

Reauthorization of the Ryan White CARE Act

A Comparative Review of Reauthorization Recommendations to Date *and* Recommendations to Maximize Care Capacity for Ohioans Living with HIV/AIDS

AIDS Action Ohio
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**A Comparative Review of Reauthorization Recommendations to Date
and
Recommendations to Maximize Care Resources for People with HIV/AIDS in Ohio**

Introduction

As Congress approaches the task of reauthorizing the Ryan White CARE Act, a range of viewpoints and recommendations have been developed and circulated to inform the scope and provisions of the reauthorized Act. Many of those recommendations, as would be expected, reflect the needs and concerns of the authoring organization or entity, and hence may fail to take into account the *complete array* of recommendations now under discussion. And none, to date, have specifically addressed the need of people living with HIV/AIDS in Ohio.

The following document provides brief background information on the Ryan White CARE Act before offering a comparative review of the twelve major sets of recommendations, written by national and regional bodies, which are now in circulation. Based on that review, it then identifies those recommendations about which there is overwhelming consensus, and those areas about which there is significant disagreement. The review, which is presented in an abbreviated, chart format, is intended to give the reader an “at-a-glance” summary of positions now being forwarded by different groups.

Following that review, we offer our recommendations based on the needs of people living with HIV/AIDS in Ohio. Our most fundamental concern is this: *some of the proposals now in circulation will result in substantially diminished resources for Ohioans living with HIV/AIDS. Ohio’s U.S. Senators and Representatives must guard against such an outcome, and community advocates are encouraged to contact their elected officials to urge a greater equity in national allocations, resulting in a fairer share of available resources for our state.*

The Ryan White CARE Act: Background

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act is the ‘payer of last resort’ for an estimated 571,000 primarily low-income, underinsured and uninsured persons living with HIV/AIDS (PLWH/A). This is nearly half of all PLWH/A in the United States. The CARE Act is the largest federally funded program designed specifically to address the care and treatment needs of PLWH/A. It is designed as a public safety net intended to fill the gaps left by other private and public programs. The CARE Act provides primary care, treatment, and a variety of support services – from transportation to housing and nutritional assistance – that ensure access to care, adherence to treatment, and retention in care. The fact that a great number of CARE Act beneficiaries are poor necessitates the full range of support services to ensure high-quality medical outcomes.

The HIV/AIDS pandemic continues to spread with an estimated (minimum) 40,000 new infections a year in the U.S. alone. Globally, there were an estimated 5 million new infections in 2005. In the U.S. African-Americans accounted for 50% of HIV/AIDS cases diagnosed in 2004

and Latinos 20%, despite representing 13% and 14% of the population, respectively.¹ Heterosexual transmission rates in women have increased from 8% in 1985 to 27% of new AIDS cases in 2003, and African-American women represent 67% of new cases among all women.² The vulnerable are increasingly likely to be poor, minorities, marginalized, and underinsured and uninsured. It is these social intricacies that make the CARE Act an essential resource for PLWH/A.

However, due to state to state variation (between and within) in CARE Act eligibility and benefits there exist geographic disparities in the quantity and quality of CARE Act funding and services. These funding disparities, coupled with variation in state MEDICAID programs, further enhance inequities in care and treatment. These issues must be addressed to ensure the most equitable and compassionate implementation of the CARE Act – and thus ensure early, high-quality and continuous access to care for all people living with HIV/AIDS.

Overview: The Review and Recommendations

In anticipation of the challenges inherent in the reauthorization of the Ryan White CARE Act, a broad range of national organizations have issued CARE Act reauthorization recommendations. The list includes advocacy/policy groups, service providers, and government agencies. Recommendations and guiding principles range in length, breadth and intent. In all, twelve major documents have been produced and distributed; the recommendations therein form the backdrop for the current debate on reauthorization.

To our knowledge, however, no one has undertaken a comparative review of the major recommendations in circulation. This document does so, but with a particular concern: how various sets of recommendations will impact people living with HIV/AIDS in Ohio.

