Strengthening the Ryan White CARE Act

EXECUTIVE SUMMARY:
Recommendations for the 2005 Reauthorization of the CARE Act from the American Academy of HIV Medicine and the HIV Medicine Association

The American Academy of HIV Medicine (AAHIVM) and the HIV Medicine Association (HIVMA) are the two leading associations of HIV medical providers and collectively represent nearly all of the clinicians who deliver HIV care in the United States. Members of AAHIVM and HIVMA who work in Ryan White CARE Act (CARE) funded programs developed these recommendations for improving the CARE Act.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act program plays a critical role in helping us meet the medical needs of our patients. We strongly support the reauthorization of this vital program. The CARE Act must be reauthorized and adequately funded to support the recommendations outlined in this document.

In addition to our recommendations for improving the delivery of services through Ryan White-funded programs, AAHIVM and HIVMA strongly support passage of the Early Treatment for HIV/AIDS Act (ETHA). ETHA is modeled after the Breast and Cervical Cancer Act and would provide states the option to offer Medicaid coverage to people with HIV before they develop AIDS and become disabled. Passage of ETHA would significantly improve the lives of low-income people with HIV by delaying the onset of AIDS through the provision of earlier and more reliable access to drug therapies and treatment.

I. Prioritize Medical Care in the Ryan White Care Act: Ensure Access to Life-Saving Medical Care — Require Title I and Title II grantees to devote at least 25 percent of their grant awards to Primary Medical Care Services and an additional 25 percent to Basic Medical Services. ¹ Continue to support essential social and support services that are critical to accessing and retaining medical care.² Strengthen linkages between medical care and social services and give priority to co-location of services whenever possible.

II. End AIDS Drug Assistance Program (ADAP) Waiting Lists: Guarantee Access to Anti-HIV Drugs to Low-Income Residents — Guarantee access to a minimum formulary of anti-HIV drugs for US residents with incomes under 300 percent of the federal poverty level, and authorized states under the Ryan White CARE Act to develop comprehensive formularies with medical advisory committees that include recognized HIV expert clinicians to oversee ADAP formulary guidelines.³⁴

¹ Primary Medical Care Services: Physician and other medical provider visits including adherence services; subspecialty care related to HIV and/or HIV treatments related to HIV such as obstetric and gynecological services and pediatric HIV specialists; medically-necessary medications including approved antiretroviral medications; laboratory tests to monitor the effectiveness and safety of treatment, including HIV viral load, CD4+T-cell testing, and medically indicated resistance tests, and clinical pharmacology consultation and services. Basic Medical Services: medically necessary oral health services; mental health services; substance abuse treatment; prevention counseling in HIV clinical settings; nutrition counseling; and hospice.

² Essential Social and Support Services: transportation, housing assistance, food, child care, emergency financial assistance, respite care services, case management, Client advocacy services, e.g., benefits and entitlement counseling and legal services including permanency planning, and health insurance co-payments and deductibles.

³ At a minimum, the formulary should include the drug therapies recommended in the federal guidelines for the use of antiretroviral agents and treatment and prevention of opportunistic infections in HIV-infected adults, adolescents, and
III. Define and Identify HIV Medical Experts: Improve Health Care Outcomes — Direct the HRSA HIV/AIDS Bureau to work in collaboration with HIVMA and AAHIVM to develop guidance documents for Ryan White-funded programs that define HIV experienced medical providers. The guidance also would highlight models of consultative relationships with expert providers for use in communities where experienced providers are not available.

IV. AIDS Education and Training Centers (AETC): Assisting Current Medical Providers Provide State-of-the-Art Care and Supporting the Next Generation of HIV medical Providers — Expand the authorization and funding of the AETC program to include programs related to providing training to new clinicians interested in entering the field and to providing incentives for individuals to enter the field of HIV medicine.

V. Support the Standard of Care: Adequately Fund Complex Medical and Psychosocial Care — Direct the HRSA to work in collaboration with the HIVMA and the AAHIVM to develop guidance on reimbursement practices that addresses basic services that are currently not being reimbursed and that addresses regional disparities in reimbursement, while retaining flexibility.

VI. Improve Quality of Care and Outcomes Evaluations — Authorize and fund the HRSA to create a Quality Management Office to centralize and improve quality improvement and assurance efforts across Titles and programs and streamline data reporting requirements. Allow grantees and sub-grantees to devote sufficient resources to conducting quality improvement efforts. The Special Programs of National Significance (SPNS) program should fund demonstration programs to evaluate the effectiveness of different models of HIV clinical Centers of Excellence.

VII. Improve Program Administration — Provide significant representation of frontline HIV clinicians on Title I and Title II planning bodies. Representation should include physicians, nurse practitioners, physician assistants, nurses, nutritionists, and mental health and substance abuse professionals. Increase all grant cycles from one to two years.

AAHIVM and HIVMA members who work in CARE Act funded programs developed these recommendations. Work group members included: Jonathan Appelbaum, MD, Kathleen Clanon, MD, Lori Fantry, MD, MPH, Judith Feinberg, MD, Barbara Gripshover, MD, Margaret Hoffman-Terry, MD Stephen O'Brien, MD, Michelle Roland, MD, Ernesto Sivilla, MD, Anita Vaughn, MD, David Weinrib, MD, and Bruce Williams, MD, MPH. Questions or comments may be addressed to AAHIVM Director of Public Policy, Greg Smiley at (202) 251-2148 or HIVMA Executive Director, Christine Lubinski at (703) 299-1215.

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children. These guidelines consist of several living documents (updated regularly as new drug therapies and research results emerge) and are maintained online at http://www.aidsinfo.nih.gov.

4 According to Kaiser Family Foundation's National ADAP Monitoring Report, 74% of the states (37 of 50) have an economic eligibility of 300% of FPL or better.

AAHIVM and HIVMA Recommendations for Improving the CARE Act
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