

**T·II CANN Editorial**

By: Gary Rose

T·II CANN is increasingly concerned by the public attacks that have been recently launched at the ADAP Working Group. For T·II CANN, our participation is governed by the unalterable fact that hundreds of thousands of uninsured and underinsured people living with HIV have received medicines that have kept them alive due primarily to the efforts of the ADAP Working Group. In addition, T·II CANN and other members of the Working Group have helped to foster similar groups in Nebraska, Colorado, Pennsylvania, Idaho, Mississippi, Connecticut, Arkansas, Tennessee, Florida, Texas, Illinois, New York, California, and other states to fight for state-level appropriations for drugs and services in those states.

In regard to our rationale for helping to start and continuing to work with the Working Group, we believe that:

1. It is morally repugnant to permit or deny access to life-saving drugs on the basis of a person's resources.
2. No one else (no other coalition existing at the time or, in most cases, since) prioritizes ADAP advocacy.
3. The Working Group has been remarkably successful in its advocacy at both federal and state level due primarily to its unusual makeup (community, industry, government, and other technical advisors).

To our knowledge, participation in the Working Group has never prevented a community member from advocating positions on issues with which there is substantial disagreement between community and industry. As graphic proof of this assertion, dozens of sign-on letters and industry/community meetings on issues relating to unresolved community/industry problems have included prominent participation by Working Group community members. Our agreement in forming the Group, however, required that any issues not directly tied to increasing access to health care for uninsured and underinsured Americans living with HIV/AIDS be handled in other venues such as the Fair Price Working Group, National Organizations Responding to AIDS, or the Health Gap Coalition.

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## Grass Roots Finds Success in Arkansas

By: Eric Camp  
Arkansas ADAP Working Group

Soon Arkansas will no longer be the only southern state, or one of the five nationally, that has never contributed state dollars toward HIV medications or services thanks to legislation passed during Arkansas' 2001 General Assembly. The effort to gain state funds for Arkansas' AIDS Drug Assistance Program (ADAP) received a major boost from two unlikely sources: Arkansas Governor Mike Huckabee (R) and Arkansas Department of Health Director Dr. Fay Boozman.

Huckabee, a former Southern Baptist minister, once tried to shut down an AIDS awareness program in a rural Arkansas high school when he served as Lieutenant Governor because it mentioned homosexuality without immediately condemning it. Huckabee believed that if the curriculum did not condemn homosexuality (same-sex sodomy is illegal in Arkansas) it must have been promoting it, and therefore the AIDS awareness curriculum was promoting the violation of state law. Huckabee, also while Lt. Governor, noted in a sermon that people with AIDS were responsible for having the disease because they were playing outside God's rules.

Dr. Boozman, while running as a Republican against U.S. Senator Blanche Lincoln, lamented the fact that President Clinton had made finding a cure for AIDS a national priority. In a speech to a civic club during his 1998 U.S. Senate campaign, he noted that Arkansas would have no epidemic if people would just obey Arkansas' laws against injection drug use and same-sex sodomy. Following Dr.

Boozman's defeat in the U.S. Senate race, Governor Huckabee appointed him to serve as Director of the Arkansas Department of Health, which administrates the vast majority of federal AIDS dollars in Arkansas. Many in Arkansas' AIDS community were vocal opponents of that appointment.

Accomplishing the goal of gaining state funding for Arkansas' ADAP seemed nearly impossible in the spring of 2000 when the AIDS community and Dr. Boozman's Arkansas Department of Health were in the midst of a very public battle. The Department wanted to divert Ryan White Title II dollars from long established community-based organizations to its own financially strapped in-home health services in county health units. The AIDS community fought the plan in public forums, the press, and through a legislative committee with oversight responsibilities. Eventually, Dr. Boozman backed down and appointed an ad-hoc committee to resolve Department-community issues. This series of events, though traumatic for many Arkansans with HIV, helped the Arkansas AIDS community gain its own identity. The subsequent ad-hoc committee got the community and the Health Department working together at a pivotal time for the ADAP effort.