The following section, then, provides a single-glance chart comparing the positions of major national entities on key questions and issues intrinsic to reauthorization of the Ryan White CARE Act. It then offers recommendations, based on that review, that will help reduce current inequities that now negatively impact the health and well-being of people living with HIV/AIDS in Ohio.

The review of recommendations examines all relevant documents recently issued by the following entities:

- ❖ AIDS Alliance for Children, Youth and Families
- ❖ AIDS Institute
- ❖ Association of Nurses in AIDS Care (ANAC)
- ❖ Centers for Disease Control and Prevention/Health Resources and Services Administration (CDC/HRSA)

¹ The Henry J. Kaiser Family Foundation. (2006). *HIV/AIDS Policy Fact Sheet: African Americans and HIV/AIDS*. Washington D.C.: The Henry J. Kaiser Family Foundation.

² KNOW HIV/AIDS (2003). *Get the facts/statistics*. Retrieved February 06, 2006, from KNOW HIV/AIDS Web site: http://www.knowhiv aids.org/facts_stats.html.

- ❖ Communities Advocating Emergency AIDS Relief/AIDS Action (CAEAR Coalition/AIDS Action)
- ❖ HIV Medicine Association (HIVMA)
- ❖ Housing Works
- ❖ National Alliance of State and Territorial AIDS Directors (NASTAD)
- ❖ National Association of People with AIDS (NAPWA)
- ❖ Southern AIDS Coalition (SAC)
- ❖ Title II Community AIDS National Network (TIICANN)
- ❖ United States Department of Health and Human Services (DHHS)

Scope of Reviewed Recommendations and Explanation of Chart

Below is a brief overview of key topic areas for which recommendations have been made by the aforementioned organizations.

Title I: Title I funds provide care and support services to eligible metropolitan areas (EMAs) with a population of at least 500,000 and 2,000 or more AIDS cases in the previous five years. Title I funds are distributed through formula funding and a competitive supplemental grant process. *Issues addressed in the recommendations include eligibility criteria, EMA boundaries, severity of need criteria, planning councils and funding structure.*

Title II: Title II provides care, treatment and support services through grants to states in the form of a base award and AIDS Drug Assistance Program (ADAP) funds. Title II also funds emerging communities (ECs), communities with between 500 and 1,999 AIDS cases over the most recent five years. Title II issues presented *include funding, ECs, Title II ADAP eligibility, funding, pharmaceutical pricing and the ADAP supplemental grant and state match.*

Title III: Title III grants are a main source of funding for uninsured and underserved communities. Title III programs include capacity building and planning grants and Early Intervention Services (EIS) designed to facilitate early entry into effective treatment. Title III recommendations cover *eligibility, programs, and unmet need and underserved populations.*

Title IV: Title IV specifically serves women, infants, children and youth (WICY) living with HIV. Recommendations range from *prioritizing youth for prevention for positives to improving prevention and surveillance of mother-to-child transmission (MTCT).* WICY also appear in other categories of recommendation.

Part F: HIV/AIDS Education and Training Centers (AETCs): AETCs are national and regional centers that train HIV/AIDS providers and non-HIV providers who provide services for people with HIV/AIDS. Recommendations were made to address *the shortage of HIV/AIDS specialists through loan forgiveness and scholarships stipulating service commitments with placement in underserved communities.*

Part F: Dental Reimbursement and Community-Based Dental Partnership Program (CBDPP): Oral health services are an important part of care for PLWH/A. Recommendations include

reaffirming the importance of these programs and expanding partnerships, if additional funding is allocated.

