



THE AIDS INSTITUTE

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

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Executive Summary, Statement of Principles: A Living History of HIV/AIDS

For over two decades, the world has been waging a war against a deadly virus. Acquired Immune Deficiency Syndrome (AIDS), caused by the Human Immunodeficiency Virus (HIV), has killed more than 524,060 people in the United States alone. While the public health community has gained much ground in preventing and treating the virus, there is still no cure. HIV and AIDS still remain a public health crisis. While deaths attributed to AIDS in the United States have decreased due to the remarkable advancements in drug therapies and medical care, transmission rates have remained relatively stable for more than five years.

AIDS has claimed more than 524,060 people in the United States alone...

Current epidemiological science is teaching us that newly infected people are more and more likely to be poor, members of a minority community, and have inadequate access to healthcare. Though medications are helping many infected individuals lead healthier and more productive lives, we are only beginning to understand the long-term impact of HIV treatment, as well as the unique interaction of HIV with other diseases, such as hepatitis and diabetes. Scenarios created during the early part of the epidemic predicted that our health infrastructure would crumble under the weight of suffering and dying AIDS patients. Reminiscent of those early scenarios, present day structures can barely support the ever-increasing numbers of people living with HIV/AIDS now entering these systems and have left many with inadequate access to healthcare, especially those for whom private health insurance is entirely out of reach.

To fight and win a war against this virus, it is incumbent upon all Americans, especially elected and appointed officials, to provide adequate and appropriate resources. These resources must provide for equitable, continuous, and consistent access to high quality healthcare and attendant support services at the point of HIV diagnosis regardless of age, race, gender, geography, sexual orientation, or socioeconomic status.

Responding to the HIV/AIDS epidemic of the 1980s and 1990s, advocates fought for and won a government response to address the medical and social needs of individuals infected with and affected by HIV/AIDS. The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, named for an infected teenage advocate, was passed in 1990 and reauthorized in 1996 and 2000. The CARE Act, a discretionary program administered by the Health Resources and Services Administration, Department of Health and Human Services, has been successful in bringing access to specialized medical care and social services to low-income people living with HIV/AIDS.

Successful in providing client and family centered services, the CARE Act provides a fair amount of local control and a level of flexibility requisite to meet the needs of local, state, and national government agencies and nonprofit sector organizations in providing these crucial services. However, there is a dire need for systemic change. There are significant challenges found in implementation of the CARE Act which need to be addressed so that the program can adequately meet the needs of the people it was designed to serve

while maintaining fiscal solvency in an environment of shrinking resources and growing need.

The CARE Act is slated for reauthorization again in 2005. This reauthorization provides an opportunity to ensure that we keep steadfast the successful provisions of the CARE Act while ensuring that the legislation, and subsequent policies and programs, improves its ability to keep abreast of the latest medical and technological advancements in providing efficient, accountable, and equitable services for all recipients.

In May of 2004, the Institute of Medicine (IOM) produced a report, mandated by the 2000 Ryan White

The IOM report recommended an entitlement program that would allow for access of essential service provision to all HIV-positive individuals.

CARE Act reauthorization, on the public financing structures of HIV/AIDS programs (*Public Financing and Delivery of HIV Care, Securing the Legacy of Ryan White*). The IOM committee charged with developing the report, comprised of experts in program provision and finance, recommended that

an entitlement-based financing structure be created that would allow for access of essential service provision to all HIV-positive individuals, from the point of HIV diagnosis, through all acuity levels and stages of disease progression. The IOM report also recommended that the CARE Act be preserved, in part, to meet additional, unique needs of people living with HIV/AIDS. Such a program would provide enormous benefits in lives saved, health maintained, as well as medical and socioeconomic costs deferred or avoided.

The report and its recommendations are supported by The AIDS Institute and should serve as the philosophical basis for the work of advocates and government officials alike; ensuring continuous and equitable access to high quality healthcare from the point of diagnosis of HIV infection for all people in need of public assistance regardless of where they

The report and its recommendations are supported by The AIDS Institute and should serve as the philosophical basis for the work of advocates and government officials alike...

live. The IOM report is instructive in the sense that the proposed system would go far in addressing the current state of quality of HIV/AIDS care and access to that care, while rectifying many of the funding problems related to the discretionary nature of the CARE Act.

To that end, programs that serve people living with HIV/AIDS who are uninsured or underinsured should adhere to the following principles:

All Necessary Medical and Attendant Support Services Should:

- Keep current with epidemiologic trends together with medical and technological advancements, given the increasingly chronic nature of HIV/AIDS.
- Provide access to cutting edge clinical trials.
- Recruit and retain competent, specialized, certified, healthcare practitioners as well as support service staff.
- Be made available to all low-income people infected with HIV/AIDS, no matter where they reside.
- Be culturally and linguistically appropriate.

Funding/Fiscal/Administrative Endeavors Should:

- Provide for a seamless system between all publicly and privately funded medical and support service systems.
- Provide for adequate infrastructure, in both physical and human resources.
- Provide for equitable and appropriate reimbursement rates to medical and support service providers.
- Build in fiscal prudence prominently featuring competition.
- Build in cost efficiencies related to purchasing and procurement as well as collective purchasing.
- Address accountability at the client, provider, and administrative levels.
- Equitably distribute resources across geographic regions.
- Utilize HIV data in funding formulas as soon as possible.
- Support expanded HIV testing and counseling in clinical settings so that it may become a part of standard medical screenings.
- Understand that there are ethical considerations related to expanded HIV testing at any level. New cases will increase the burden on existing, under-funded care systems.

Structure/Impact Should:

- Reduce disease-related stigma.
- Reduce confounding social factors for people living with HIV/AIDS such as racism, homophobia, and sexism.
- Reduce other socioeconomic and medical confounders such as poverty and homelessness, and medical conditions related to mental health, history of substance abuse, hepatitis, tuberculosis, and sexually transmitted diseases.
- Build personal dignity into Quality Management and Continuous Quality Improvement.
- Empower people living with HIV/AIDS to make choices, based on objectively assessed needs, to benefit their medical and social outcomes without creating a dependency system.
- Provide philosophical guidance to service provision systems to focus on preventing disability rather than encouraging physical and mental disability.
- Allow recipients to return to work without losing their healthcare benefits and not force them to choose between healthcare and the dignity of work.
- Provide for meaningful input into healthcare planning by people living with HIV/AIDS.

Towards Care that is Competent, Consistent and Fair

In summation, by realistically assessing the programmatic and administrative changes desperately needed in the CARE Act, and contextualizing the CARE Act funding system in the wider government sponsored service provision system; we can avert a deepening public health crisis and the ensuing burden on our public health infrastructure.

The ultimate goal of this concerted response is to provide continuous access to quality care beginning at the point of HIV diagnosis so that people living with HIV/AIDS might attain their health, social, and work-related goals.

Optimally, a system designed from the Institute of Medicine's committee report recommendations would provide enormous benefits in lives saved, health maintained, and medical and socioeconomic costs deferred or avoided. It would also result in significant public health benefits by removing barriers to HIV testing. Finally, it would help to alleviate existing strains on the CARE Act allowing it to fill gaps in care and provide the range of essential support services required to meet the complex challenges created by HIV disease.

Until there is a cure, we must ensure that no person infected with HIV/AIDS suffers needlessly. We must strive to create and maintain a government response to this disease that is competent, consistent, and fair. Human dignity deserves no less.

We must ensure that no person with HIV/AIDS suffers needlessly. Human dignity deserves no less.

Section I: Description of The AIDS Institute and Why this Project Has Been Undertaken

The AIDS Institute (TAI) is a national nonprofit public policy research, advocacy, and education organization based in Washington, DC, and Florida. Since 1992, TAI has sought to improve HIV/AIDS research, prevention, healthcare, social support services, and housing programs through public policy and education. In recent years the organization has expanded this role to the areas of Hepatitis, Sexually

This paper is intended to stimulate further discussion on HIV/AIDS care in the US among the AIDS community, the Congress and the Administration.

Transmitted Infections, and Tuberculosis. While an independently incorporated agency, TAI is associated with the Division of Infectious Diseases and Tropical Medicine at the University of South Florida College of Medicine.

The reauthorization of the CARE Act provides an opportunity to improve HIV/AIDS services for a large group of persons living with HIV/AIDS. For that reason, and since there has been a dramatic shift in the domestic epidemic since the 1990s, TAI has participated in previous reauthorizations and is actively participating in this year's reauthorization. Since the last reauthorization we have seen rapid advances in medical care and treatment, as well as a corresponding reduction in mortality and morbidity.

TAI began preparing for this reauthorization two years ago by conducting public policy research about the relationship between CARE Act and Medicaid services; analyzing cost containment in CARE Act ADAP services; and researching the growing co-infection of HIV/AIDS with hepatitis B and C. These and other research papers may be found on the TAI website at: www.theaidsinstitute.org.

In addition, a TAI staff working group on reauthorization, including participation by the TAI Board of Directors, was established. That work group has reviewed data and internal and external recommendations, met with various interested parties and experts, and deliberated on important issues. Moreover, the agency has actively participated in a national coalition on reauthorization and serves as the co-chair of that body. This national coalition has deliberated about reauthorization issues and met with elected officials regarding the importance of the HIV/AIDS care system and, in particular, the CARE Act.

