Fourth Annual ADAP Educational Forum Convened In Washington

Part One Of A Two Part Series

Contributed By: James C. Arvantes, Associate Consultant at Martin Medical Services in Washington, D.C. and editor of Positive Populations, a quarterly newsletter examining infectious disease health care policies and program management in correctional settings.

The fourth annual ADAP Educational Forum convened in Washington, D.C. on May 20-22, a ground breaking event that brought together more than 250 ADAP administrators, state AIDS directors, Medicaid, and correctional personnel to identify and to address challenges and problems. During the two day conference, speakers repeatedly referred to ADAP as “the payor of last resort,” a program that fills in the gaps for other health care programs, serving as a life line for thousands of patients with HIV and AIDS lacking adequate health insurance. It has, in the process, played a key role in reducing the number of AIDS-related deaths during the past few years.

The introduction of protease inhibitors and combination therapies has sparked dramatic increases in ADAP costs and utilization rates, forcing the drug assistance programs to balance patient access with available resources. This year’s meeting was intended to look beyond ADAP, focusing to a greater extent on other programs such as Medicaid and private health insurance.

“ADAPs are not going to be able to keep up with ever increasing case loads and the heavy financial burdens,” said William Arnold, Executive Director of the T•II CANN, who chaired the meeting. “We have to look for other means of expanding access and making sure that people who need access to effective treatments have it.”

“This means an expanded role for Medicaid to provide coverage for people with HIV disease before they become sick and disabled,” Arnold said. “Under existing rules, many people with HIV and AIDS do not qualify for Medicaid until they become sick and disabled.”

ADAPs must also take advantage of opportunities to purchase insurance whenever appropriate as a way of defraying costs while expanding health care coverage. In addition, correctional institutions now house large numbers of people with HIV and AIDS. Most offenders, however, spend less than two years behind bars and, as a result, ADAPs serve many people with HIV and AIDS who are released from prisons and jails. This necessitates closer cooperation between ADAPs and correctional institutions.

This year’s forum highlighted inherent difficulties in healthcare delivery within corrections and some correctional health care models for treating HIV behind bars. Continued on page 4
Editors note: T•II CANN Board Member Jeff Coudriet will write this regular feature about real people, who are living with HIV/AIDS, and/or caring for and advocating on behalf of people living with HIV/AIDS; as well as the problems, challenges, and triumphs that they are experiencing.

T•II CANN recently had the chance to speak with Steve Waldron, the Coordinator of the Central New York HIV Care Network in Syracuse, New York.

T•II CANN: What are some issues that might be unique to upstate New York?

SW: We trail behind the epicenter trends, such as in New York City, and we have never hit the volume impact of the epidemic there, of course, but there has been a very clear and significant presence. In small cities and rural communities like ours, you can count it on several hands. But how you design a system to serve people can be very difficult. People feel remote in a number of different ways. We had to ask ourselves how we design certain services to be provided in satellite outstations and others in centralized care facilities, which we needed to find a way to get people to. There are certain historic patterns for planning in rural areas and above all you have to respond creatively. There’s never going to be a large enough constituency to put a whole program in any one place.

T•II CANN: I bet. Are there other challenges?

SW: There are other items relating to issues people have in rural areas. People in the more northern counties of the state still live in fear of being identified. We recently did a round of forums with PWAs in Syracuse, Utica, and Watertown. In Watertown, most of the people who attended were affected parties—family members, friends, loved ones, etc. We have found that when we design public programs, we need to make the topic broad—for example, we do a mini conference in each area once a year to bring in doctors and others to talk about treatment options. People feel like they can blend in better in a bigger crowd like that. There’s no lack of thirst for knowledge or community, but I think that stems from people’s fear of being identified. It can be an uphill struggle to get the 25 percent PWA involvement and the 25 percent minority participation that we want to get.

T•II CANN: What has New York State’s response been to the issues you face outside of New York City?

SW: It is hard for programs up the ladder to truly understand the issues affecting these smaller local areas, even when funding processes are designed to be sensitive to local concerns. I would give the AIDS Institute in New York good grades for trying very hard to reflect the concerns all around the state. Genuine effort and progress is being made. The state is in the midst of a budget crisis. There were to be $2.4 million in cuts to existing programs, permanency planning, treatment adherence, etc., which had been announced last year. We did some heavy advocacy work with local officials who represent us in Albany and the Assembly restored the cuts and added $10 million. The Senate restored some budget cuts but not for AIDS, so we’re holding the line with the same money.