Special Projects of National Significance (SPNS): SPNS grants facilitate research and development of innovative and replicable service delivery models. Recommendations range from *utilizing SPNS funding for evaluation of Centers of Excellence to increased accountability for how research is being put into practice.*

Minority AIDS Initiative (MAI): The MAI funds programs that benefit racial and ethnic minorities and are distributed through CARE Act titles. Recommendations include *increasing resources for outreach and education linking minority populations to services, and ensuring that MAI awards do not supplant local HIV/AIDS resources.*

Support Services, Core Medical Services, Core Formulary: *Support services* are crucial to attaining and maintaining access to high quality care. Recommendations stress the importance of social services. *Core formularies* and *core medical services* are topics about which there remain diverse perspectives.

Other topics addressed in the sets of recommendations include *treatment for comorbidity and co-infection, prevention services, coordination and accountability, infrastructure and capacity expansion, requests for increased funding, and hold harmless provisions (which allow EMAs to retain a specified percentage of the original base award, thus offering protection from annual decreases in funding).*

Note: The IOM Report

The Institute of Medicine (IOM), upon the direction of Congress, issued a report in 2005 that critically examined the entire system of HIV/AIDS care in the United States. The published document, *Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White*, goes far beyond an analysis of the Ryan White CARE Act to critique how Medicaid/Medicare, the RWCA, the VA, and other systems work together – or fail to work together – to maximize medical incomes for all persons with HIV/AIDS in the U.S.

The IOM report concludes that if the U.S. is to achieve a medically-defined standard of care for all U.S. residents living with HIV/AIDS, a fundamental restructuring of HIV/AIDS financing and service delivery systems will be necessary – a restructuring that would supplant the Ryan White CARE Act and Medicaid/Medicare with a new system of standardized, efficiently delivered care.

The recommendations in the IOM document, however, are not included in this document for several reasons. First, it is not specific to reauthorization of the Ryan White CARE Act. And second – and more pragmatically – the IOM authors propose a system of care that will require a notably larger investment of public resources in order to be successful. As we indicate later in this report, we do not believe it is realistic, in 2006, to make recommendations that are based on

an expectation of dramatically increased government funding – clearly, the current national policy environment would not support such an expectation.

Nevertheless, the IOM report is mentioned here because we believe it represents truly innovative thinking about how to address the long-term challenges of HIV/AIDS care delivery and financing. As such, it deserves more discussion – and the report is well-worth reading for those interested in models based on equity and universal standards of care.

Note: About AIDS Action Ohio

AIDS Action Ohio is an informally organized alliance composed of the five largest community-based HIV/AIDS care and prevention organizations in Ohio: AIDS Resource Center Ohio; the AIDS Taskforce of Greater Cleveland; AIDS Volunteers of Cincinnati, the Columbus AIDS Taskforce; and the Ohio AIDS Coalition. Collectively we annually provide HIV/AIDS care and prevention services in nearly every Ohio county, and serve tens of thousands of people with HIV/AIDS and their families, and persons at risk of HIV infection.

