

## HIV/AIDS AND THE RYAN WHITE CARE ACT

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### Overview

The Ryan White CARE Act (RWCA) is a comprehensive law designed for people living with HIV who have no other means of obtaining medical care. The RWCA was due for reauthorization on September 30, 2005 and is now expired. Meanwhile, the prevalence of HIV in the US and the cost of care for each person with HIV/AIDS continues to increase. Although current RWCA funding is inadequate to meet the needs of HIV/AIDS patients, previous press reports have stated that the RWCA would be reauthorized at the current funding level. This policy brief discusses the RWCA, the principles proposed by the Presidential Advisory Council on HIV/AIDS, and the status of the HIV epidemic in the US. The use of the rapid HIV test and settings where this screening test is utilized will also be discussed.

### What Clinicians Can Do:

- Recognize that 40,000 new HIV infections occur annually in the United States. Women, adolescents, and ethnic minorities are considered at-risk populations.<sup>1</sup>
- Support the use of **Rapid HIV Testing** for patients in settings where they may be lost to follow up (e.g., emergency rooms) and in centers that typically have a high HIV+ prevalence (e.g., mental health and substance abuse treatment centers).
- Train members of the transdisciplinary health care team to counsel patients who have tested HIV positive by rapid test, to provide on-going counseling for HIV-positive patients, and to counsel high risk HIV-negative patients.
- Encourage **Routine Voluntary HIV** testing, especially in high prevalence areas, for pregnant women, and in public facilities.<sup>2</sup>
- **Follow the elements of successful prevention programs proposed by the CDC:**
  - Employ surveillance methods to determine the HIV risks in your local community.
  - Coordinate HIV counseling, testing, referral, and partner counseling with medical care, treatment, and prevention services.
  - Promote HIV/AIDS education and risk reduction activities in your clinic or community.
  - Recognize and treat other STIs.<sup>3</sup>

<sup>1</sup> Centers for Disease Control and Prevention. "HIV Prevention Strategic Plan Through 2005." January 2001. <http://www.cdc.gov/nchstp/od/news/prevention.pdf>

<sup>2</sup> Centers for Disease Control and Prevention. "Revised Guidelines for HIV Testing, Counseling and Referral." *MMWR Weekly*. February 1999. <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5019a1.htm>

<sup>3</sup> Centers for Disease Control and Prevention. National Prevention Intervention Network. "Elements of Successful HIV Programs." <http://www.cdcnpi.org/scripts/hiv/programs.asp>

## Background

The Ryan White CARE Act (RWCA) addresses the funding of health care for people living with HIV. It is the payer of last resort when there are no other forms of coverage for patients. However, the RWCA funding is the third largest payer of health care to persons with HIV, behind only Medicaid and Medicare. The Act was passed in 1990 and reauthorized in 1996 and 2000. Funding for the RWCA is appropriated through four Titles and additional programs such as the AIDS Education and Training Centers (AETC). Each title is designed to cover the unmet needs of HIV patients and has an impact on primary care, prevention, and early intervention services either directly or indirectly as outlined below:

**Title I (*Metropolitan areas*)** distributes funding to cities disproportionately affected by HIV/AIDS. Eligible metropolitan areas have at least 2000 cumulative AIDS cases and a population greater than 500,000. Title I services include primary care, early intervention services (counseling, testing, and referral), case management, and inpatient services.

**Title II (*States and ADAP*)** provides federal grants to states, territories and jurisdictions. Funding includes primary care services such as early intervention and ambulatory care in addition to home-based health care, insurance coverage, medications, outreach and support services. Each year a portion of Title II funding is earmarked for the AIDS Drugs Assistance Program (ADAP) that primarily provides HIV related medications and also treatment support and insurance coverage. The ADAP is the largest CARE Act program and 80% of ADAP clients have income levels at 200% or below the poverty level.