Within weeks, at the conclusion of a legislative committee's interim study regarding Arkansas' assistance to its citizens living with HIV, the largely Democratic committee questioned the leadership of the Health Department for not request-

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ing state funding for Arkansas' ADAP. They asked community leaders to organize the grassroots and to meet with Health Department leaders and the State Board of Health on the issue before the Legislative Session, which would begin in seven months.

During the meeting with Health Department leaders, Dr. Boozman surprised many by finding a reason to support state ADAP funding. This happened during a discussion of a March 2000 study published in the *New England Journal of Medicine* that found that heterosexual HIV transmission from a person with an HIV viral load of less than fifteen hundred was rare. Dr. Boozman decided this study made state ADAP funding a "public health issue." To him, this study made state ADAP funding an issue of prevention as well as treatment. Politically, it was a way conservatives could support HIV prevention without getting into politically unpopular issues like needle exchange, sex education in schools, or condom distribution. He then stated that he would not only endorse state ADAP funding legislation, the

Department would draft it and sponsor it. Dr. Boozman also sought and gained the support of the State Board of Health and the Governor while garnering key sponsors for the legislation from each political party.

After gaining information from Florida AIDS Action, Georgia's AIDS Survival Project, and T•II CANN at Southeast Regional ADAP Conferences in Atlanta and Tampa, the Arkansas ADAP Working Group (AAWG) was formed as an ad-hoc umbrella organization designed to line up and focus those interested in the state-funding issue. The group researched Arkansas-specific data supporting its cause, conducted dozens of statewide trainings, built a mailing list and database with eighteen hundred mostly faith-based AIDS advocates across the state, built a website, raised necessary funding, organized several letter-writing campaigns, obtained a lobbyist, maintained relations with the press, and many other tasks.

Historically, during legislative sessions in Arkansas, lobby groups serve "lunches" or "dinners" to help feed their citizen lawmakers and to lobby them for specific legislation. To give lawmakers a positive impression of the "AIDS community," a catered catfish luncheon was held on the Capitol grounds. The idea was to dispel images of AIDS advocates as a bunch of irritating, angry, screaming, leather-clad, social outcasts. Such images and "Act-Up"-style activities backfire in a poor, conservative, rural, southern state like Arkansas. As the Session began in January, lawmakers instead saw images of ordinary people, many from churches in their districts, who were respectful and knowledgeable about the issue. Over 250 lawmakers and statewide AIDS advocates sat at the same table and talked about the issue in true southern "fish-fry" fashion.

Senate Bill 34, known as "The HIV Medications Act of 2001," was passed in the Session without opposition. This bill, signed into law February 13 by Governor Huckabee, made spending state dollars on HIV medications official state policy.

## Early Treatment for HIV Act

On June 5, Nancy Pelosi and Richard Gephardt reintroduced the Early Treatment for HIV Act (H.R. 1591 in the 106th Congress) or ETHA. This legislation would allow low-income individuals living with HIV to qualify for Medicaid coverage earlier in the course of their disease. The Presidential Advisory Council on HIV/AIDS has identified the passage of this legislation as a top priority because early treatment for HIV infection saves lives and reduces health care costs as progression from HIV to full-blown AIDS is prevented or delayed.

ETHA would permit states to apply for waivers from the Center for Medicare and Medicaid Services (CMS, formerly HCFA) under revised budgeting criteria that would allow greater flexibility.

We urge you to contact your member of Congress to support HR 1591, or ETHA. ■

The last battle was to find the funding. Due to major tax cuts in the last two Sessions, state revenue projections were the lowest lawmakers had seen in many years and state revenue reserves (once holding nearly \$100 million) had been depleted. A substantial raise in teacher salaries was the major goal of the Session, and was expected to take all of the anticipated increase in general revenues for the biennium. The grim scenario grew even more bleak later in the Session when revenue forecasts were dropped even lower. Many popular programs, including Arkansas' Medicaid program and drug-and-alcohol addiction treatment programs, had to substantially cut their budgets to protect teacher raises.