Ryan White CARE Act Reauthorization Recommendations 2005-2006*

	NAPWA	DHHS	CDC/HRSA	AIDS INSTITUTE	HIVMA	ANAC	SAC	NASTAD	CAEAR / AIDS ACTION	AIDS ALLIANCE for Children, Youth, and Families	HOUSING WORKS	TIICANN
TITLE I Eligibility			Formula should use measurement of advanced HIV (CD4 ≤ 350)						1500 estimated living AIDS cases (ELCs); Transfer top tier ECs to EMAs			Expand to 1500 countable AIDS cases
TITLE I Severity of need			Use severity of need in supplemental funding ²						HHS convene process of HIV need criteria to ensure supplemental funding is fair			
TITLE I Planning Council		Voluntary and advisory bodies to mayors; structured by mayors		4% maximum of Title I & II for community planning	Clinicians have significant representation on bodies		Distribute funds to states only; use planning bodies if state determines efficiency	Oppose new mandates on participation requirements	•33% PLWH/A •Local jurisdictions decide length of appointment		Meaningful participation of CARE consumers (PLWH/A) in all planning processes	
TITLE I Funding			•Increase formula portion to 75% •Distribute based on #PLWH (CD4 ≤ 350)	•Increase formula to 75% •5% Title I & non-ADAP Title II emergency set aside (i.e. waiting lists)	25% award to primary medical care and additional 25% to basic medical care		•Combine Title I & II •Create two appropriations: Care (Base) and Treatment (ADAP)	Eliminate women, infant, children and youth (WICY) proportional spending	•Use HIV data by 2007 •Allow Early Intervention Services(EIS) circumstantially	Prioritize care for WICY		Fund appropriately before hold harmless provisions
TITLE II FUNDING			Distribute based on #PLWH (CD4 ≤ 350)	5% Title I & non-ADAP Title II emergency set aside (i.e. cost containment, waiting lists)	25% award to primary medical care and additional 25% to basic medical care		•Combine Title I & II •Create two appropriations: Care (Base) and Treatment (ADAP)	•Increase minimum Title II base to \$500,000 •20% of annual increase to supplemental funds •Eliminate WICY proportion		Prioritize care for WICY		
TITLE II Emerging Communities								•Permanent eligibility (1500 ELCs) •Redirect to states with no EMA				Permanent eligibility
TITLE II AIDS Drug Assistance Program (ADAP) Eligibility					Access at ≤300% FPL							
TITLE II ADAP Funding		Redistribute unspent TITLE I & II funds to ADAP based on severity of need		Redirect unexpended funds from all Titles to ADAP			Direct 2% of Title I to ADAP supplemental (3%) for severe need	\$60m increase in funds or redirect unexpended funds				\$120m/yr increase or tap non-ADAP Titles
TITLE II ADAP Prescription Pricing				Consistency across programs and wrap around MEDICARE PART D			VA pricing schedule or lower	Extend Federal Ceiling Price (FCP)	Lowest prices available to federal govt			
TITLE II ADAP Supplemental grant/state match			•20% ADAP increases to new supplemental awards process •Temporarily reduce match if state in need	Temporary match removal if state proves financial need			Maintain 1:4 match	Expand grant criteria and eliminate state match				Fund at 50% annual ADAP increases
TITLE III				•EIS eligibility ≤ 350% FPL •New services and funds focused on poorest				•Revise Title III •Flexibility for Early Intervention Services (EIS) and 'Prevention for Positives' incorporation into CARE programs	•Expand planning and capacity building grants and EIS to org. serving minority communities •New projects in rural/underserved areas			Prioritize funds to states with no TITLE I
Core Services		75% TITLE I-IV funds to be used for core medical services		Minimum set of medical services			•No carve-outs ³ •Community processes to build systems of care	Oppose any mandate more limited than current law and % set-asides for services	Oppose mandated set of Title I services or % set-asides		Mandatory minimum	
Core Formulary		Maintain list of core Rx and prioritize for funding		At minimum include recommendations of DHHS	Minimum formulary developed by states			Oppose core formulary and nationwide FPL eligibility			Mandatory minimum	Comprehensive formularies
Testing		Encourage opt-out testing ¹				Voluntary		Oppose 'opt-out' and mandatory newborn test				

* Condensed summary of key issues ¹ Opt-out routine HIV testing is administered to all pregnant women, unless they indicate that they would not like to be tested. Opt-in testing is done only upon request.

² A 'severity of need' for core services index (SNCSI) index has been proposed, by the DHHS, in order to ensure that the neediest are served first. Measurement variables range from HIV data to income to poverty, and should include other factors that influence access to care and treatment. ³A carve-out is a percentage set-aside of funds for specific services.