**Title III (*Grants to Primary Care Organizations*)** provides grants directly to non-profit or public organizations providing HIV primary care services. Title III grants are divided into Capacity Building, Early Intervention Services (EIS) and Planning Grants. EIS includes counseling on prevention and risk reduction; anti-retroviral and prophylactic therapies; on-going oral, nutritional, and psychosocial care; case management; and treatment of HIV-associated health problems such as substance abuse. Capacity building grants support the infrastructure of primary care organizations with short-term (1-3 year) funding. Planning grant funds last one year and are intended for research and coordination of primary care for the needs of HIV patients.

**Title IV (*Women, Infants, Children, and Youth*)** specifically addresses the needs of women, young adults, children, and infants with HIV. Services include primary and specialty care, psychosocial support, logistical support, case management and outreach.

In addition, the RWCA includes other programs, such as the AIDS Education and Training Centers (AETC), designed to train health care providers to treat HIV/AIDS patients. The RWCA also includes a Dental Reimbursement Program.<sup>4</sup>

### **Who is At-Risk Today?**

The largest numbers of new reported HIV infections are due to men who have sex with men (MSM) and intravenous drug users (IVDU). Increasingly at-risk are women via heterosexual contact, adolescents due to high risk behaviors, and racial/ethnic minorities. African Americans represent the largest population of new HIV infections. Latinos represented nearly one-fifth (19%) of all new cases in 1999, yet represent only 13% of the total US population. The rates of HIV infection in Asian/Pacific Islanders and Native Americans are also increasing, making these groups at-risk. Geographically, increases in HIV are reported across the country. However, the Southern states continue to have the highest prevalence.<sup>5</sup>

### **Reauthorization**

On July 27, 2005, the Secretary of Health and Human Services met with the President's Advisory Committee on HIV/AIDS and announced the five principles that would be focused on for the 2005 reauthorization.

These principles are as follows:

- 1) ***Serve the Neediest First.*** The plan is to develop an objective indicator to determine severity of need for RWCA services such as prescription drugs and access to primary or specialty care.
- 2) ***Focus on Life-Saving and Life-Extending Services.*** The goal of this principle is to identify core medical services in order to prioritize life-prolonging services. Recipients of RWCA grants would be required to use 75% of Ryan White funding for these services. Another component of this principle is to develop a list of core ADAP medications including treatment (antiretrovirals) and prophylaxis medications.
- 3) ***Increase Prevention Efforts:*** In response to the 25% of HIV positive patients who are unaware of their serostatus, this principle requires states to implement routine voluntary HIV testing in public facilities and among private healthcare providers.
- 4) ***Increase Accountability:*** This includes requirements for states to submit HIV population data and to coordinate funding and services more effectively with metropolitan areas. It will require grantees to report client data and performance reports, to keep the RWCA as a payer of last resort and work with clients to find other means to access health care.
- 5) ***Increase Flexibility:*** This principle is meant to allow redistribution of unallocated balances on a needs basis, and to allow planning councils to serve as voluntary and advisory bodies to mayors.<sup>6,7</sup>

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<sup>4</sup> US Department of Health and Human Services. "Ryan White Care Act." <http://hab.hrsa.gov/law.htm>

<sup>5</sup> Centers for Disease Control and Prevention. "HIV Prevention Strategic Plan Through 2005." *op cit.*

<sup>6</sup> Kaiser Daily HIV/AIDS Report: "HHS Proposes Principles for Ryan White CARE Act Reauthorization; Focus Is on Need-Based Grant Distribution." July 28, 2005. [www.kaisernetwork.org](http://www.kaisernetwork.org)

<sup>7</sup> US Department of Health and Human Services. "Ryan White Care Act Reauthorization Principles." July 27, 2005. <http://www.hhs.gov/news/press/2005pres/ryanwhite.html>

Despite the planned reauthorization of the RWCA, proposed funding remains flat for all programs except ADAP. President Bush's proposal requests \$2.1 billion for FY 2006 and an increase of \$10 million for ADAP.<sup>8</sup> However, other advocacy groups such as the National Minority AIDS Council have recommended that a \$1 billion increase will be necessary to cover the increasing costs of HIV medications.<sup>9</sup> The establishment of core medications in the second principle is meant to address the increasing cost of HIV medications. However, drug resistance to HIV medications is increasing and a correlation between the limited/periodic availability of antiretrovirals and the development of resistance has been established. In order to minimize antiretroviral resistance, the ACU discourages policy that would strictly limit the variety of drugs offered to persons living with HIV.