This paper describes The AIDS Institute's basic views about long-term HIV/AIDS care in the United States for those individuals who must rely on the public health system, as well as the more short-term issues associated with the 2005 CARE Act reauthorization. It is intended to stimulate further discussion in the AIDS community, the Congress and the Administration. Furthermore, it will be used by the agency as a framework to discuss reauthorization with elected officials and others involved in the process of reauthorizing the CARE Act.

Section II: A Living History of AIDS and HIV

It was June of 1981 when the Centers for Disease Control and Prevention (CDC) published its Morbidity and Mortality Weekly Report (MMWR) describing unusual occurrences of rare skin cancers and pneumonia among young homosexual men (www.cdc.gov/mmwr). According to scientists, there were cases that predate these first clusters, but the report was the first systematic gathering of case level data about the new illness. The following year, the CDC gave this syndrome a formal name: Acquired Immune Deficiency Syndrome (AIDS).

1981- unusual occurrences of rare skin cancers and pneumonia are reported in young homosexual men.

That same year, 1982, Congress held its first hearings on AIDS and the disease's transmission was finally linked to blood. At this time, the CDC identified four categories of "high risk" individuals: homosexuals, hemophiliacs, intravenous drug users, and Haitian nationals. With the creation of these categories came the creation of identifying behaviors which put individuals at risk for AIDS and placed the risk solely on categories of people. Arguably, this activity plants the seeds of stigma for AIDS infected individuals. It was not until a year later that the CDC added female sexual partners of men with AIDS as the fifth risk group. Also in 1983, at the first United States Conference on AIDS in Denver, CO, a group of people living with AIDS (PLWAs) stormed the stage and presented a statement on the rights of PLWAs born of frustration and outrage they experienced in preceding days. This statement of rights is referred to as *The Denver Principles*.

By the close of 1983, there had already been 1,292 AIDS deaths. In 1984, the virus that causes AIDS, later named Human Immunodeficiency Virus (HIV), was isolated by the French Pasteur Institute and, separately and a bit later, by the United States' National Cancer Institute. In an attempt to safeguard

By the end of 1983, more than 1,292 people in the US had died from AIDS.

patrons, the City of San Francisco closed bathhouses, an act which elicited significant objections from community members citing personal liberties and freedom.

Finally, after publicly ignoring an impending epidemic, in 1985, President Reagan mentioned the word AIDS in response to a reporter's question. That same year, an antibody test was approved by the U.S. Food and Drug Administration (FDA) which allowed blood banks to start screening the public blood supply. Also in 1985, Ryan White, an Indiana teenager with AIDS, was barred from his school, initiating Ryan White's emergence into public life as a spokesperson against AIDS stigma and discrimination. Ryan became the first "mainstream" AIDS advocate and allowed the general public to begin considering the real impact of the disease regardless of previously held stereotypes of risk groups.

1985 – Indiana teenager Ryan White was denied access to school and became the new face of AIDS advocacy.

In 1986, President Reagan mentioned AIDS in a speech to Congress regarding the "Future of America" and by this time 16,301 people in the US had died from AIDS. That year finally brought some hope to AIDS sufferers as zidovudine (or AZT) was approved by the FDA as the first antiretroviral medication and

Congress appropriated \$30 million in emergency funds to states in an effort to provide AZT to residents. In response to the proposed public cost of AZT, the AIDS Coalition to Unleash Power (ACT UP) was formed and continued over the years to fight for early approval of experimental medications, reasonable public prices, and access to medicine on clinical trials for PLWAs. At the same time, the United States added HIV to a list of “dangerous contagious diseases” which excluded individuals from immigrating to the U.S. and mandated that all applicants be tested. In the same year, the AIDS memorial quilt was first displayed on the National Mall in Washington, DC, and Randy Shilts’ “And the Band Played On” was released. Congress adopted a Jesse Helms sponsored amendment banning the use of federal funds for AIDS education materials that “promote or encourage, directly or indirectly, homosexual activities.” Many people refer to this piece of legislation as the “no promo homo” policy.

By 1988, during the administration of George H.W. Bush, members of the federal government began responding to AIDS as the U.S. Surgeon spent an unprecedented amount of resources mailing AIDS education materials to all households in the U.S. Also, Congress passed the U.S. Health Omnibus Program Extension (HOPE) Act of 1988 authorizing federal agencies to fund AIDS testing and prevention education. Meanwhile, the National Institutes of Health (NIH) organized the AIDS Clinical Trials Group (ACTG) and established the Office of AIDS Research (OAR). As the decade came to a close, scientists issued guidelines for treating an opportunistic infection, *Pneumocystis carinii* pneumonia (PCP), responsible for the suffering and death of many PLWAs. By this time, the world had lost famous individuals such as Alvin Ailey, Robert Mapplethorpe, Liberace, and Rock Hudson to AIDS while scores of everyday loved ones were taken. In fact, in 1990 alone, more than 18,447 people succumbed to AIDS.

As the new decade dawned, Congress enacted the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990, designed to provide funding for community based HIV/AIDS care and treatment, ameliorating the burden being placed on the public health system, especially in large cities being devastated by the epidemic. Sadly, Ryan White passed away only months before the piece of legislation bearing his name and carrying his legacy was enacted. Over the years, the CARE Act has evolved and continues to provide essential and life saving services to hundreds of thousands of low-income or underinsured people living with HIV and AIDS. (The CARE Act is discussed in much more detail in following sections).

With awareness about AIDS beginning to grow, the first National Conference on Women and AIDS was held, the FDA finally approved AZT for pediatric use, and the Americans with Disabilities Act of 1990 was passed to protect individuals with disabilities, including people with HIV and AIDS, from discrimination.

Helping reshape public opinion on HIV/AIDS, in 1991, Earvin “Magic” Johnson publicly announced that he was infected with the AIDS virus.

In 1990, Congress enacted the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, named after the deceased teen AIDS activist Ryan White.

Emergency (CARE) Act of 1990, designed to provide funding for community based HIV/AIDS care and treatment, ameliorating the burden being placed on the public health system, especially in large cities being devastated by the epidemic. Sadly, Ryan White passed

1991 – basketball superstar Earvin Magic Johnson announces he has AIDS, helping change public opinion about who can get the disease.

Magic, an internationally famous basketball star, showed the public that the virus did not discriminate against race, religion, gender, or sexual orientation. Magic also helped to motivate the African-American community to increase their testing rates and prevention education. In the same year, Congress passed the Housing Opportunities for People with AIDS (HOPWA) Act of 1991, designed to help people living with AIDS find and keep adequate housing.

The Eighth International AIDS Conference planned to be held in Boston, was moved to Amsterdam due to the US immigration ban. In 1993, President Clinton established the first cabinet-level position related to AIDS, named the White House Office of National AIDS Policy (ONAP). Since AIDS is partially defined by the infections or diseases that manifest as a result of deficient immune responses, the CDC, in 1993, expanded its definition to include diseases prevalent among intravenous drug users and conditions specific to women. By doing so, more individuals would receive an AIDS diagnosis than before as more conditions became accepted as manifestations of decreased immune function. This change had significant ramifications for low-income women as an AIDS diagnosis was required for many of the services funded by states and the federal government. Without an AIDS diagnosis, many women were not eligible for the services that they so desperately needed. The CDC's expansion of the AIDS definition provided more women access to life saving services and treatment.

Responding to the need for an increased level of national mobilization, the first annual "AIDSWatch" brought hundreds of advocates, including many PLWAs, to Washington, DC, to speak with their Congressional representatives about increased HIV/AIDS funding, prevention education, and awareness.

After having discovered the vertical transmission rates (mother to child) of HIV positive pregnant women, researchers set out to find a course of treatment to reduce the seroprevalence rates of newborns.

By 1994, AIDS had become the leading cause of death for 25 – 44 year olds in the US.

In 1994, the U.S. Public Health Service began recommending the use of zidovudine, or AZT, by pregnant women. This decision was based on an NIH-funded study, dubbed "076", which demonstrated an up to 70% reduction in vertical transmission of HIV using the medication. Additionally, the FDA approved the first non-blood based antibody test, an oral test, and AIDS became the leading cause of death for all Americans aged 25 – 44 years.

Great advances were made in the areas of therapy and treatments in the late 90's. In 1996, the FDA approved a viral load test that measured the amount of HIV virus in the patient. This test had far reaching implications for therapies. Ushering in a new age of HIV treatment, the first protease inhibitor, saquinivir, was approved by the FDA.

1996 – HAART begins to provide hope for people living with HIV/AIDS.

With the approval of the first protease inhibitor and, soon after, the first non-nucleoside reverse transcriptase inhibitor (NNRTI), nevirapine, the phrase Highly Active Antiretroviral Therapy (HAART) was introduced. This system of treatment combined different classes of medications to attack the virus on numerous fronts. With the advent of new treatment options came renewed hope for the future as this

innovative system of treatment lead to dramatic decreases in the mortality rate of HIV/AIDS infected individuals.