The AAWG joined a host of well-established lobby groups (AARP, Arkansas Children's Hospital, Arkansas Medical Society, Arkansas School Nurses Assn., Arkansas Rural Firefighters Assn., etc.) in a effort to establish a "Health Care Trust Fund" to be funded by a raise in the state's tobacco tax. If passed, it would have provided a permanent funding stream for Arkansas' ADAP and many popular health causes; how-

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# Ryan White CARE Act: Amendments of 2000

By: Chris Aldridge, HIV/AIDS Prevention  
and Care Program Specialist  
NASTAD, Washington, D.C.

In October of 2000, the Ryan White CARE Act was reauthorized for the second time, providing funding to care and treatment programs for an additional five years. Changes throughout the CARE Act reflect several themes to better address the changing epidemic and to meet the needs of those who are HIV positive. These themes include identifying individuals who are HIV positive but not receiving care and treatment; building stronger linkages between prevention, care, and other services; developing capacity in and focusing resources on underserved communities and communities disproportionately impacted by the epidemic; and ensuring quality services.

Title I of the CARE Act, which provides assistance to eligible metropolitan areas (EMAs), and Title II, which provides funds for care and treatment to states, have several changes that are similar, although implementation of these changes will vary under each title. First, to increase the number of people aware of their HIV infection and link them with appropriate care and treatment, the CARE Act now allows a portion of Title I and II funds to be used for early intervention services (EIS) similar to Title III. EIS includes counseling, testing, referral, and primary care services. In addition, under Title II, up to \$30 million was authorized to support grants to states for partner counseling and referral services (PCRS).

Another important change, is the inclusion of HIV surveillance data into Title I and II allocation formulas beginning in fiscal year (FY) 2005. As the number of individuals diagnosed with AIDS has steadily declined through use of

highly active antiretroviral therapy (HAART), the number of individuals living with HIV has increased. Inclusion of HIV data will better reflect how EMAs and states currently are affected by the epidemic. The Institute of Medicine (IOM) will produce a report to guide the Secretary of Health and Human Services (HHS) in implementing this provision. If by July 1, 2004, the Secretary determines national HIV surveillance data is not sufficiently accurate to incorporate in the funding formulas, then HHS must provide states with technical assistance to allow HIV data to be included by FY 2007. To prevent sudden shifts in funding, limits have been placed on how much a grantee may lose in a single fiscal year due to the inclusion of HIV data.

Changes in both Title I and II also emphasize expanding consumer input into the planning process. For Title I, 33 percent of Planning Council members must be Title I consumers unaligned (i.e., not employed by or on the board of a Title I grantee). Title I Planning Councils are also required to include HIV prevention providers, housing or homeless services providers, and formerly incarcerated individuals as part of their membership. Similarly, the CARE Act suggests that Title II consortia should include similar participants in their planning processes. The comprehensive planning process for both Titles I and II has been expanded as well, with emphasis being placed on developing strategies to identify HIV positive individuals and link them to care, and to eliminating health disparities in underserved communities.

Both Titles I and II supplemental grants attempt to direct more fund-

## In Brief . . .

**Editor's Note:** Due to limited space in *The Voice*, the T•II CANN Editorial Committee is often faced with the daunting task of deciding which important information to include with each issue. Since this information is often important to our readers, T•II CANN has created the "In Brief" column to provide this information in a summary format and direct you to the source.

- Recently NASTAD conducted an emergency survey of State ADAPs. The survey further provides evidence of the urgent need for providing an "emergency supplemental appropriation" of \$50 million in FY 2001 and the need to insure that FY 2002 appropriations secure an additional \$120 million funding increase. This information is currently being reviewed within Congress and within the Administration. To obtain a copy, contact The ADAP Working Group, (202) 588-1775.
- The Florida congressional delegation has requested the support of the Subcommittee on Labor, Health, and Human Services and Education in the House of Representatives, for an "emergency supplemental appropriation" for FY 2001 and the needed increase for FY 2002 of \$120 million. A copy of this letter may be obtained by contacting The ADAP Working Group, (202) 588-1775. ■

ing toward underserved communities, but with very different processes. For Title I, one-third of each EMAs supplemental grant will be based on severe need. Co-factors such as syphilis, hepatitis B, and hepatitis C will be considered when determining severe need for an EMA. For the Title II supplemental, the CARE Act creates a provision for "emerging communities," defined as urban areas with total AIDS cases between 500 and