Ryan White CARE Act Reauthorization Recommendations 2005-2006*	NAPWA	DHHS	CDC/HRSA	AIDS INSTITUTE	HIVMA	ANAC	SAC	NASTAD	CAEAR / AIDS ACTION	AIDS ALLIANCE for Children, Youth, and Families	HOUSING WORKS	TICANN
Prevention		Require availability of voluntary testing services in public facilities and at private providers						Oppose mandates and % set-asides that require abstinence only messages	Implement CDC's 'Advancing HIV Prevention Initiative'	*Prioritize youth *Improve prevention of mother-to-child transmission (MTCT)		
Support Services	Ensure access to comprehensive services: nutrition, housing, transportation, groceries, legal services, etc.			Crucial to adherence to medical care: nutrition, transportation, housing assistance, child care, legal assistance	Support link between medical and support services and co-location: transportation, housing, advocacy, food, etc.		Focus on support services to attain care and treatment	Maintain flexibility between medical and support services based on locally determined need				
Coordination/Accountability HRSA and other delivery systems		Require state and local care delivery coordination		Improve coordination of federal funding sources			Establish collaboration and coordination across all Titles and federal agencies	Require documentation of HRSA collaboration with state in grant process Reduce duplication in requirements	Improve coordination between HRSA, federal programs and federal funding streams	Enhance coordination of all Titles and relevant federal agencies		
Coordination/Acct Payer of last resort		*Stronger provisions *HHS to conduct audits		Require all pertinent federal programs work closely in planning and provision of services			Reaffirm and recognize to address gaps in care	*Revise requirement *Allow wrap-around and flexibility for limited access to services				
Coordination/Acct Quality Care	Close disparities in quality and quantity of health and social services			Need clear standard of health and social outcomes	*Create a Quality Management Office *Define HIV experienced providers			Revise requirements and add flexibility to choose strategies				
Coordination/Acct Coordinated services	Ensure access to comprehensive services								Care and prevention planning coordination			Attach ETHA as amendment*
Coordination/Acct Reporting		*Submit HIV data by FY07 *Eliminate double counting		*Use HIV data in formula funding *Reform double counting			*Name-based HIV reporting by 2007 *If Title I & II combined double counting is eliminated	*Include CDC data from all states *Oppose name-based reporting mandate	*Name and non-name national HIV/AIDS data *Eliminate double counting			
Coordination/Acct Portability				Develop ADAP portability options								
Coordination/Acct Administrative Requirements				*Simplify Title I & II community planning (max 4% of funds) *Simplify burden on grantees and sub-grantees	Increase all grant cycles from one to two years	Preserve four part TITLE structure	Require state plan submitted to HRSA to indicate reach of CARE Act in every state and territory	*Reduce burden on states *Reduce/minimize unfunded mandates (i.e. unmet need, quality management)	Require annual HRSA report on use of evaluation and technical assistance funds			Conduct ADAP needs assessment
Coordination/Acct Severity of need		HHS develop severity of need for core services index (SNCSI) to determine formula allocations among states and EMAs							Eliminate statewide coordinated statement of need requirement			
Infrastructure/Capacity Expansion									Add 'Infrastructure and Capacity Expansion Program' to Part F			
Increased funding				Increase appropriations and ensure other major HIV/AIDS programs not destabilized		Adequate funding through appropriations mechanism	\$95m increase (\$35m to Emerging Communities (ECs), \$60m to ADAP)	Increase authorizing levels for all components of CARE Act			*\$513m increase in FY06 *More equitable funding mechanisms	
Hold Harmless		Eliminate hold harmless to reduce taking away from cities with newer epidemics	Increasing TITLE I (75/25) would reduce hold harmless	Reduce over time (Title I from 15% to 21% and Title II 1.5% per year over five years)			*Eliminated if Title I & II combined *Loss and gain caps (No gain >23%/yr and loss cap 2006-10 at 2%,3%,4%,5%,6%)	*Revise and repeal Title II hold harmless *Title II base and ADAP earmark to reflect 1.5%/yr loss with maximum 7.5% over 5 year period	Phased in Title I reduction over five year period and until no longer required (% reduction 4,4,4,4,5)			

