid HIV testing. Incorporation of prevention messages into trainings can help reduce the spread of HIV.

## 21. Enactment of the Early Treatment for HIV Act

### Recommendation:

- If the Early Treatment for HIV Act (ETHA) has not been signed into law at the time of CARE Act reauthorization, it should be enacted into law as part of CARE Act reauthorization.

### Rationale/Background:

- Generally, Medicaid does not provide access to care until HIV has progressed so much that a person becomes disabled by AIDS. ETHA gives states the option of amending their Medicaid eligibility requirements to include pre-disabled poor and low-income people living with HIV. ETHA would help to bring Medicaid eligibility rules in line with federal government guidelines on the standard of care for treating HIV.
- The CARE Act was designed to fill gaps in health care and services that prevented so many people living with HIV and AIDS from accessing appropriate care and treatment and to help address the overwhelming strain on local health and service resources. Treatment advances, requiring access to care and treatment prior to Medicaid eligibility, have placed significant strains on CARE Act resources. Given limited CARE Act resources, many parts of the country have growing waiting lists for access to life-saving medications, and limited access to comprehensive care, treatment and services. ETHA will help address this problem.
- Providing earlier access to Medicaid, and care, treatment and services through the CARE Act, will help to preserve the health of people living with HIV, and significantly reduce AIDS-related deaths in the United States.

**CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment  
Committee Members**

**CO-CHAIRS**

**ROBERT E. FULLILOVE, ED.D.**  
Associate Dean  
Columbia University  
Mailman School of Public Health  
617 West 168th Street  
New York, NY 10032  
Phone: (212) 740-7292  
Fax: (212) 795-4222  
Email: ref5@columbia.edu

**JESSE MILAN, JR., J.D.**  
Vice President for Health Communications  
Constella Health Sciences  
8401 Colesville Road  
Suite 200  
Silver Spring, MD 20910  
Phone: (301) 562-1004  
Fax: (301) 562-1001  
Email: jmilan@constellagroup.com

**DESIGNATED FEDERAL OFFICIALS**

**ELIZABETH JAMES DUKE, PH.D.**  
Administrator  
Health Resources and Services  
Administration  
5600 Fishers Lane, Room 14-05  
Rockville, MD 20857  
Phone: (301) 443-2216  
Fax: (301) 443-1246  
Email: bduke@hrsa.gov

**RONALD O. VALDISERRI, M.D., M.P.H.**  
Deputy Director  
National Center for HIV, STD, and TB Prevention  
Centers for Disease Control and Prevention  
CDC Corporate Square  
1600 Clifton Road, N.E.  
Mail Stop E07  
Atlanta, GA 30333  
Phone: (404) 639-8002  
Fax: (404) 639-8600  
Email: rovl@cdc.gov

**MEMBERS**

**TERJE ANDERSON, M.S.W.**  
Executive Director  
National Association of People with AIDS  
1413 K Street, N.W.  
Washington, DC 20005-3442  
Phone: (202) 898-0414 x 101  
Fax: (202) 898-0435  
Email: tanderson@napwa.org

**A. CORNELIUS BAKER**  
Executive Director  
Whitman-Walker Clinic  
1407 S Street, N.W.  
Washington, DC 20009  
Phone: (202) 797-3511  
Fax: (202) 797-0242  
Email: cbaker@wwc.org

**RENEE Y. COBOS, M.D.**  
St. Jude Heritage Medical Group  
3626 North Hermosa Place  
Fullerton, CA 92835  
Phone: (714) 526-7076  
Fax: (714) 526-7077  
Email: rycobos@aol.com

**CARLOS DEL RIO, M.D.**  
Emory University School of Medicine  
Department of Medicine  
69 Butler Street, S.E.  
Atlanta, GA 30303  
Phone: (404) 616-3600  
Fax: (404) 880-9305  
Email: cdelrio@emory.edu

**DAVID FARABEE, PH.D.**  
Research Psychologist  
University of California, Los Angeles  
Drug Abuse Research Center  
11050 Santa Monica Boulevard  
Suite 150  
Los Angeles, CA 90025  
Phone: (310) 312-0500 x 550  
Fax: (310) 312-0552  
Email: dfarabee@ucla.edu

**PATRICIA FLEMING**  
HIV/AIDS Consultant  
Patricia S. Fleming Associates  
6009 Massachusetts Avenue  
Bethesda, MD 20816  
Phone: (301) 320-5420  
Fax: (301) 263-0013  
Email: pfleming@erols.com

**DONNA FUTTERMAN, M.D.**  
Director, Adolescent AIDS Program  
Montefiore Medical Center  
111 East 210th Street  
Bronx, NY 10467  
Phone: (718) 882-0322  
Fax: (718) 882-0432  
Email: futterma@aecom.yu.edu

**DELIANA GARCIA**  
Director, International Research and Development  
Migrant Clinicians Network, Inc.  
1001 Land Creek Cove  
Austin, TX 78746  
Phone: (512) 327-2017  
Fax: (512) 327-0719  
Email: dgarcia@migrantclinician.org