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1,999 over the previous five years (just under the qualifications for a Title I EMA). Triggered by a \$20 million increase in Title II base (non-ADAP) funding, the provision sets-aside 50 percent of Title II base increases for emerging communities or \$10 million, whichever is greater. Of the funds designated for emerging communities, half will be distributed among those urban areas with 1,000 to 1,999 AIDS cases reported and half will be distributed among urban areas with 500 to 999 AIDS cases. This provision was implemented in FY 2001.

Youth (ages 19 to 25) are now included in the women, infants, and children set-aside for both Titles I and II. Funding directed toward women, infants, children, and youth (WICY) must be proportional to their representation in the local epidemic. EMAs and states may request a waiver of all or part of this requirement if other programs are already serving these populations. Finally, EMAs and states are now required to establish quality management programs to assess and improve care providers' implementation of the Public Health Service (PHS) treatment guidelines.

Several changes were made to ADAP in the reauthorized CARE Act. Three percent of the ADAP earmark is now set-aside for states with severe needs, particularly those states that do not cover all antiretroviral medications, have limited or no OI drug coverage, or states with financial eligibility set at 200 percent of federal poverty level (FPL) or less. States must apply for these funds; however, the funds are distributed through a formula based on AIDS cases. States must provide a 25 percent match to receive supplemental funding. Another change to ADAPs allows states to use 5 to 10 percent of their ADAP allocation to support medical monitoring and adherence programs. States may also begin using ADAP funds for insurance purchasing and maintenance, as long as it is cost-effective and the insurance provides comprehensive coverage of HIV medications.

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## MESSAGE FROM THE BOARD: 20th Anniversary of AIDS March

**I participated in the 20th Anniversary of AIDS March in Washington, D.C. on June 3.**

Organized by the Names Project, the march was led by a group of children from camps dedicated to children with HIV. With a sizeable contingent from ActUp Philadelphia, hundreds of AIDS activists marched from the White House to the Capitol steps (2.3 miles). Once there, a number of speakers shared their personal and group



messages about keeping AIDS advocacy effective in the face of disappointing White House and Congressional leadership on domestic and international AIDS funding. Delegate to Congress from D.C., Eleanor Holmes Norton, spoke of the severe challenges to the African American Community and to the District of Columbia in dealing with the effect of this disease. Other speakers followed on the Capitol steps for some 2 1/2 hours, with the mall and the Washington Monument in the background. Speakers expressed disappointment that The Ryan White CARE Act was flat funded, and that the U.S. contribution to the "global AIDS fund" was at the \$200 million level.

The reading of the names from the Quilt Panels was moving, as I recognized dozens of names - including my partner Michael Parker, who died in 1992. In many ways I found the march and rally a fitting tribute to those no longer

with us. I marched in the 10th Anniversary demonstrations in New York, in 1991. My suburban rural community brought eight busloads into New York City for that demonstration. Times Square was crowded and I was not able to get close enough to actually see the speakers' podium. Thank goodness for big TV screens. However, the modest size of this Washington crowd on a beautiful spring day in the Nation's Capital illustrated how much work we have left to do



to "Renew the Struggle." Someone said "AIDS demonstrations are important. If they don't see you in the streets they think you don't vote." As Delegate Eleanor Holmes-Norton so eloquently put it "this is an issue where if the people lead, your leaders at both ends of

Pennsylvania Avenue will follow. AIDS is not over and we all must continue the work to lead our leaders in the continuing fight against AIDS." Mrs. Holmes-Norton was right, there remains HIV/AIDS advocacy work still to be done - here and around the globe. AIDS is not over and all of us have work to do at the community, county, city, state, and federal level. Further, as a world

leader, our country must also act globally. I suspect there will be no rest for the weary until "AIDS is over." Indeed, we must all find the energy and commitment to "renew the struggle" one more time. ■