By 1997, death rates in some areas of the country had dropped by as much forty percent. Understanding the impact of this new wave of treatments and therapy options, Congress approved the FDA Modernization Act which allowed for an accelerated approval process for new medications and the dissemination of off-label information for approved medications. Unfortunately, by 1998, medical providers and PLWAs started to notice some serious side effects of HAART, as well as treatment failures for certain individuals. At this time, physicians started to become increasingly aware of the individualized responses that people had to HAART and began to seriously consider the research implications. In this same year, the Minority AIDS Initiative was created after significant public outrage from African-American leaders who declared a “state of emergency” for their community. The Congressional Black Caucus (CBC) requested that the Administration respond similarly.

In what seemed like an amazing turn of events, Donna Shalala, Secretary of the Department of Health and Human Services announced that her department had determined, through existing research, that needle exchange programs are effective in reducing the spread of HIV and AIDS and did not encourage the use of illegal drugs. President Clinton, despite his own Secretary of Health and Human Services’ report, did not lift the ban on the use of federal funds for needle exchange programs.

By the turn of the century, 21.8 million people worldwide had died from HIV/AIDS. Great strides had been made in terms of treatment and therapies, as well as in terms of accessing treatment and care. Infrastructure that had not existed before AIDS that had been created to serve PLWAs had effects beyond the infectious disease. At this time, and based on the advancements in the United States, the focus of many advocates’ efforts started to turn outside of the country to developing nations around the world. In the year 2000, the United States and the United Nations declared HIV and AIDS a national and world security threat. That same year, the 13th International AIDS Conference was held for the first time in a developing nation, South Africa, which helped expose the impact of AIDS on developing nations. Additionally, Congress appropriated its first significant sum of money to the Global AIDS and Tuberculosis Relief Act and as part of the Millennium Declaration, which features the Millennium Development Goals, including helping to halt the spread of HIV/AIDS. Domestically, the first expansion waivers (under 1115) were approved in DC, Maine, and Massachusetts. These waivers allow Medicaid programs to offer services to people with HIV without ever having had an AIDS diagnosis.

1998 – African American leaders declare a state of emergency for their community, launching the Minority AIDS Initiative.

By 2000, 21.8 million people worldwide had died from AIDS prompting both the US and United Nations to declare AIDS a national and world security threat.

In his 2003 State of the Union Address, President George W. Bush astonished the world by announcing a plan to contribute \$15 billion over five years to address the AIDS crisis in some of the world's most devastated countries. Congress met his challenge and passed the President's Emergency Plan for AIDS Relief in a matter of months. President Bush then appointed Randall Tobias as the nation's first Global AIDS Coordinator, which carries the rank of an Ambassador.

In June 2004, President Bush announced his support for reauthorization of the CARE Act, and addressed the waiting list in the AIDS Drug Assistance Program with a one time \$20 million in additional funding. Meanwhile, the Institute of Medicine released a study that finds that over 233,000 people in the United States do not have consistent access to Highly Active Anti-Retroviral Treatment (HAART).

Section III: Summary of the CARE Act

PURPOSE

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act is a Federal law designed to ensure access to quality healthcare for people living with HIV/AIDS (PLWAs). This program funds primary healthcare and supportive services that remove barriers to care while helping people enter and stay in care. The CARE Act was first enacted by Congress in 1990 and was reauthorized in both 1996 and in 2000. Both reauthorizations included revisions that help ensure that the CARE Act is current with medical and support service advances. Currently, more than 500,000 people access CARE Act services.

This vital program was created to fill in gaps of coverage that may exist for the under/uninsured, and those on Medicare or Medicaid whose benefits may not be sufficient. The CARE Act is designed to ensure

The Ryan White CARE Act was created to fill gaps in care coverage and is a payer of last resort.

that a person living with HIV/AIDS has access to needed services from point of diagnosis through treatment to hospice services, if need be.

Although comprehensive in nature, the Ryan White CARE Act is intended to be the payer of last resort for those needing services. Initially, the program was developed to address the burden that would have been placed on the United States' public health infrastructure and the emergency care sites that were seeing a large number of AIDS patients. Projections from the time it was enacted detail that annual new infections would have strained the health infrastructure to the point of collapse.

In order to bridge gaps in service at the local level, despite being a federal program, the CARE Act utilizes various mechanisms to provide funding to states, cities and individual community based organizations. This multifaceted approach is accompanied by a system of allocating funds based on both formula and competitive grants processes.

The Health Resources Services Administration (HRSA), which oversees the CARE Act for the US Department of Health and Human Services, has adopted the following as the guiding principles for CARE Act programs:

- Revise care systems to meet emerging needs.
- Ensure access to quality HIV/AIDS care.
- Coordinate CARE Act services with other healthcare delivery systems.
- Evaluate the impact of CARE Act funds and make needed improvements.

STRUCTURE

In order to meet the diverse needs of the people living with HIV/AIDS and their individual communities, the CARE Act contains five funding streams; Titles I-IV and Part F. Title I is a combination of formula and competitive funding for metropolitan areas. Title II is a combination of formula and competitive grant funding for state and territory health departments. Title III provides funding to clinics in traditionally underserved rural and urban areas via competitive grants. Title IV provides funding for programs that serve the needs of women, children and their families through competitive grants. Part F provides funding for dental services, a network of AIDS Education and Training Centers, evaluation programs, and Special Projects of National Significance.

TITLE I: GRANTS TO ELIGIBLE METROPOLITAN AREAS

In order to qualify for Title I funding, an Eligible Metropolitan Area (EMA) with a population of more than 500,000 inhabitants must report at least 2,000 AIDS cases during the most recent 5 year period. Currently, there are 51 EMAs. In 1991, the first year of the CARE Act, there were 16 EMAs. Funding for an EMA is sent directly from the Federal Government to the local grantee (typically the Mayor's Office of the largest city in the EMA). Then, the allocation of the funding is determined by a local planning council that is mandated to have PLWA representation. The planning councils then determine how funding for the 24 CARE Act services is to be spent in their EMA.

In 1991, there were 16 Eligible Metropolitan Areas, today there are 51 EMAs.

TITLE II: GRANTS TO STATES AND TERRITORIES

Title II funds are available to the 50 US states, Washington DC, and the territories. Title II is divided into two parts. The first part is funding for the provision of medical care and support services for PLWAs. The second component is the AIDS Drug Assistance Program (ADAP) which funds the purchasing of Anti-Retrovirals and other medications.

Care and Services

Currently, approximately one-third of Title II funding goes toward providing various healthcare and support services. Each state/territory has autonomy over the allocations process for its programs. A majority of care and service dollars are used to support local health departments and community based organizations that provide services to PLWAs.

An additional aspect of the Title II care and service program is the advent, in 2000, of the "emerging community" grants. This new program came about as a result of the fact that metropolitan areas may be dealing with heavy burdens related to the AIDS epidemic, but may not qualify for Title I status. Hence, metropolitan areas that report more than 500 but less than 2,000 AIDS cases in the past 5 years are qualified for this funding.

AIDS Drug Assistance Program (ADAP)

Under Title II, states and territories use federal and local funds to provide medications for PLWA residents of that state/territory. Each grantee has the ability to develop ADAP program rules as they see fit. There are no Federal minimums about what medications should be on an ADAP formulary. Additionally, each grantee is responsible for determining eligibility criteria for PLWA access to the ADAP. States, after reaching a certain threshold of AIDS cases, are required to contribute a certain percentage of funding for ADAP.

As a result of the 2000 reauthorization of the CARE Act, three percent of the overall ADAP appropriation is allocated for grantees indicating "severe need" for added resources.

TITLE III: EARLY INTERVENTION SERVICES

Title III competitive award grants are designed to help support and bolster early intervention services for PLWAs in rural and urban core areas. This is done via two methods. The first is the provision of funding to existing providers who wish to increase their HIV treatment capacity. The second is the provision of funding for providers interested in providing HIV services that need additional resources to plan for the capacity building required to deliver the Early Intervention Services.

Early Intervention Services Grants

Title III funding is comprised of competitive grants that are awarded directly to health care providers, rather than to cities or states and territories (as in Title I and II). Typically, Title III funding is provided to university and hospital medical centers, federally-funded Community and Migrant Health Centers, and other clinics.

As the trend for new HIV and AIDS cases has been growing rapidly in the South and other rural areas,

In response to the growing southern AIDS crisis, Title II EIS grants are being awarded in small towns and rural areas.

many of the Title III Early Intervention Services grants in recent years have been awarded to providers in small towns and rural areas.

Planning Grants and Capacity-Building Grants

The HIV/AIDS epidemic continues to spread into regions and areas that are deficient in HIV/AIDS medical and supportive service providers. In order to combat this, planning grants and capacity-building grants have been established to assist with developing an interested party's ability to provide the needed medical and supportive care.

TITLE IV: GRANTS TO SERVE WOMEN, CHILDREN, YOUTH, AND FAMILIES

Title IV grants are competitive grants that are designed to meet the special needs that women, children, youth and their families face when living with HIV. These grants help to coordinate medical care for families when one or more family members are living with HIV. Additionally, Title IV helps provide access to services that might otherwise not be available to a family dealing with HIV/AIDS, from neonatal and pediatric specialty care, obstetric and gynecologic care, to clinical trial access. Moreover, Title IV can provide access to medical care for caregivers of HIV positive children as well as supportive services such as emergency housing, transportation, and peer support.