* Early Treatment for HIV Act (ETHA) is the proposal to expand MEDICAID coverage to individuals living with HIV
NAPWA (National Association of People with AIDS) DHHS (U.S. Department of Health and Human Services) CDC/HRSA (Centers for Disease Control and Prevention/Health Resources and Services Administration) HIVMA (HIV Medicine Association)
ANAC (Association of Nurses in AIDS Care) SAC (Southern AIDS Coalition) NASTAD (National Alliance of State and Territorial AIDS Directors) CAEAR (Communities Advocating Emergency AIDS Relief) TICANN (TITLE II Community AIDS National Network)

Ryan White CARE Act Reauthorization Recommendations
AIDS Action Ohio

Assumptions

In making RWCA reauthorization recommendations that will best serve the needs of people living with HIV/AIDS in Ohio, we make, at the outset, several operational assumptions.

1. We recognize that overall funding for the RWCA is likely to be flat. This leads us to conclude that recommendations that depend for their logic on the expectation of substantially increased funding are likely to be viewed as unrealistic, and will not contribute to the reauthorization discussions soon to take place in Congress.
2. We expect that proposals to eliminate or revise current double-counting are likely to be highly contentious but that, in the end, double-counting as a mechanism for determining formula funding may not continue in its present form.
3. We expect that, while some regions will vigorously argue for preservation of hold harmless provisions in allocations, those protections will be eliminated or fundamentally revised in the interests of greater equity of funding distribution across the country.
4. We expect that final legislation will contain elements that help reduce disparities in ADAP access and ADAP formularies across state boundaries.

General Principles

In early December of 2005 AIDS Action Ohio members collectively agreed on a set of general principles to guide reauthorization. These are presented first; more specific recommendations follow.

The general principles issued in December are as follows.

Congress should:

- Continue funding of the Ryan White CARE Act as an emergency response to the crisis of the HIV/AIDS epidemic in the United States, and support funding levels that correspond to the rising number of HIV/AIDS cases.
- Within the provisions of reauthorization, ensure equity in the resource distribution and the provision of a minimum standard of care for all Americans living with HIV/AIDS.
- Distribute Ryan White CARE Act funding based on living HIV cases (which includes AIDS cases) instead of reported AIDS cases only. Doing so would more accurately reflect the distribution of HIV-related illness across the United States, and respond to the needs of states that have experienced a rapid growth in HIV infection in recent years.
- Eliminate or greatly reduce the impact of double counting. This would result in a movement of Title II dollars to states that have a) no Title I EMA, or b) a Title I EMA that only serves less than 50% of the state's HIV/AIDS population (such as Ohio). This would not affect Title I distributions.

- Continue to allow for the provision of case management as a “Core Service” supported by the CARE Act. Research data are clear and extensive on the impact case management has on maximizing positive medical outcomes for people with HIV/AIDS. Ancillary support services play a critical role in enhancing treatment adherence and patient health, and doing so in a manner that is efficient and cost-effective. The definition of “Core Services” under the Act must encompass all those services deemed vital in helping patients enter and remain in a system of comprehensive care and treatment that will enhance medical outcomes and reduce further transmission of HIV.
- AIDS Action Ohio does not support a carve-out by percentage of funds for core medical or any other particular set of services, unless “Core Services” is defined broadly and flexibly. Rather, local conditions and local control should guide the allocation of dollars to maximize the effect of local responses to the epidemic.
- Continue to support and adequately fund all other provisions of the Ryan White CARE Act, including Title III, Title IV, Special Projects of National Significance, the HIV/AIDS Training Education Centers, the Dental Reimbursement Program, and the Community-Based Dental Partnership Program. Funding should be provided to continue support of CARE Act data reporting, evaluation, and quality assurance mechanisms.

General Areas of Agreement across Recommendations

We note that there are broad areas of agreement in the various sets of recommendations that have been issued by the organizations and bodies listed on previous pages. We concur with many of those recommendations, including the following.