Also, with a growing HIV positive population "flat funding is reduced funding."<sup>10</sup> People with HIV/AIDS are living longer due to modern medications. Therefore, supporting increased funding of these medications to match the increased lifespan of AIDS patients is necessary if the epidemic is to be controlled. Funding has remained at roughly \$2 billion for the past three years.<sup>11</sup> Despite this, the CDC estimates that there are 40,000 new HIV infections each year.<sup>12</sup> Funding for Title III alone has decreased by \$3 million since 2003.<sup>13</sup> While this may suggest that primary care services for HIV patients are adequate, 2001 figures show that only 50% of at risk populations have appropriate access to preventive services, medical care and treatment.<sup>14</sup> The necessity for EIS is demonstrated by the estimated 25% of the HIV+ population who do not know their serostatus.<sup>15</sup> More concerning was a multicenter study finding 77% of men who have sex with men (MSM) who tested positive for HIV were unaware of their HIV status. These 493 men who tested positive reported a total of 2253 sexual partners over six months.<sup>16</sup>

Early Intervention Services (EIS) are also necessary to delay the progression of positive HIV status to AIDS. One study between 1994-1999 found that 41% of HIV+ people were diagnosed with AIDS within one year of their initial HIV test.<sup>17</sup> Clearly, advances with medical care and counseling interventions are imperative.

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<sup>8</sup> Kaiser Daily HIV/AIDS Report, July 28, 2005, *op cit*.

<sup>9</sup> Damon Dozier. "Public Policy Agenda 2005." National Minority AIDS Council. Government Relations and Public Policy Division.

<sup>10</sup> The Asian and Pacific Islander American Health Forum. "Asian & Pacific Islander American Health Forum Expresses Concern Over Proposed Changes on HIV/AIDS Care." July 29, 2005.

<sup>11</sup> US Department of Health and Human Services. Health Resources and Services Administration. "Funding History". <http://ftp.hrsa.gov/hab/fundinghis04.xls>

<sup>12</sup> Centers for Disease Control and Prevention National Center for Health Statistics. "AIDS/HIV Fast Stats." <http://www.cdc.gov/nchs/fastats/aids-hiv.htm>

<sup>13</sup> US Department of Health and Human Services, "Funding History," *op cit*.

<sup>14</sup> Centers for Disease Control and Prevention. "HIV Strategic Plan Through 2005." *op cit*.

<sup>15</sup> Centers for Disease Control and Prevention. "Advancing HIV Prevention: New Strategies for a Changing Epidemic --- United States, 2003." *MMWR Weekly*. April 18, 2003/52(15): 329-332. <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5215a1.htm>

<sup>16</sup> DA MacKellar, et al. "Unrecognized HIV infection, risk behaviors, and mis-perceptions of risk among young men who have sex with men---6 United States cities, 1994-2000." *J Acquir Immune Defic Syndr*. 2005 Apr 15;38(5):603-14.

<sup>17</sup> JJ Neal and PL Fleming. "Frequency and predictors of late HIV diagnosis in the United States, 1994-1999." Presented at the 9th Conference on Retroviruses and Opportunistic Infections, Seattle, Washington, February 24-28, 2002.

The 180,000-200,000 people in the US unaware that they are HIV positive reveals the limitations of current testing services.<sup>18</sup> HIV positive individuals unaware of their serostatus may lack access to primary care and also may be the lost to follow up after testing. Thirty-one percent of people testing HIV+ at CDC funded public testing did not follow up for results.<sup>19</sup>

Other advocacy groups are expressing their concern over the already thinly spread CARE Act funding. Concerns are raised regarding the shifting of funds away from one population in need to serve another population in need. For example, a press release from the Asian and Pacific Islander American Health Forum recently expressed concern over plans to shift more money to rural settings. Yet rural practices rely on RWCA programs such as AETC to maintain the care of persons living with HIV. One recipient noted, “without support from the AETC, many of us would not have been able to keep up with the ongoing education needed to be proficient in the care of HIV/AIDS patients.”<sup>20</sup> The requirement of 75% of RWCA funding to go to “core medical services” (Principle 2) was cited for its possibility to stifle support programs such as translation and interpretation services necessary for adequate care.<sup>21</sup>