**William (Bill) Arnold  
C.E.O./Vice Chair, T-II CANN**



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Several changes were made to the perinatal provision under Title II of the CARE Act. The CARE Act now authorizes up to \$30 million to support counseling, testing, and treatment of pregnant women and infants. A portion of these funds is designated for states with mandatory testing programs for newborns or those with significant reductions in perinatal HIV transmission, and the portion of funds set aside for these programs increases over time. Perinatal funds not set aside are awarded to states based on reductions in the incidence of perinatal HIV transmission, increases in the acceptance of HIV testing in pregnant women, and the rate at which pregnant women receive HIV services. The Secretary is also required to contract with the Institute of Medicine (IOM) or another entity to study barriers to the routine testing of pregnant women and newborns. The IOM has declined to perform this study, however, so the Office of the Inspector General for the Department of Health and Human Services will conduct it instead.

Changes to other CARE Act Titles also reflect the overriding themes in the reauthorized CARE Act. For Title III, a priority has been placed on directing future grants toward rural and underserved communities. In addition, 5 percent of appropriations for Title III can be used for primary care and EIS capacity building grants, up to \$150,000 over a 3-year period, in underserved communities.

Title IV no longer requires that a significant number of clients be enrolled in clinical trials. Instead it specifies that grantees must document the linkages between care and research, provide education on opportunities to participate in HIV/AIDS clinical research, and develop quality management programs similar to requirements under the other titles. Also, for Title IV, the Secretary must study ways to expand access to clinical research for women and children in communities underserved by such projects. Changes to Part F of the CARE Act include new language that stresses the importance of HIV training for gynecologists and obstetricians, the development of treatment protocols for women, and

expanded distribution of the *Public Health Service Guidelines* to providers.

Other provisions in the reauthorized CARE Act, not specifically associated with any Title, provide a requirement for the Secretary to develop a process to coordinate planning, funding, and implementation of all federal HIV/AIDS programs across the Health Resources Services Administration (HRSA), Substance Abuse and Mental Health Services Administration (SAMHSA), the Center for Medicare and Medicaid Services (CMS, formerly HCFA), and CDC. In addition, the Secretary must find ways to streamline the Title I and II application process. Other initiatives include working with Title I and II grantees and the Federal Bureau of Prisons to coordinate care for prisoners released back into the community; and working with the IOM to determine the most appropriate epidemiological measures for financing and delivering health care to the poor and underserved. ■

## NY and CA Waiver Update

In May 2001, the Center for Medicare and Medicaid Services (CMS, formerly HCFA) approved a Medicaid waiver for New York's Family Health Plus (FHP) proposal. With the expansion to start in September, the state will phase in coverage for parents (whether disabled or not, or on Medicare or not) in families earning up to 150 percent of poverty (\$1,451/mo. for two; \$1,829 for three; \$2,206 for four; etc.), after deducting \$90 of wages, up to \$175 per child in paid child care costs, and up to \$50 in received child support payments.

New York's FHP waiver will also cover both disabled and non-disabled childless adults under 65,

who are not on Medicare, and have incomes under 100 percent of poverty (\$716/mo. for one and \$968 for two), with the same deductions allowed for families (federal law actually gives those who have been found disabled the more generous SSI income deductions, but the state's plan appears to ignore this).

One peculiar feature of the New York waiver will figure Medicaid eligibility using the new \$716 income level for those disabled not yet on Medicare; but will keep the lower \$617 income level for giving Medicaid to those disabled who are on Medicare. This will mean that those in their two-year

Medicare waiting periods will enjoy a higher Medicaid income level, but will then lose it when Medicare starts.

California has a similar waiver application pending with the CMS, formerly HCFA, although it proposes to use 200 percent of poverty to cover both disabled and non-disabled parents (\$1,935/mo. for two; \$2,438 for three; \$2,942 for four; etc.), using the same income deductions as New York. However, California will not cover non-disabled, childless adults (but it already gives Medicaid to the disabled using an income level of \$945/mo., whether or not they're on Medicare). Detailed summaries of ALL states' Medicaid waivers and other expansions are available from [tomxix@ix.netcom.com](mailto:tomxix@ix.netcom.com) ■

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Unfortunately, some leading advocates have come to adopt a somewhat paternalistic attitude that suggests concerns surrounding access can be made secondary to other issues having to do with patents, pricing, or even personal grievances. This ethical prioritization seems to be the basis of many complaints regarding the ADAP Working Group (e.g., since we can not agree on all issues with our coalition partners, we can no longer participate in good faith in that coalition). Unfortunately, if such a rule were universally applied, all coalition activity would become impossible.