PART F

Part F is comprised of two separate programs that aid in the care and treatment of PLWAs, although not necessarily by providing direct patient services. The two programs are the AIDS Education and Training Centers (AETC) and the Dental Reimbursement program.

AIDS Education and Training Centers

In order to assure that people living with HIV/AIDS receive optimal medical care, the CARE Act funds the AIDS Education and Training Centers (AETC). The AETCs are a system of regional, university-based training programs whose purpose is to educate healthcare providers about advances in the treatment of HIV/AIDS. There are a total of 11 regional centers, and more than 70 associated sites, around the country that are responsible for providing training to physicians, nurses and other health professionals. Additionally, there are four national programs within the AETC network that overarch the regional focus of each AETC. They are:

1. **National Minority AETC:** intended to improve the quality of care in minority communities by providing training to healthcare professionals that addresses cultural issues around healthcare. Using this approach, the goal is to develop more local leaders and improve minority participation in the healthcare system.
2. **National Resource AETC:** responsible for developing and providing resources used to educate healthcare professionals.
3. **National Evaluation AETC:** offers assistance with the development and efficacy measurement of professional health education programs.
4. **National Clinicians' Consultation:** offers up-to-the-minute information and individualized, expert case consultation.

HIV/AIDS Dental Reimbursement Program

Recognizing that a key to overall healthcare for PLWAs is access to quality dental services, the Ryan White CARE Act makes provision for the reimbursement of dental care services. Aside from being able to

maintain sound oral health to prevent or treat oral opportunistic infections, dental care is also strongly linked with a PLWA's ability to maintain nutritional intake, which is vital to combating HIV/AIDS.

ADDITIONAL ASPECTS OF THE CARE ACT

Apart from the five structured Titles of the CARE act there are two additional components that reach across all the Titles: The Special Projects of National Significance and the Minority AIDS Initiative.

Special Projects of National Significance

Special Projects of National Significance (SPNS) are novel projects that are undertaken with the purpose of improving the service delivery system for PLWAs. These programs are proposed, implemented, and then evaluated. The findings from these programs are then shared with the entire service community. Additionally, SPNS successes are eventually incorporated and standardized into CARE Act programs. SPNS projects address a wide variety of issues including the development of ways to increase PLWA treatment retention rates, designing programs for PLWAs with multiple health diagnoses (i.e. hepatitis C, diabetes, mental health issues, etc.), and increasing the enrollment in treatment of marginalized populations.

Minority AIDS Initiative

As the HIV/AIDS epidemic has developed in the United States, the number of racial and ethnic minorities severely impacted by HIV/AIDS has increased dramatically. In order to address this issue, in 1999 the Minority AIDS Initiative was funded by Congress to ensure that resources were being utilized to provide medical and supportive services to emerging HIV/AIDS populations. As a result, each Title of the Care Act has a mandate to dedicate a minimum amount of funding to addressing the needs of minorities.

Section IV: Summary of the Institute of Medicine

Summary of the IOM Report “Public Financing and Delivery of HIV/AIDS Care”

In May of 2004, the Institute of Medicine (IOM) produced a report, mandated by the 2000 Ryan White CARE Act reauthorization, on the public financing structures of HIV/AIDS programs for low-income individuals (*Public Financing and Delivery of HIV Care, Securing the Legacy of Ryan White*). The results of the report are to be used to help guide the HHS, who commissioned the study, and other decision makers in the 2005 reauthorization of the CARE Act to meet current and future challenges of the HIV/AIDS epidemic. The IOM Committee on Financing and Delivery of HIV Care, comprised of experts in program provision and finance, was convened to develop a framework for a system of public financing and delivery of primary care and health-related support services for low-income, uninsured, and underinsured individuals with HIV.

The IOM report recommended a new federally funded program for low-income PLWAs that provides early access, continuous coverage and uniform benefits.

After several years of work, the committee recommended the establishment of a new federally funded program for low-income HIV infected persons that provides early access, continuous coverage, and uniform benefits to best meet the needs of those with HIV/AIDS. The new entitlement program, administered by the states and financed by the federal government, would allow for access to essential service provision to all HIV-positive individuals, from the point of HIV diagnosis through all acuity levels and stages of disease progression.

The IOM report also recommended that the CARE Act be preserved, in part, to meet additional, unique needs of people living with HIV/AIDS. The new program would provide enormous benefits in lives saved,

The AIDS Institute supports the IOM report and its recommendations.

health maintained, and medical and socioeconomic costs deferred or avoided. The report and its recommendations are supported by The

AIDS Institute and should serve as the philosophical basis for the work of advocates and government officials alike as they focus on the 2005 reauthorization of the Ryan White CARE Act.

Specifically, the IOM recommends ensuring continuous and equitable access to high quality healthcare from the point of diagnosis of HIV infection for all people in need of public assistance regardless of where they live. The IOM report is instructive in the sense that the proposed system would go far in addressing the current state of quality of HIV/AIDS care and access to that care, while rectifying many of the funding problems related to the discretionary nature of the CARE Act.

Analysis of a Current Broken System

In order to reach its recommendations, the IOM committee first studied and analyzed the current financing and delivery of publicly provided HIV/AIDS services. They concluded that the current system is:

complex and undermines the significant advances made in the development of new technologies to treat HIV/AIDS, such as highly active antiretroviral therapy (HAART). Many individuals experience delays in treatment access or are provided only limited options for specific drugs or important laboratory monitoring. As a result, each year there are missed opportunities to reduce mortality, morbidity, and disability among individuals with HIV infection. It is not uncommon for patients to receive care for the first time with advanced disease stages. The fact that about 40,000 new AIDS diagnoses and 16,000 deaths occur each year further indicates that our current system is failing to ensure adequate health care for persons living with HIV infection (CDC, 2002). A similar number of new infections each year indicated that the threat to the public's health from HIV continues (Fleming et al., 2000).¹

While the report identifies numerous successes of HIV/AIDS care in the US, mainly the dramatic drop in the number of deaths from AIDS, the IOM identified new and difficult challenges including:

the central role of adherence to the therapeutic regimen and the attendant risk of drug resistance to HAART; the changing demographics of the epidemic and the challenges presented by those changes; and, the increasing incidence of both medical and social comorbid conditions among people living with HIV/AIDS. Most importantly, the course of the illness has changed. Individuals with HIV are living longer and require care that is more suited to that for a chronic illness rather than an acute terminal illness.²

The Ryan White CARE Act, when initially written in 1990, addressed the acute needs of those living and, unfortunately, dying of an acute illness. With the advent of HAART, therapy today for most consists of a number of prescription drugs delivered in outpatient settings and requires access to high-quality primary care. In addition, many individuals require a variety of other services including substance abuse and mental health treatment, case management, and prevention services. The care delivery system, and the financing that supports it, has struggled to adapt to the shift in the locus of service delivery and to integrate HIV care among numerous and multidisciplinary providers.³

The IOM identified other problems as well, mainly that there are significant inequities in access to the standard of care for HIV across geographic and demographic populations. According to IOM Committee Chair Lauren LeRoy,

¹ IOM report, executive summary, page 3.

² Ibid,

³ ibid.,

Much of this disparity is related to the patchwork of financing mechanisms across the country and the programs' widely disparate eligibility requirements and benefit packages, all of which result in fragmentation of coverage and significant variations in the type of services available to people with HIV in each state. For many people, the current system does not allow for sustained access to highly active antiretroviral therapy, or HAART, and services that support adherence to treatment. The lack of sustained access to HAART is a clear indicator of poor quality care. Without this treatment, individuals face increased illness, disability, and death. Furthermore, the committee noted that the current federal-state partnership for financing HIV care is unresponsive to the fact that HIV/AIDS is a national epidemic with consequences that spill across state borders.⁴

The Committee reached these conclusions after it examined two federal programs that provide services to HIV infected people - Medicaid and Ryan White CARE Act. It concluded:

both allow for a tremendous amount of variability in the benefits an HIV-infected person can receive. Benefits in one area often fall well below those considered standard in others. The federal-state partnership, embodied in the Medicaid program, in particular, allows states to respond to the epidemic in significantly different ways that may not be the most efficient or effective in light of the nationwide epidemic. HIV-infected individuals living in one state may not be eligible for Medicaid services in another state because of differences in income thresholds or they may receive fewer or more services because the benefit packages vary in each state (e.g. limitations on prescription drugs or coverage of case management, hospice services).⁵

The Committee found similar inequities in the delivery of services under the Ryan White CARE Act, which is designed to fill the gaps in care left by Medicaid. They found:

Access to HAART and primary care, for example, varies significantly by state and city of residence, in part due to varying income eligibility requirements for the AIDS Drug Assistance Program (ADAP) under Title II of the Ryan White CARE Act and in part due to the varying resource allocation decisions made by localities. Substantial state variation also occurs in the types of drugs covered and number of prescriptions allowed (Morin et al, 2002). Budget shortfalls can also lead to further restrictions in the ADAP program, such as enrollment caps or benefit limitations, as they did in June of 2003.⁶

According to the IOM, 233,000 PLWAs who know their HIV status do not have access to HAART.