## Recommendations

### Routine Voluntary Testing

Routine testing (offered to all patients regardless of the purpose of their visit) versus targeted testing (offered only based on perceived risks) has been a somewhat controversial issue.<sup>22</sup> The CDC’s 2003 “Strategies” encourages routine testing for “all patients in all high HIV-prevalence clinical settings and to those with risks for HIV in low prevalence clinical settings”. Routine testing has been found to be cost effective when the prevalence of HIV in a given population is greater than 1%.<sup>23</sup> Taking a sexual history often fails to illicit at-risk behavior. Routine testing would allow health care system providers to recognize more patients with HIV, to diagnose HIV in early stages, and to diagnose HIV in perceived low-risk populations.<sup>24</sup>

### Rapid Testing

The third reauthorization principle, *Increase Prevention Efforts*, encourages RWCA grantees to follow the CDC’s recommendations in the “CDC Advancing HIV Prevention Initiative.” Prominently featured in this CDC initiative is Rapid HIV Testing. Rapid HIV tests should be implemented for greater access to the 25% of the HIV+ population who do not know their serostatus and the 30% of the HIV positive individuals who remain uninformed of their diagnosis after testing. Rapid HIV tests differ from the traditional

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<sup>18</sup> CDC MMWR Weekly. “Advancing HIV Prevention,” *op cit*.

<sup>19</sup> Centers for Disease Control and Prevention Division of HIV/AIDS Prevention. “Quick Facts: Rapid Testing April 2003 – April 2004.” [http://www.cdc.gov/hiv/rapid\\_testing/materials/QuickFact\\_April2004.htm](http://www.cdc.gov/hiv/rapid_testing/materials/QuickFact_April2004.htm)

<sup>20</sup> AETC National Resource Center. “Evidence of Success: Delta Region AETC Service Area: Arkansas, Louisiana, Mississippi.” <http://www.aids-ed.org/aidsetc?page=et-stories-delta>

<sup>21</sup> Kaiser Daily HIV/AIDS Report. July 28, 2005, *op cit*.

<sup>22</sup> Beckwith, et al. “Testing for HIV Infection: Should It Be Routine?” *Resident and Staff Physician*. 2003.

<sup>23</sup> Centers for Disease Control and Prevention. “Advancing HIV Prevention,” *MMWR Weekly*. *op cit*.

<sup>24</sup> Beckwith, et al. *op cit*.

HIV tests in that they are *point-of-care*: testing and results are available at one visit.<sup>25</sup> The result of a rapid HIV tests may be ready in 20 minutes. As with the ELISA HIV test, positive results are preliminary and should be followed up by confirmatory testing.<sup>26</sup>

In addition to use in hospitals, clinics and emergency departments, non-traditional or community-based settings may prove to be a compelling access point for at-risk groups. The CDC has demonstrated that targeting at-risk populations with community-level interventions has decreased HIV transmission in MSM, IVDU, and women.<sup>27</sup> Adding rapid HIV testing to the regimen of community-based interventions could increase access to the 25% of the HIV population who do not know their serostatus. These community-level interventions may include but are not limited to opiate treatment programs and behavioral health programs for mental health and substance abuse services. With IV drug use, one of the major causes of HIV transmission, rapid testing should be available in the centers that treat this population, such as behavioral health and substance abuse centers. The test also has utility in labor and delivery ward for mothers unsure of their serostatus. Rapid testing in labor was found to be “feasible and accurate” in a study conducted among four of Chicago’s hospitals.<sup>28</sup>

The average acquisition cost of a rapid HIV test is \$12-\$15.<sup>29</sup> One study found rapid HIV testing to be cost effective in the urban emergency department setting. The study took into account labor and test costs, resulting in \$29.80 per test.<sup>30</sup> One study confirmed that in one half-day, health care staff can be efficiently trained to carry out the rapid test.<sup>31</sup> Counselors were included in the study. Four rapid HIV tests have been FDA approved: OraSure, OraQuick, Reveal G2 Rapid, and UniGold Recombigen. The Uni-Gold rapid test can be reimbursed by Medicaid and Medicare, other rapid tests may also be reimbursed.