- Congress should include operational provisions in CARE Act reauthorization that permit optimal pricing for medications paid for the ADAP programs.
- Titles III and IV of the Ryan White CARE Act have allowed expansion of services to previously unserved or underserved persons with HIV/AIDS, such as rural populations, women, and children. Titles III and IV must remain a critical component of the reauthorized Act.
- Likewise, the small investment made under the Act in Special Projects of National Significance (SPNS) have yielded significant results in the development of innovative practices and improved standards of care. SPNS funding, therefore, should continue.
- Other portions of the CARE Act that should be retained include the AIDS Education and Training Centers (AETCs), which have successfully expanded medical and behavioral health system capacity to serve the needs of people with HIV/AIDS; Part F, which has helped thousands of people with HIV/AIDS access dental services that are critical to oral health and overall general health; and the Minority AIDS Initiative, which has helped target resources to communities and populations disproportionately impacted by the epidemic in the United States. These initiatives should also be retained.
- There is also widespread agreement on the need to define, based on current clinical standards of care, minimum available drug formularies, to be supported through ADAP and other programs, so that quality of care for individuals living with HIV/AIDS is less dependant on geography. AIDS Action Ohio concurs with that goal, and adds that while Ohio has not yet joined the list of 14 states that at some point in the past five years had

ADAP waiting lists, the ADAP system in Ohio is highly vulnerable and, without adequate federal assistance, cannot be expected to sustain itself into the future.

- There is widespread agreement on the need to ensure better coordination of service delivery and financing mechanisms within the CARE Act overall, and between CARE Act implementation and other federal and state programs. This agreement is tempered by the general assessment that enhanced coordination and quality assurance should not come at the expense of overly burdensome administrative requirements at the local level that impede providers from providing necessary care and services.
- There is widespread agreement that one of the unique and critical features of the Ryan White CARE Act is the degree to which it mandates local input from service consumers and providers in determining local care needs, and allocating resources based on those determinations. Title I Planning Councils and Title II Consortia are eminent examples of this requirement. We believe that structured opportunities for such input and decision-making should be preserved.
- Finally, there is widespread agreement on the need to define fundable “core services” in a manner that best supports enhanced medical outcomes for people with HIV/AIDS (see discussion below).

Areas of Disagreement across Recommendations

A review of the various and diverse recommendations issued to date also finds areas of disagreement. Two that deserve mention relate to 1) HIV testing and 2) HIV prevention initiatives to be funded under the CARE Act.

AIDS Action Ohio does not take an opinion of these two issues. We do, however, raise some concerns. First, in relation to testing, we are concerned that new provisions adequately protect the confidentiality of individuals getting tested, incorporate effective pre- and post-test counseling, and do not have the effect of dissuading members of vulnerable populations – such as undocumented workers – from getting tested. Second, in relation to prevention, we are aware that there are many sound reasons to facilitate a better integration of care and prevention services across the board. We add, however, that the needs of individuals who are HIV-, or whose HIV serostatus is unknown, should not come at the expense of a legitimate need to focus greater prevention resources towards HIV+ persons in order to reduce transmission of the virus.

Ohio Concerns and Recommendations: Definitional Ambiguities

This and the following section address specific concerns and recommendations AIDS Action Ohio offers in relation to reauthorization impacts on Ohioans living with HIV/AIDS.

The reauthorization principles forwarded by HRSA and others contain terms and language that are ambiguous – and a resolution of that ambiguity is essential before we can determine whether the needs of people with HIV/AIDS will be well served.

First, HRSA and others have recommended that a fixed percentage of Ryan White CARE Act funds (generally 75%) be set aside to pay for Core Services. While there is no disagreement that primary care, diagnostics, and medications would and should be included in the definition of “Core Services,” there is uncertainty about whether the definition will be appropriately flexible and comprehensive enough to include ancillary services that are essential to the achievement of desired medical outcomes. Foremost among ancillary services that must be included in the definition of Core Services is case management – both medical case management, and community-based case management. The data are clear: case management services, across the board, result in higher medical outcomes – they facilitate and increase clinic visits, they contribute to better adherence, and they help achieve greater stability for patients who, without such stability, would be less likely to effectively utilize medical services. There is no doubt: case management services are a vital part of the “core” necessary to achieve CARE Act goals.