⁴ Statement by Lauren LeRoy, President and CEO, Grantmakers In Health and Chair, Committee on the Public Financing and Delivery of HIV Care, Public Briefing. May 13, 2004, Washington DC.

⁵ Executive Summary, p. 7

⁶ Ibid, p. 8

The IOM determined that an astonishing 233,000 people in the United States who know their HIV status do not have consistent access to HAART. As a locally controlled, discretionary program that relies on annual appropriations by Congress, CARE Act programs cannot ensure continuity of care from year to year, nor can they ensure that all eligible individuals infected with HIV will receive a minimum basic set of services...⁷

IOM Committee Recommendation

In order to improve the current broken system, and to address the needs of the future, the IOM committee recommended the establishment of a federally funded entitlement program called the HIV

The IOM committee recommends the creation of a federally funded, state administered, entitlement program titled the HIV Comprehensive Care Program (HIV-CCP).

Comprehensive Care Program (HIV-CCP) that would treat low-income individuals with HIV and would be administered by the states.

To assist the states in implementing the program, the federal government would pay for costs directly attributable to efficient administration of the program. To receive federal funding, states must ensure compliance with federal standards and operate programs according to principles of accountability and transparency. Under the federally sponsored program, the federal government would relieve the states of the full cost of providing care to HIV infected individuals through their Medicaid programs.⁸

The program has several primary design features that are critical to achieving the goals of the program. They are: eligibility requirements; benefits; access to experienced providers and provider reimbursement; quality and program management efficiencies; and interaction with other programs.

Eligibility

- Open to individuals with HIV whose family income is under 250 percent of the federal poverty level (FPL), which is around \$23,000.
- Individuals with HIV infection whose family income is above 250 percent of the FPL would be allowed to establish eligibility for coverage by spending-down or buying-in on a sliding scale basis.

Benefits

- Each eligible individual with HIV would be entitled to a uniform, federally defined benefit package that reflects the standard of care for HIV/AIDS.
- Benefits would include HAART and other drug therapies, primary care services, obstetrics and reproductive health services for HIV-infected women, case management, prevention services, mental health treatment, and substance abuse treatment.

⁷ *ibid*, p. 8

⁸ *ibid*, p. 12.

Provider Reimbursement

- Provider reimbursement would be set at the Medicare reimbursement rates.

Cost Offsets

- Recommends that Congress implement measures that lower the cost of drugs, such as applying Federal Ceiling Price or the Federal Supply Schedule price currently used by some major federal programs.
- This would lead to an estimated discount off of Medicaid ARV prices of 9 to 25 percent.

Improving Quality and Programmatic Efficiencies

- To be determined by the state, e.g., some states may administer through their Medicaid agency.
- Create demonstration projects for Centers of Excellence as models of care—the assembly of highly trained, experienced HIV providers and coordination of their activities to provide support for HAART adherence and access to medical and non-medical services. It is assumed that a wide range of providers, including community based providers who have experience and expertise working with the affected populations, will be a part of these Centers. Centers of Excellence would receive funding for data collection and program evaluation.

Within the first year of implementation the IOM recommended program would enroll 285,000 PLWAs.

Coordination with Other Programs

- Ryan White CARE Act programs would be altered and would provide services to those not eligible for the new entitlement program.
- Ryan White CARE Act would provide ancillary services such as assisting individuals in enrolling in the new federal program, filling in any remaining service gaps, and supporting delivery system improvements.
- Title III would play an important role by funding community health centers, hospital or university-based medical centers by participating as Centers of Excellence, and/or would provide services to those in need not covered by the program.

The Potential Benefits

- In its first year of implementation, the recommended program would enroll approximately 285,000 individuals with HIV/AIDS.
- The majority of these people are currently receiving Medicaid, however, 58,697 individuals would gain access to Highly Active Antiretroviral Therapy.
- Premature deaths would decrease by 55.9 percent over 10 years, from 35,489 to 15,664 deaths.
- Through prevention counseling it is estimated that more than 3,000 new infections could be prevented annually.

Cost

- The Committee estimates that the incremental cost of providing HAART to 58,697 individuals for ten years in 2002 dollars is \$2.65 billion.

According to the IOM, 58,697 people would gain access to HAART and premature AIDS deaths would drop by 55.9% over 10 years.

- Adding the cost of the other elements that the committee recommends for comprehensive care is estimated to be \$5.56 billion, discounted, over 10 years.
- The cost per quality-adjusted life-year gained by implementing the program is \$42,972 in 2002 dollars; an amount that is comparable to other widely accepted healthcare investments.

Section V. Necessary Medical and Attendant Social Care

After considering and assessing the current situation regarding care and treatment of low-income people living with HIV/AIDS in the US, and in light of the current provisions of the Ryan White CARE Act, The AIDS Institute proposes that a reauthorized CARE Act adhere to the principles noted below:

Keep Current with Epidemiological Trends Together with Medical and Technological Advancements

In order to offer proper medical care, Ryan White CARE Act grantees and providers must be kept current in epidemiological trends, together with medical and technological advancements. If there is an outbreak in a certain population subgroup, providers should be made aware of this and be on the outlook for it so that it can be properly treated.

In addition to offering competent and well trained medical providers (see discussion below), the care and treatment that Ryan White CARE Act providers offer must be current. Given that there are changes and rapid advancements in the treatment of HIV/AIDS, CARE Act providers should have access to the most current life-saving treatments. There are recognized standards of care that establish the selection of treatments from all FDA-approved anti-HIV medications. Each of the federal HIV treatment guidelines is a living document developed by experts in the field, supported by the latest clinical research and clinical practice experience, as well as responsive to the arrival of newly approved medications within each class.

The Public Health Service (PHS) HIV Treatment Guidelines are widely accepted as the standard of care for HIV and AIDS. The world's best HIV research doctors, who also have real life experience in treating patients, develop these guidelines. This distinguished panel reviews and updates the guidelines periodically and they, in our view, are the best qualified to develop the drug formularies.

The AIDS Institute supports that in the administration of Ryan White CARE Act services, medical providers must follow the PHS HIV Treatment Guidelines.

Provide Access to Cutting Edge Clinical Trials

One way to provide cutting edge medical care to those living with HIV/AIDS is through participation in clinical trials. HIV/AIDS clinical trials are necessary in determining the safety and/or effectiveness of drugs, vaccines, other therapies, or new ways of using existing treatments. They can be used as a mechanism for making promising new treatments available for those who are faced with no other treatment options. Treatment options can be limited both by personal fiscal constraints and viral resistance. Clinical trials also allow those individuals that have resistance to all FDA-approved therapies to attempt a therapy before it is available to the general public, while it is still in the trial phases. The costs for these trials frequently are shared by pharmaceutical manufacturers and the government. Compassionate use programs are a product of pharmaceutical companies which make investigational new pharmaceuticals available for the same group. Pharmaceutical companies sponsor both expanded access and compassionate use programs.

The Ryan White CARE Act already calls for coordination of clinical trials between the National Institutes of Health (NIH) and Ryan White CARE Act grantees. The AIDS Institute supports this cooperation and wishes that this cooperation be expanded. The 2000 reauthorization called for enhancing and expanding voluntary access to these trials, “especially in communities that are not reasonably served by such projects”. Efforts should be undertaken to ensure that this cooperation is occurring and arrangements between the NIH and Ryan White CARE Act grantees are being carried out.

The AIDS Institute supports cooperation between NIH and Ryan White CARE Act grantees to provide access to clinic trials for PLWAs.

Further, groups who are not usually provided access to clinical trials should be included in them on a priority basis.

Recruit and Retain Competent, Specialized, Certified, Healthcare Practitioners as well as Service Staff

According to the American Academy of HIV Medicine (AAHIVM), with the advent of HAART, HIV disease might now be considered a manageable lifelong illness for many individuals. Since HIV-positive patients can now live longer, healthier lives, they require less hospital and late-stage care and more long-term care that involves assistance in many aspects of living with HIV/AIDS and working with multidisciplinary healthcare teams. New technology, increased drug options, and changing treatment guidelines are making treatment and care increasingly complex. Additionally, HIV-positive patients can develop many noninfectious complications from their disease and the medicines used to treat the virus.⁹

In this environment, identifying experienced HIV healthcare providers with up-to-date knowledge of HIV medicine has become crucial to improving the quality of, and access to, effective HIV medical care.¹⁰

The Academy also reports that patients living with HIV/AIDS have better outcomes when they receive their healthcare from providers and facilities with more experience in treating HIV positive patients. Because of reduced morbidity, mortality, and inpatient costs as a result of state-of-the-art outpatient treatment, such care models are cost-effective compared with the alternatives.¹¹

To help persons living with HIV/AIDS receive quality medical care, many organizations have created various ways to identify those with sufficient experience and expertise in delivering HIV healthcare. The American Academy of HIV Medicine, to improve both quality of, and access to, HIV medicine for persons living with HIV/AIDS, has established a definition of an HIV Specialist that is based on specific evidence and maintenance of continuing competency in key aspects of HIV medicine. With its definition of the AAHIVM HIV Specialist™, the Academy (a) defines the specific skills and qualifications that HIV healthcare providers should possess to be credentialed as an HIV Specialist, (b) obtains evidence of these skills and

⁹Position Statement on The HIV Specialist: Definition and Qualifications, The American Academy of HIV Medicine, April 2004, p. 1.