**JUDY GOFORTH PARKER, PH.D., R.N.**  
Legislator  
Chickasaw Nation  
Route 1  
Box 406  
Ada, OK 74820  
Phone: (580) 332-3840  
Fax: (580) 310-5785  
Email: jparker@mailclerk.ecok.edu

**GALE E. GRANT, M.A., C.P.P.**  
Director, Adolescent Sexual Health Programs  
Virginia Department of Health  
Abstinence Education Initiative  
1500 East Main Street  
Suite 105  
Richmond, VA 23219  
Phone: (804) 225-3697  
Fax: (804) 786-0917  
Email: ggrant@vdh.state.va.us

**LORETTA SWEET JEMMOTT, PH.D.**  
Van Ameringen Professor  
University of Pennsylvania School of Nursing  
42 Guardian Drive  
Philadelphia, PA 19104  
Phone: (215) 898-8287  
Fax: (215) 573-9193  
Email: jemmott@nursing.upenn.edu

**THOMAS LIBERTI**  
Chief, Bureau of HIV/AIDS  
Florida Department of Health  
4052 Bald Cypress Way  
Bin A09  
Tallahassee, FL 32399-1715  
Phone: (850) 245-4477  
Fax: (850) 414-0038  
Email: tom\_liberti@doh.state.fl.us

**RON MACINNIS, M.P.H.**  
Senior HIV Policy Advisor  
USAID  
1325 G Street, N.W.  
Suite 400  
Washington, DC 20005  
Phone: (202) 219-0473  
Fax: (202) 219-0518  
Email: rmacinnis@afr-sd.org

**DOROTHY MANN**  
Executive Director  
Family Planning Council  
260 South Broad Street  
10th Floor  
Philadelphia, PA 19102  
Phone: (215) 985-2616  
Fax: (215) 732-1252  
Email: dorothy@familyplanning.org

**SANDRA S. McDONALD**  
President/Founder  
OUTREACH, Inc.  
730 Spring Street, NW  
Atlanta, GA 30308  
Phone: (404) 249-6999  
Fax: (404) 249-6991  
Email: msmac159@aol.com

**JEAN FLATLEY MCGUIRE, PH.D.**  
Assistant Commissioner  
Massachusetts Department of Public Health  
250 Washington Street  
3rd Floor  
Boston, MA 02108  
Phone: (617) 624-5303  
Fax: (617) 624-5399  
Email: j.mcguire@neu.edu

**FREDA MCKISSIC BUSH, M.D.**  
East Lakeland OB-GYN Associates  
1020 River Oaks Drive  
Suite 320  
Jackson, MS 39209  
Phone: (601) 936-1400  
Fax: (601) 936-0671  
Email: jbush43906@aol.com

**ARNOLD PERKINS**

Alameda County Health Care Services Agency  
1000 Broadway  
Suite 500  
Oakland, CA 94607  
Phone: (510) 267-8000  
Fax: (510) 267-3223  
Email: aperkins@co.alameda.ca.us

**BENY J. PRIMM, M.D.**

Executive Director  
Addiction Research and Treatment Corporation  
22 Chapel Street  
Brooklyn, NY 11201  
Phone: (718) 260-2950  
Fax: (718) 260-9492  
Email: bprimm@artcny.org

**M. KEITH RAWLINGS, M.D.**

President  
Integrated Minority AIDS Network, Inc. (IMANi)  
400 South Zang Boulevard  
Suite 1220  
Dallas, TX 75208  
Phone: (214) 942-5400  
Fax: (214) 942-7230  
Email: mkrawlings@imanihiv.org

**STEPHEN TABET, M.D., M.P.H.**

Assistant Professor of Medicine  
University of Washington  
1100 Fairview Avenue, North, J3-100  
P.O. Box 19024  
Seattle, WA 98109  
Phone: (206) 667-2057  
Fax: (206) 667-7711  
Email: stabet@hvtm.org

**ALEJANDRO TORREZ**

6628 Caro Street  
Paramount, CA 90723  
Phone: (562) 529-3952  
Email: alxt76@hotmail.com

**ANTONIA M. VILLARRUEL, PH.D.**

Associate Professor  
University of Michigan School of Nursing,  
Center for Health Promotion  
400 North Ingalls Building  
Suite 4320  
Ann Arbor, MI 48109  
Phone: (734) 764-9519  
Fax: (734) 647-0351  
Email: avillarr@umich.edu

**MILDRED WILLIAMSON, PH.D., M.S.W.**

Administrator, Woodlawn Health Center  
Cook County Bureau of Health Services  
6337 South Woodlawn Avenue  
Chicago, IL 60637  
Phone: (312) 747-7705  
Fax: (773) 955-4758  
Email: jazzroots@aol.com

**CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment  
CARE Act Reauthorization Workgroup (5/30/03)**

Terje Anderson  
Cornelius Baker  
Freda McKissic Bush  
Renee Cobos  
Judy Goforth-Parker  
Tom Liberti  
Sandra McDonald  
Jesse Milan  
Keith Rawlings  
Stephen Tabet  
Alex Torrez  
Mildred Williamson