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
AIDS Resource Center Ohio
AIDS Taskforce of Greater Cleveland
AIDS Volunteers of Cincinnati
Columbus AIDS Task Force
Ohio AIDS Coalition

Jennifer Panzo, Principal Researcher

February 27, 2006
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.\textsuperscript{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.\textsuperscript{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)


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

<table>
<thead>
<tr>
<th>Category</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TITLE I: Eligibility</strong></td>
<td>Formula should see measurement of advanced HIV (CD4 ≤ 350)</td>
</tr>
<tr>
<td><strong>TITLE I: Severity of need</strong></td>
<td>Use severity of need in supplemental funding*</td>
</tr>
<tr>
<td><strong>TITLE I: Planning Council</strong></td>
<td>Voluntary and advisory boards to mayors; structured by mayors</td>
</tr>
<tr>
<td><strong>TITLE I: Funding</strong></td>
<td>Increase formula to 30% of Title I (PLWH &amp; non-ADAP Title II emergency set-aside)</td>
</tr>
<tr>
<td><strong>TITLE II: Funding</strong></td>
<td>Distribute based on Title II (CD4 ≤ 350)</td>
</tr>
<tr>
<td><strong>TITLE II: Emerging Communities</strong></td>
<td>Permanent eligibility (1500 ELCs)</td>
</tr>
<tr>
<td><strong>TITLE IIADAP: Drug Assistance Program (ADAP) Eligibility</strong></td>
<td>Access at &lt;$185 FPL</td>
</tr>
<tr>
<td><strong>TITLE IIADAP: Funding</strong></td>
<td>Distribute expected from Title I &amp; Title II emergency set-aside to states</td>
</tr>
<tr>
<td><strong>TITLE IIADAP: Prescription Pricing</strong></td>
<td>Consistency across programs and wrap-around MEICARE PART D</td>
</tr>
<tr>
<td><strong>TITLE IIADAP: Supplemental grant/state match</strong></td>
<td>25% ADAP increases to new supplemental awards process</td>
</tr>
<tr>
<td><strong>Core Services</strong></td>
<td>75% TITLE I HIV funds to be used for core medical services</td>
</tr>
<tr>
<td><strong>Core Formulary</strong></td>
<td>Maintain list of core Rx and priorities for funding</td>
</tr>
<tr>
<td><strong>Testing</strong></td>
<td>Encourage opt-out testing*</td>
</tr>
</tbody>
</table>

* Combined summary of key issues. * 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. * 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. * Opt-out is a percentage set-aside of funds for specific services.
Prevention

- Maintain flexibility between medical and support services.
- Require availability of voluntary testing services in public facilities and at private providers.
- Express opposition and set-asides that require adherence only to particular messages.
- Implement CDC's 'Advancing HIV Prevention Initiative'.
- Prioritize youth immunization and prevention of mother-to-child transmission (MTCT).

Support Services

- Ensure access to comprehensive services: nutrition, housing, transportation, groceries, legal services, etc.
- 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.
- Support link between medical and support services and co-location: transportation, housing, advocacy, food, etc.

Coordination/Accountability HRSA and other delivery systems

- Require state and local care delivery coordination.
- Establish collaboration and coordination across all Titles and federal agencies.
- Require documentation of HRSA collaboration with state in grant processes.
- Reduce duplication in requirements.
- Improve coordination between HRSA, federal programs and federal funding streams.
- Enhance coordination of all Titles and relevant federal agencies.

Coordination/Accountability State and local delivery systems

- Strengthen provider/county to conduct audits.
- View all pertinent federal programs work closely in planning and provision of services.
- Realign and prioritize state services.
- Revise requirements and add flexibility to choose strategies.
- Revise requirements and add flexibility to choose strategies.

Coordination/Accountability State and local delivery systems

- Require and improve access to comprehensive services.
- Improve access to comprehensive services.
- Ensure access to comprehensive services.
- Care and prevention planning coordination.
- Attach ETHA as amendment.

Coordination/Accountability Reporting

- Submit HIV data by FY07.
- Eliminate double counting.
- Name-based HIV reporting by 2007.
- All Title I & II combined double counting is eliminated.
- National HIV/AIDS data eliminated.
- Name and non-name reporting mandated.
- Decrease burden on states.
- Reduce/minimize double counting.

Coordination/Accountability Portability

- Develop ADAP portability options.
- Conduct ADAP needs assessment.

Coordination/Accountability Administrative Requirements

- Ensure adherence to medical care: nutrition, housing, transportation, groceries, legal services, etc.
- Specify burden on grantees and subgrantees.
- Increase all grant cycles from one to two years.
- Preserve four part TITLE structure.
- Reduce burden on states.
- Reduce/minimize unfunded mandates (e.g., annual need, quantity management).
- Require annual HRSA report on use of evaluation and technical assistance funds.
- Conduct ADAP needs assessment.

Coordination/Accountability Severity of need

- Determine state plan submitted to HRSA to indicate reach of CARE Act in every state and territory.
- Reduce burden on states.
- Reduce/minimize unfunded mandates (e.g., annual need, quantity management).
- Require annual HRSA report on use of evaluation and technical assistance funds.
- Conduct ADAP needs assessment.

Coordination/Accountability Program

- Implement CDC's 'Advancing HIV Prevention Initiative'.
- Prioritize youth immunization and prevention of mother-to-child transmission (MTCT).

Infrastructure/Capacity Expansion

- Increase authorizing levels for all components of CARE Act.
- Increase appropriations and ensure other major HIV/AIDS programs not destabilized.
- Adequate funding through appropriations mechanism.
- Eliminate state/denial coordinated statement of need requirement.
- Reduce/minimize unfunded mandates (e.g., annual need, quantity management).
- Conduct ADAP needs assessment.

Increased funding

- Increase appropriations and ensure other major HIV/AIDS programs not destabilized.
- Adequate funding through appropriations mechanism.
- Eliminate hold harmless from FY07.
- More equitable funding mechanisms.

Hold Harmless

- Rearrange Title I & II combined accessibility and gain caps.
- Reduce over time (Title I from 15% to 21% and Title II from 15% to 21% per year over five years).
- Reduce Title I/II hold harmless (75/25) would reduce hold harmless.
- Enact hold harmless for new positions.
- Reduce and repeal Title I & II hold harmless.
- Title II base and ADAP Title II hold harmless.
- Title II base and ADAP hold harmless.
- 5% per year over five year period.
- Phased in Title I reduction over five year period and until no longer required (5% reduction 4, 4, 4, 4, 4).
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 dependent 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.

References