¹⁰ Ibid.

¹¹ Ibid.

qualifications from a broad range of practiced HIV healthcare providers, and (c) does so on a continual basis as clinically relevant information continues to change.¹²

The AIDS Institute supports the effort of the Academy and other HIV medical provider groups in ensuring there are HIV specialists who can offer expert care and supports that Ryan White CARE Act medical providers meet a minimum level of competency. An HIV-diagnosis in the family doctors' office or by a primary care doctor should immediately trigger a referral to specialized care. Primary care doctors need to be trained to recognize symptoms,

The AIDS Institute believes an HIV-diagnosis by a family doctor or primary care physician should immediately trigger a referral to an HIV specialist.

recommend testing, and become a part of a referral network so that newly diagnosed patients can be linked to specialized care immediately. Further, healthcare professionals in emergency departments and emergency medical personal should be effectively trained and have access to the same network. This will not only benefit those living with HIV/AIDS, but ensure the government is buying cost effective services and the care they are funding is sufficient.

In order to recruit competent medical providers, Ryan White CARE Act medical providers, including doctors, nurses, and other practitioners, must be adequately compensated. In order to retain them, compensation levels must remain competitive.

The Ryan White CARE Act should continue its system of educating and training HIV medical practitioners and providing Technical Assistance to grantees so that they can offer the most cutting edge healthcare.

Underlying the medical support that the Ryan White CARE Act provides are the attendant support services that assist CARE Act clients in accessing and adhering to their medical care. That staff, as well, must be adequately trained and sensitive to those living with HIV/AIDS.

Care Must Be Made Available to all Low-Income People Infected with HIV/AIDS, No Matter Where They Reside

The Ryan White CARE Act must meet the needs of all low-income people with HIV/AIDS, no matter where they reside. Not only does this mean the care and treatment offered by Ryan White CARE Act providers should be comparable across the country, but that if a client moves from one area to another, that client should still be able to easily access services. As a predominately federal funded healthcare program, the Ryan White CARE Act is meant to fill in the gaps left by Medicaid, Medicare, state programs, and private insurance programs for low-income people with HIV/AIDS. The end result of all these programs should be comparable services for every client, no matter where they reside. In reality, the current public healthcare system for people with HIV/AIDS is a patchwork of care, with where you reside being one of the significant factors in determining the quality of your healthcare.

¹² Ibid.

A low-income patient's quality of healthcare is determined by a number of factors, including 1) Medicaid benefits offered by the states; 2) Medicare benefits; 3) Ryan White CARE Act benefits; and 4) Private Health Insurance.

Medicaid currently provides the largest source of public funding for HIV/AIDS care in the U.S. In

In FY05, it's estimated that federal Medicaid spending on AIDS will total \$5.7 billion.

FY2005, it is estimated that federal Medicaid spending on AIDS will total \$5.7 billion.¹³ If past indicators hold true in FY2005, an additional \$4.3

billion will be spent by the state s on Medicaid AIDS care. To be eligible for Medicaid, beneficiaries must be low-income and meet certain other eligibility requirements, including being disabled. According to the IOM's report, *Public Financing and Delivery of HIV/AIDS Care*, the federal government provides matching funds to states that meet certain minimum federal standards in operating their Medicaid programs. States have broad flexibility in designing their Medicaid programs and, consequently, there is significant variation in eligibility, benefits, provider payments, and other aspects of the program at the state level.¹⁴

The IOM report continues:

Within broad national guidelines established by federal statutes, regulations and policies, states have broad flexibility standards, the type, amount, duration and scope of services provided, provider payments and other aspects of the program at the state level....State Medicaid policies vary considerably even among similar-sized and or adjacent states, thus, a person who is eligible for Medicaid in one state might not be eligible in another state; and the services provided by one state may differ from those of another state.¹⁵

Medicare is the second largest source of federal financing of HIV/AIDS care, accounting for \$2.9 billion in FY2005.¹⁶ In order to be eligible to receive Medicare, one must be disabled, have sufficient work history to qualify for disability insurance, and live long enough to qualify for Medicare.¹⁷ Although Medicare currently does not provide prescription drug coverage, it will do so beginning January 1, 2006.

Medicare is the second largest federal source of HIV/AIDS care financing at \$2.9 billion in FY 2005.

The Ryan White CARE Act is a discretionary federal program, with some state contributions, meant to provide coverage for low-income people with HIV/AIDS after other sources of public and private healthcare programs are exhausted. Most of the more than \$2 billion of Ryan White CARE Act funding is distributed to the states and cities disproportionately affected by AIDS through a formula based on a weighted average of

¹³ Kaiser Family Foundation, HIV/AIDS Policy Fact Sheet, US Federal Funding for HIV/AIDS, the FY 2006 Budget Request, February 2005, p.2.

¹⁴ IOM Report on Public Financing, p. 62.

¹⁵ *ibid*, pp. 62-3.

¹⁶ Kaiser HIV/AIDS Policy Fact Sheet, p. 2.

¹⁷ IOM Report on Public Financing, p. 64.

cumulative AIDS cases. Consortium and planning councils in the states and cities are responsible for setting priorities as to how and where the funds should be allocated within each state and city.

The amount each state or city receives through formula under the Ryan White CARE Act is based primarily on the number of AIDS cases. It does not take into account the number of people who have HIV, but who have not yet developed AIDS, the poverty rate or unemployment rate in the area, the number of people who have health insurance, the generosity of a state's Medicaid program, or state and local contributions to HIV/AIDS healthcare programs. Nor does the formula allocation take into account the cost of care in an area, the availability of services, and other special needs such as the level of substance abuse. In the awarding of Ryan White CARE Act supplemental awards, some of these factors are considered. [Note: In the IOM report, *Measuring What Matters: Allocation, Planning and Quality Assessment for the Ryan White CARE Act*, many of these issues were discussed and analyzed.

Due to variations in each state and locality that are not factored into the formula distribution and other

Under the current system, a client in one state or area may receive dramatically different care and treatment than a client in another state or area.

awards of the Ryan White CARE Act, a client in one jurisdiction will receive far different care and treatment than a client in another jurisdiction. An examination of the AIDS Drug Assistance Program (ADAP) of the Ryan White CARE Act, which provides critically

important life-saving drugs to low-income people with HIV/AIDS, exemplifies the variation from one state to another.

According to the National ADAP Monitoring Project, resource constraints and state discretion have resulted in significant variations in access to the range of drugs offered across the country. Some examples of the variation include:

- Client eligibility ranges from 125 percent of the Federal Poverty Level (FPL) in North Carolina to 500 percent FPL or higher in Delaware, Maryland, Massachusetts, New Jersey, and Ohio.
- The number of drugs on ADAP formularies ranges from 25 in Louisiana to nearly 500 in New York. Three jurisdictions reported that they had an open formulary (Massachusetts, New Hampshire and New Jersey).
- Seventeen states do not provide all FDA-approved antiretroviral medications, including one state (South Dakota) that does not provide any protease inhibitors.
- Fifteen states provide less than ten of the full set of 16 drugs highly recommended by the Public Health Service/Infectious Disease Society of America (PHS/IDSA) Guidelines for the prevention and treatment of opportunistic infections. One state (Louisiana) does not provide any of these drugs or drugs for other HIV-related conditions.
- Ten states do not cover Fuzeon, the first FDA-approved drug in a new class (fusion inhibitors).

- Twenty-four states report coverage of drugs for the treatment of hepatitis C (HCV), a major co-morbidity for people with HIV. Twenty-two states offer hepatitis A and B vaccines, recommended for those at risk and living with HIV.¹⁸

Due to a growing case load, minor federal funding increases, state budget constraints, along with the existing Ryan White CARE Act formula system, states have had to institute waiting lists, capped enrollments, and additional cost containment measures such as limiting drug formularies, tightening eligibility requirements, or limiting the quantity of prescriptions a client can receive per month.

Variation between jurisdictions, even within the same state, occurs in other Ryan White CARE Act programs as well. For example, access to and the quality of healthcare services can be determined by whether the client lives in a Title I Eligible Metropolitan Area (EMA) or not.

Whether an area has Title III or IV grantees, Ryan White CARE funded Dental Clinics, or received Title I or II Supplemental awards will also directly impact a client's healthcare. Allocation decisions recommended by a community's planning council or a state's consortium are additional factors that determine a client's healthcare in a jurisdiction.

While private health insurance covers a significant share of HIV/AIDS healthcare, most low-income people with HIV/AIDS are not insured or are under-insured, and therefore, must rely on publicly funded healthcare programs. In any event, private healthcare insurance benefits vary from one jurisdiction to the other, sometimes in response to state laws.