But other services are also critical to the achievement of desired goals. It does little good, for example, to offer medications or diagnostic monitoring to individuals who do not have transportation to a local clinic; it is difficult to provide meaningful, coordinated medical care for individuals who have no stable housing; and the science of HIV care is now clear that maximum benefits from pharmaceutical regimens can only be achieved if individuals are also receiving appropriate nutritional services.

When we also note the overwhelming incidence of poverty among Ryan White CARE Act service consumers, it becomes clear that “Core Services” must be defined as those direct medical and non-direct ancillary services that, together, are essential to the achievement of desired medical outcomes for people with HIV/AIDS, including the examples given above, and other services deemed critical based on assessments of local need.

Second, some have recommended that a better indicator of funding needs for a local or state community is “Severity of Need” rather than a simple count of the number of persons living with HIV or AIDS. While there is much to be said for this proposal, we are again concerned about definitional ambiguity. A narrow definition of “severity of need” – like a narrow definition of “core services” – will not account for the range of challenges and barriers people with HIV/AIDS face as they seek to access and effectively utilize services. “Severity of need,” in our opinion, should not only take into account diagnostic markers such as CD4 count and viral load, but should also take into account local poverty rates, the strength and effectiveness of local systems of primary care and public health overall, the percentage of people with HIV/AIDS who are also struggling with mental illness and substance abuse, rates of co-morbid conditions such as hepatitis, and other, similar factors.

Third, there are a variety of opinions about what constitutes a “core formulary” for ADAP access and funding purposes. While the ADAP program in Ohio remains viable, it is also vulnerable, and it is our shared opinion that the definition of “core formulary” should be based on acceptable standards of care, and roughly equivalent across geographic boundaries. While a comprehensive list of antiretroviral medications remains the heart of a standard of care formulary, formularies must also include other medications necessary for effective management of HIV illness in patients.

Ohio Concerns: Impact of Recommendations on Ohio Budgetary and Service Capacity

At the top of the list of concerns raised herein by AIDS Action Ohio, however, is the budgetary impact on care and services for people living with HIV/AIDS in Ohio.

If our first assumption is true – that we are not likely to witness any meaningful increase in funding for the Ryan White CARE Act overall – then some of the recommendations now being forwarded will have a negative budgetary impact on Ohio, and result in reductions in service capacity and quality.

Specifically, the double-counting and hold harmless provisions of the Act have resulted in inequitable funding distributions between states and regions, and within states. These provisions favor the east and west coasts, and negatively impact Midwestern states and the south. Retained, those provisions would preserve the inequity, and result in actual losses of Ryan White dollars for Ohio.

Some analysts have noted, for example, that elimination of the double-counting provision alone, combined with a switch to HIV seropositivity rather than diagnostic AIDS to determine cases, could result in a gain in as much as \$5 million for care and services in Ohio.³ On this point, we want to be clear: **such a gain would not represent a case of “different winners and losers” under reauthorization; rather, it merely corrects the current inequities.**

Unfortunately, most of the recommendations that have been distributed to date are not accompanied by budget analysis, making it difficult to determine in each case the budgetary impact on Ohio. **Such analysis needs to be carried out before the Ryan White CARE Act is reauthorized, and we urge public officials representing Ohio to insist on such analysis by the OMB or other neutral bodies before “signing off” on legislation.**

This point cannot be emphasized enough, and bears repeating: some of the proposals now in circulation will result in substantially diminished resources for Ohioans living with HIV/AIDS. Ohio’s U.S. Senators and Representatives must guard against such an outcome, and community advocates are encouraged to contact their elected officials to urge a greater equity in national allocations, resulting in a fairer share of available resources for our state.

³ National Alliance of State and Territorial AIDS Directors (2005). *Ryan White Reauthorization: The Truth About “Double Counting.”* www.nastad.org

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