### **Counseling and Referral**

Counseling services remain a cornerstone in the adequate prevention of HIV. Health care staff must be trained to adequately counsel patients and refer to other HIV-related services as appropriate. Advances must be made in settings where clinicians have limited time to counsel patients such as in emergency departments. Training for rapid HIV testing must include counseling as well as procedural training. Manufacturer training for rapid tests is adequate to carry out rapid test protocols, but it does not meet CDC requirements. In order to successfully train the transdisciplinary health care team, we must support training centers such as RWCA funded ATECs. These centers focus on

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<sup>25</sup> Centers for Disease Control and Prevention and US Department of Health and Human Services. “Quality Assurance Guidelines for Testing Using the Ora-Sure Rapid HIV-1 Antibody Test.” [http://www.phppo.cdc.gov/DLS/pdf/HIV/QA\\_Guidelines\\_OraQuick.pdf](http://www.phppo.cdc.gov/DLS/pdf/HIV/QA_Guidelines_OraQuick.pdf)

<sup>26</sup> New York State AIDS Institute. “Criteria for the Medical Care of Adults with HIV Infection: Diagnostic, Monitoring, and Resistance Tests for HIV.” [http://www.hivguidelines.org/public\\_html/a-tests/a-tests.htm#intro](http://www.hivguidelines.org/public_html/a-tests/a-tests.htm#intro)

<sup>27</sup> Centers for Disease Control and Prevention. “HIV Strategic Plan Through 2005.” *op cit*.

<sup>28</sup> Mardge Cohen, et al. “Using Point-of-Care Testing to Make Rapid HIV-1 Tests in Labor Really Rapid.” *AIDS* 17(14):2121-4.

<sup>29</sup> Patrick Keenan, et al. “Rapid HIV Testing: Wait Time Reduced from Days to Minutes” *Post Graduate Medicine* Vol 117, No 3, March 2005. [http://www.postgradmed.com/issues/2005/03\\_05/keenan.htm](http://www.postgradmed.com/issues/2005/03_05/keenan.htm)

<sup>30</sup> Eileen Couture, et al. “Relative Cost of Performing Rapid HIV Testing in a High-volume Urban Emergency Department Setting.” *Academic Emergency Medicine*. Vol 12, No. 5 2005.

<sup>31</sup> Koum Kanal, et al. “Evaluation of the proficiency of trained non-laboratory health staffs and laboratory technicians using a rapid and simple HIV antibody test.” *AIDS Research and Therapy*, 2005 (2): 5.

training health care providers who serve diverse populations such as minorities, rural, homeless, incarcerated, and RWCA funded sites. In order to adequately treat HIV+ patients, people testing positive must have access to appropriate referral services. Referrals may include case or medical management, partner counseling, reproductive health services, mental health services, legal services, and STD screening. Guidelines for counseling and referral are listed in the CDC's Revised Guidelines for HIV Counseling, Testing, and Referral.<sup>32</sup> In addition, guidelines for counseling during labor and delivery are explained in the CDC's "Rapid HIV-1 Antibody Testing during Labor and Delivery for Women of Unknown HIV Status: A Practical Guide and Model Protocol."<sup>33</sup>

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<sup>32</sup> Terje Anderson, et al. "Revised Guidelines for HIV Counseling, Testing, and Referral." CDC MMWR, Nov. 9, 2001. <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5019a1.htm#top>

<sup>33</sup> Margaret Lampe, et al. "Rapid HIV-1 Antibody Testing during Labor and Delivery for Women of Unknown HIV Status: A Practical Guide and Model Protocol." CDC Division of HIV/AIDS Prevention Jan. 30, 2004. [http://www.cdc.gov/hiv/rapid\\_testing/rt-labor&delivery.htm](http://www.cdc.gov/hiv/rapid_testing/rt-labor&delivery.htm)