Taken together, Medicaid, Medicare, Ryan White CARE Act, and private insurance, all of which provide healthcare to low-income people with HIV/AIDS, as described above, offer varying degrees of coverage depending on where you live. The AIDS Institute finds this unacceptable and supports a program that offers coverage and benefits to all low-income people with HIV/AIDS, no matter where they live.

The AIDS Institute finds disparities in care unacceptable and supports a program offering coverage and benefits to all low-income PLWAs, no matter where they reside.

If this was attained, the issue of portability of services from one jurisdiction to another within a state or from one state to another would also be more easily addressed. The current Ryan White CARE Act "counts" the client at the place of diagnosis. But, reality is that clients do not always stay in that place and frequently move for a variety of reasons. Someone with HIV/AIDS may move back to where they grew up to be with their family, who can help provide for them, while someone else may wish to move to a different climate or to take on a new job.

Unfortunately, to further illustrate the geographic disparities in care, some individuals decide to move their residences to locations with more expansive service offerings. Whatever the circumstances, The AIDS Institute believes that not only should every low-income person with HIV/AIDS be able to access the same

¹⁸ National ADAP Monitoring Report, Annual Report, NASTAD, Kaiser Family Foundation, and AIDS Treatment Network, April 2005, pp.9-10 and 13

type of healthcare no matter where they live, the services that are offered to them should be portable so that they can access that care with relatively ease when they move into another jurisdiction.

Be Culturally and Linguistically Appropriate

For CARE Act providers to offer proper medical attention and care it is essential that it be offered in a culturally and linguistically appropriate manner. Given the varied and distinct populations affected by HIV/AIDS in the United States, this may pose more of a challenge than the treatment of other diseases and medical conditions. These added challenges must be taken into account in the development and administration of CARE Act programs. If done properly, the results will not only pay off in more people who are healthy, but in healthier and happier families. Additionally, it should help serve as a prevention tool, and reduce the transmission of HIV to others. Consider these facts:

- According to the CDC, at the end of 2003, nearly 50 percent of people living with HIV/AIDS in the United States were African American and approximately 12 percent were Hispanic. Thus, approximately 62 percent were racial or ethnic minorities.¹⁹
- From 1998-2002, a growing number of AIDS cases occurred in African Americans, Asian/Pacific Islanders, and American Indian/Alaska Natives.²⁰
- When examining the impact of AIDS on racial and ethnic minority women, the disproportionate share is even more pronounced.
- African Americans accounted for 67 percent of female cases in 2003; Hispanics accounted for another 15.6 percent.²¹
- Among males, 66.2 percent of reported AIDS cases in 2003 were among racial and ethnic minorities, 44 percent among African Americans and 19.76 percent among Hispanics.²²

According to HRSA, approximately one-half of the current CARE Act clients live at or below the Federal Poverty Level.²³ CARE Act clients commonly live in more dire circumstances than do other people living with HIV disease, and HIV-infected people in general are more likely than the non-infected population to be economically disadvantaged.²⁴

While the vast majority of people with AIDS live in large cities, there is growing evidence that the incidence of AIDS is growing in rural America. This is best exemplified by the increased incidence of AIDS in the South. The South now has the greatest number of people estimated to be living with AIDS in the U.S. While the South represents a little more than one-third of the U.S. population (34 percent), it accounts for 41 percent of the people estimated to be living with AIDS. While the prevalence rate is going down in other

¹⁹ <http://www.cdc.gov/hiv/stats/2003SurveillanceReport/table9.htm>

²⁰ CDC, *HIV/AIDS Surveillance Report*, 2002; 14:12. Table 3.

²¹ <http://www.cdc.gov/hiv/stats/2003SurveillanceReport/table5.htm>

²² <http://www.cdc.gov/hiv/stats/2003SurveillanceReport/table5.htm>

²³ HRSA, *The AIDS Epidemic and the Ryan White CARE Act, Past Success+Future Challenges, 2004-2005*, p. 27

²⁴ Bozzette, SA, et al, The care of HIV-infected adults in the United States; *New England Journal of Medicine*, 1998; 339(26):1897-904.

regions of the country, the reverse is happening in the South, rising from 35 percent in 1993 to 40 percent in 2001.²⁵

People with HIV/AIDS also experience other problems as well. Since about a quarter of all new AIDS cases were contracted through intravenous drug use (IDU)²⁶, it is clear that many people with AIDS have substance abuse issues. Many experience severe

The South now has the greatest number of people estimated to be living with AIDS, accounting for 41% of people estimated to be living with AIDS.

mental illness. In the US and Europe, it is estimated that severe mental illness occurs in 20 to 50 percent of the people living with HIV.²⁷ An added problem for many people with AIDS is homelessness or poor

In the US & Europe, it's estimated that severe mental illness occurs in 20-50% of people living with HIV.

housing conditions. The U.S. Department of Housing and Urban Development (HUD) estimates that one-third to one-half of all people living with AIDS “are either homeless or in imminent danger of losing their

homes.”²⁸ Additionally, approximately one-third of people living with AIDS also carry the hepatitis C virus, which further complicates their treatment and health outcomes.

With an understanding and acceptance of these co-morbidities, medical and social service providers can better deliver proper medical care under the Ryan White CARE Act. In order for that to happen, CARE Act programs must provide for the proper training, planning, and financial resources. Given the varied populations affected, this is no small feat.

According to HUD, one third to one half of all PLWAs “are either homeless or in imminent danger of losing their homes.”

The actual medical providers working for a grantee must also be cognizant of their patients’ characteristics and be respectful of them when offering and suggesting care and treatment. This can best be accomplished by first having a competent intake system and competent case workers. The Ryan White CARE Act system should ensure that medical providers can be made aware of their patients’ cultural and linguistic needs.

If the CARE Act ensures that medical care is offered in a culturally and linguistically appropriate manner, the health of the patients is apt to improve. This should assist in adherence to medication and services, and additionally serve as a tool towards better prevention.

²⁵ Kaiser Family Foundation, “HIV/AIDS and other Sexually Transmitted Diseases in the Southern Region of the United States: Epidemiological Overview, p. 3.

²⁶ Ibid.

²⁷ Friedland, GH> *HIV Therapy in “Triple-Diagnosed” Patients; HIV Infection, Drug Use, and Mental Illness.* Cases on the Web 5. San Francisco; International AIDS Society-USA.

²⁸ U.S. Department of Housing and Urban Development. *HIV/AIDS Housing.* 2004.

Section VI: Funding/Fiscal/Administrative

Funding/Fiscal/Administrative Endeavors Should:

- Provide for a seamless system between all publicly and privately funded medical and social service systems. Ryan White should be the bridge between systems and ensure that people are not left behind or without access to care. Overlap and duplication of services would be reduced.
- Provide for adequate infrastructure, in both physical and human resources. Infrastructure includes: physical resources - buildings, geographically appropriate locations, transportation, and clinics; as well as human resources – trained providers, appropriate medical care providers (RN's, ARNP's, PA's, ID docs, etc.) case managers, support for family caregivers, referral network information and training to all providers.
- Provide for equitable and appropriate reimbursement rates to medical and social service providers. Reimbursement rates should be competitive to ensure an appropriate number of providers are interested in providing services. Also, the number of anticipated providers should be projected based on case rates for an area or region, geographical location should not be a barrier to rates or access to providers, available providers should be included in a referral network to allow for client choice, appropriate care (and types of care) should be universally available and not restricted geographically.
- Build in fiscal prudence prominently featuring competition. Fiscal responsibility should be maintained at all levels of the system of care. Appropriate levels of fiscal guidelines should be maintained for federal, state and local grantors as well as all grantees. Training and support should be available at all levels to prevent fiscal abuse. Competition should be encouraged at all levels of contracting. Efforts should be made to ensure multiple applicants for services with strong emphasis on fiscal prudence and accountability.
- Build in cost efficiencies related to purchasing and procurement as well as collective purchasing. Commonalties in purchasing should be maintained by grantors, i.e.: computers, software, training, technical assistance, space allocation, and rent formulas to assist grantees. Collective purchasing should be used whenever possible; pharmaceuticals, and equipment collective pricing to allow grantees and providers the option to purchase from collective bidding rather than individual bidding.
- Address accountability at the client, provider, and administrative levels. This concept relates to fiscal prudence but also contains accountability for quality of care, quantity of services, appropriateness of care, removal of barriers, “checks and balances” at all levels, and identification of duplicate and burdensome processes throughout the system. Accountability should also have a component of training and technical assistance to help “repair” any identified issues. The cost of a new provider is much higher than working to update a current provider.

- Equitably distribute resources across geographic regions. Resources should be based on case count which will facilitate equitable distribution. Increased emphasis should be placed on accountability for grantors to ensure geographical coverage and appropriate level of providers within their geographical areas. Access to care should be portable across geographic lines to ensure provider availability and equal access to equal care in regions lacking infrastructure and providers.
- Utilize HIV data in funding formulas as soon as possible. HIV data is already being collected and can be utilized now. Identifying the areas where data is not available must be addressed to begin utilization of HIV data for planning, funding, and distribution.
- Support expanded HIV testing and counseling in clinical settings so that it may become a part of standard medical screenings. Utilize and support health departments to expand HIV testing, counseling, and training, including lab support. Increase training and utilize AETCs and other medical associations to increase testing awareness in clinical provider's settings. Additionally, making HIV testing part of routine medical care could help to further reduce stigma, support prevention efforts, and identify positives in the non-symptomatic stages, before disease progression can complicate treatment success. This would improve the patients' long-term prospects and prevent them from leaving the workforce due to health concerns.