In any case, the need for this coalition has increased dramatically. Last year, the Working Group's estimate of program need for ADAP was not met for the first time since 1998 and, as a result, the national program is at least \$50 million short for this fiscal year. This has resulted in ADAP program restrictions in a number of states with more states guaranteed to limit access to ADAP late this summer and in the fall. At press time, 10 state ADAPs have closed enrollment to new clients. Prior to the end of FY2001, there are expected to be seven more states that will cap enrollment or institute other program restrictions (see box). In addition, a number of states with a history of fiscally stable ADAPs (e.g., California, New York, and Pennsylvania) report the potential need to implement ADAP restrictions based

on current funding levels and projected trends and program utilization.

The next fiscal year (2002) will be much worse. Unless we can move the Administration to reconsider the flat funding of all AIDS programs, ADAP will be burdened with another \$120 million shortfall, in which case, all state ADAPs will be hard pressed to continue providing access to people living with HIV. Then we will return to the days of rationing AIDS medicines via reductions in formularies, capped or closed programs, or other desperate measures.

If there are more effective (or more ethical) means of assuring ADAP funding under the budget proposed by the Bush Administration, then others in the community should become much more visible in initiating such strategies immediately. For T•II CANN, the needs are too immediate to put at risk what has been, to date, a successful coalition effort on the sole ground that industry and community have interests in conflict. We only ask that members of the community who may disagree with striving to bridge this funding gap through the ADAP Working Group be more circumspect and not damage our efforts even if they are unwilling to support them. In the end, the only people who will be hurt by our public disagreements are uninsured and underinsured people living with AIDS across the country. ■

**State ADAPs with waiting lists**

- |          |                |
|----------|----------------|
| Alabama  | Maine          |
| Arkansas | Montana        |
| Georgia  | Oklahoma       |
| Indiana  | South Carolina |
| Kentucky | South Dakota   |

**State ADAPs that expect to institute waiting lists and/or other access restrictions before the end of FY2001**

- |          |               |
|----------|---------------|
| Idaho    | Oregon        |
| Florida  | Rhode Island  |
| Maryland | West Virginia |
| Missouri |               |

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ever, it failed to pass in committee.

House Bill 1789 was introduced as a simple ADAP appropriation bill asking for state general revenue dollars. It stalled in the Joint Budget Committee for over a month while its sponsors tried to locate another funding source. Just when it appeared all hope was lost, Governor Huckabee agreed to support Arkansas' ADAP with state General Improvement Funds. These funds are typically reserved as a "brick-and-mortar pork account" used to patch roofs on civic buildings and fix roads in the home districts of lawmakers. With the unanimous passage of House Bill 1789 as amended and Senate Bill 574 in the final days of the Session, Governor Huckabee gained the authority to provide state funds for Arkansas' ADAP.

When the dust settled after the Session, it was clear the support of two individuals typically perceived as "villains" of the Arkansas AIDS community had played a major role in securing Arkansas' first state contribution to its ADAP. The Governor now is authorized to spend up to \$600,000 over the biennium for Arkansas' ADAP (which is matchable up to 4-to-1 by federal ADAP Supplemental dollars). At press time, an announcement of the actual contribution amount was expected within days. ■

**CORRECTION**

T•II CANN received several comments regarding funding for mortgage payments and other unusual issues mentioned in the article, "Housing Assistance: Beyond HOPWA" from the January/February 2001 *Voice*. For a detailed, revision

of the article which fully addresses these points, please email [tomxix@ix.netcom.com](mailto:tomxix@ix.netcom.com) or contact the editor at (973) 579-3622.

*The Voice* Editorial Committee apologizes for any inconvenience.



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