HIV testing needs to become a part of standard medical screenings in the US.
- Understand that there are ethical considerations related to expanded HIV testing, at any level. New cases will increase the burden on existing, under-funded care systems. Mathematical certainty demonstrates that in attempting to locate more individuals through testing and outreach, the numbers of individuals requiring care and treatment will increase. Despite this fact, identification of the disease is the first step to isolating its spread. It must be remembered that this is not isolation of the individual but isolation of the spread of HIV/AIDS through knowledge and awareness. By improving reporting systems, both planning and funding levels can be better prepared for oncoming cases.

Section VII: Structure/ Impact

Based on these factors, it is clear that programs serving uninsured or underinsured people living with HIV/AIDS should adhere to the following principles:

- Reduce disease-related stigma. There is no quick solution to the problem of AIDS-related stigma. Change must happen, but it is simply pragmatic to expect it to be slow and difficult in coming. What can make it easier is for HIV patients to have some peace of mind in knowing that their needs

Living with a deadly, stigmatized disease is enough of an obscenity without also having to deal with the daily stresses of accessing care and treatment.

for care are going to be met; security that comes from knowing they will not have to quit their jobs; serenity in truly believing that they can stay healthy enough to continue to care for their families and remain in the

workforce. Living with a deadly disease to which stigma is attached is enough of an obscenity without also having to deal with the day to day stresses of worrying about maintaining access to care and treatment.

- Reduce confounding social factors for people living with HIV/AIDS such as racism, homophobia, and sexism. By standardizing HIV testing and counseling in mainstream medical care, establishing and continuing prevention programs that address AIDS at its root causes, and being open to discussing the role sexuality plays in the spread of the epidemic, we can eliminate racism, homophobia, sexism, and AIDS itself. The reality continues to be that any person from any corner of this country is susceptible to HIV infection.
- Reduce other socioeconomic and medical confounders such as poverty and homelessness, as well as medical conditions related to mental health, history of substance abuse, hepatitis, tuberculosis, and sexually transmitted diseases.

There is substantial overlap between HIV and other disease conditions. It's estimated that 10-25% of HIV-infected people are co-infected with viral hepatitis. Additionally, up to 40% of PLWAs also live with a mental health condition.

- Build personal dignity into Quality Management and Continuous Quality Improvement.
- Empower people living with HIV/AIDS to make choices based on objectively assessed needs as this will benefit their medical and social outcomes without creating a dependency system. The HIV/AIDS care system should focus on helping people lead normal, productive lives instead of making them feel that their lives are solely about dealing with a disease. Care and services should be available for people who want to work and be independent if that is what they choose.
- Provide philosophical guidance to service provision systems/personnel to focus on preventing disability rather than encouraging physical and mental disability.
- Allow recipients to return to work without losing their healthcare benefits. PLWAs should not have to

choose between healthcare and dignity of work. HIV/AIDS stigma is fueled by antiquated public policy. It puts people living with HIV/AIDS in fear of losing access to the very care that restored their health when they muster the courage to return to the workforce. It is becoming a reality that you can live healthy with HIV and work. Government and industry need to realize the benefits of allowing HIV-positive people to work and seriously consider the economic consequences of so many PLWAs being pulled from the workforce due to this disease.

- Provide for meaningful input into healthcare planning by people living with HIV/AIDS. Involving people living with HIV/AIDS in the planning process empowers the clients but also affords providers the unique opportunity to learn first-hand what works within the system, as well as what needs improvement and how it can be improved. Without PLWAs, program design may suffer set backs and breed resentment among the very communities the programs are designed to serve.

Section VIII: Towards Care that is Competent, Consistent, and Fair

Other Options Considered

Before reaching its final recommendation, the IOM committee analyzed a number of other options and decided in each case that it would not meet their criteria for an acceptable solution. Below are the options the IOM committee considered and the reasoning on why each was rejected.

1) Expand the Ryan White CARE Program by increasing annual appropriations so that all Titles of the program are able to provide medical and social services to low-income individuals with HIV.

This option would have the advantage of building on an established system that has a built in component for addressing local needs. However, because it is a state-based program, it does not have uniform eligibility standards or a uniform benefits package including a standard minimum drug formulary. The CARE Act also is a discretionary program that is subject to the annual appropriations process so it would not be a guaranteed funding source. Increasing funding for the program also does not address the current disparities that exist in the allocation of funds.

2) Expand Medicare eligibility to People with HIV.

This option would be modeled after the program for individuals with end-stage renal disease. The benefits of a Medicare expansion include:

- It is a national rather than state-based program and coverage would be provided without requiring disability and without a 24-month waiting period.
- Medicare physician reimbursement rates are considered adequate.
- It would provide a stable funding source that is not subject to the annual appropriations process.
- Efficient administrative systems and data collection are already in place.

However, because it is not a means tested program, using Medicare would grant eligibility to all people with HIV regardless of income. Also, due to Medicare's financial constraints (financial solvency projected until 2026) it is not feasible for the program to support universal coverage for people with HIV.

A significant disadvantage of providing access to healthcare services to people with HIV through Medicare is its limited benefits package that does not include case management and, until January 2006, will not include prescription drug coverage. Even in January 2006 it is still unclear whether the coverage available will support the standard of care for people with HIV. Furthermore, the plan requires high levels of cost sharing for individuals between 150 and 250 percent of federal poverty, including a gap in coverage that leaves individuals with no coverage between \$3,600 and \$5,850 in drug expenses.

3) Budget-Neutral Medicaid Expansion

Several states have applied for Section 1115 waivers to expand Medicaid to individuals with HIV before they become disabled. This proposal would standardize and facilitate this process through a number of mechanisms: require standard eligibility requirements across states; require standard benefits packages; and ease the budget neutrality requirement. However, under this proposal there is no guarantee that all states would apply for expansion waivers or implement the standard packages. Additionally, it does not address the provider reimbursement issue that is a significant barrier to healthcare for Medicaid beneficiaries. It also would rely on a state/federal funding partnership leaving the program subject to state fiscal pressures.

4) Create an Optional Medicaid Eligibility Group

This option would allow states to offer Medicaid coverage to people with HIV before they become disabled and is modeled after a state option that allows them to offer eligibility to low-income individuals infected with tuberculosis. Additionally, it would allow states to provide coverage to people with HIV before they become disabled without meeting the budget neutrality requirements of a Section 1115 waiver. However, it still relies on the current Medicaid benefits and reimbursement structures that vary greatly from state to state, as well as relying on states to contribute additional funds without an incentive to do so.

5) Create an Optional Medicaid Eligibility Group with Increased Federal Matching Funds

This option is similar to options 3 and 4 except that it would entice states to offer coverage to this group by offering increased federal matching funds (ranging from 65 to 84 percent) for services provided to this population. However, it still does not address the disparities that exist with regards to benefits and reimbursement rates, and even with the increased match it leaves the population vulnerable to state fiscal pressures.

6) Federal Block Grants to States for HIV Care Similar to State Children's Health Insurance Programs

Under this option, states could elect to receive a block grant that would be determined based on the number of people with HIV in the state and the estimated cost of providing healthcare services to this population. States would be required to match federal funds but the federal government would pay for 65 to 84 percent of the cost of care. This approach would allow states to enhance a number of components that are not adequate in many Medicaid programs, including benefits packages and reimbursement rates, and grants states the flexibility to develop innovative HIV delivery systems such as Centers of Excellence. However, this approach would not guarantee a uniform benefits package; would allow states to cap enrollment if they exceed the block grant funding; and would not guarantee participation by all states.

Section IX: 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 the longer-term issues as this paper has attempted to do. The following points are intended to influence longer-term solutions, as well as the immediate CARE Act reauthorization process.

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 Bureau 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.

Section X: Closing

The AIDS Institute is committed to making the HIV/AIDS care system in the United States a system of high quality, life saving and life enhancing services available and accessible to all people living with HIV/AIDS regardless of jurisdiction or ability to pay. Such a system involves far more than the Ryan White CARE Act. *TAI supports the eventual implementation of many of the IOM report recommendations cited previously to achieve this goal. That being said, and realizing that such a change is long-term; TAI fully supports the 2005 reauthorization of the CARE Act with consideration of the points made above.*

CARE Act reauthorization, as always, requires the cooperation and participation of many entities including people living with HIV/AIDS; medical providers; national, regional, and local AIDS organizations; CARE Act grantees and program providers; Administration officials and Congress, etc. The AIDS Institute has worked cooperatively with these entities in the past and will continue to do so as the reauthorization process moves forward. It is in this spirit of cooperation and conversation that The AIDS Institute has provided this paper, and, in particular, the points of consideration made above.