T•II CANN: And there are a lot of new issues emerging aren’t there?

SW: Our casework is becoming more complicated as people are thriving under medical care, so we are responding to issues people face when they have a more chronic illness. Programs must plan on providing people with certain new services potentially over a long period of time. This dynamic is having some impact on keeping people at the table as advocates because people burn out over time. There is a change in...
Many times I have heard the phrase: “Boy are you lucky,” or “Aren’t you lucky?” When I reflect upon those statements there are a couple of things that come to mind. First of all, I feel very lucky to have gotten involved in the HIV/AIDS advocacy. I have met so many wonderful people who are infected or have been affected by HIV/AIDS. I have developed a number of sincere friendships through my efforts. I remain amazed by their personal strength. This courage and fortitude has given me additional energy to keep moving forward with the tasks at hand.

We often become overwhelmed at the sheer enormity of Congressional appropriations for Ryan White or the re-authorization of the CARE Act which is so important to people living with HIV. Many of these efforts on the state and federal level take untold hours of time from the lives of committed individuals. And sometimes, after long and arduous meetings, lobbying, and travel, the conclusion of these efforts seems so far away.

With the appointment of the new senate minority whip, U.S. Senator Harry Reid of Nevada, I believe that the HIV/AIDS community has also been blessed with a voice that will not fade during the protracted processes in Washington, D.C. Senator Reid is a senior member of the Senate Appropriation Committee. Not only has he been a friend of mine for many years, but he has been a friend of the HIV/AIDS community.

“Over the past decade we have made great strides in our search to combat the HIV/AIDS virus. Much of that progress has come at the grass roots level through the efforts of those whose lives have been touched by this disease,” said U.S. Senator Harry Reid. “This is an issue that impacts more than individuals, it affects families, businesses, and every community in Nevada and across the nation. I continue to support the ADAP and I applaud the work of Herbert Perry of Las Vegas in promoting this critical issue. Herb’s efforts have increased awareness in Nevada and have resulted in funding for AIDS programs from the Nevada State Legislature.”

Lucky? We are all lucky in one way or another!

Herbert Perry, LPA/EA Chair and CFO of T•II CANN

Editor’s Note: Herb has served on numerous community AIDS related boards.

Congress Requests GAO (General Accounting Office) Review Of All Federally Funded AIDS Programs—Including The Ryan White CARE Act

A recent letter from Majority Leader Dick Armey (R-TX), Commerce Committee Chairman Tom Bliley (R-VA), and U.S. Representative Tom Coburn (R-OK) to the General Accounting Office (GAO) requesting audits of AIDS programs, has caused concern to AIDS advocates as processes leading to Reauthorization of the CARE Act (expiring in September 2000) are initiated. The problem, according to CARE Act supporters, is that Mr. Armey has no history of support for AIDS issues. Also, Dr. Coburn (while very supportive of some HIV/AIDS programs, e.g., ADAP) has often clashed with AIDS advocates over the importance of some support programs considered by many of us to be vital in a true HIV continuum of care, and some feel he has been overly influenced by very rigid personal opinions around morality and public health policy. Advocates also express concern that the audit is requested solely by “conservative” Republican members although moderate Republicans and Democrats were willing to assist in the crafting of the request. In addition, community concerns were triggered by the tone of the letter to the GAO which contained "loaded" phrases such as “possible fraud and abuse.” Finally, it struck some community members as an early attempt to politicize discussions surrounding Reauthorization of the CARE Act in spite of what has been a remarkable history of bipartisan support for the legislation.

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Like past conferences, this year’s event served as an educational and networking vehicle for program participants, providing an in-depth look at a variety of topics and issues. As always, the meeting highlighted emerging developments and trends, among them:

• The Health Care Financing Administration (HCFA) is in the process of evaluating an 1115 (a) waiver submitted by Maine that would extend Medicaid eligibility to “pre-disability” people with HIV who have not yet become sick and disabled with AIDS. HCFA is looking closely at the issue of budget neutrality, a federal provision that says the state cannot spend more under the waiver than it would have spent without the waiver.

  “We are committed to reaching our decision with Maine in the near future,” said Kathleen King, an Executive Associate Administrator for HCFA. “We have weekly conference calls with the state to discuss these things.”

She described the waiver process as a “fairly arduous one” in which all the involved parties must agree on the budget neutrality provisions, including “other parts of the Clinton Administration.” King, responding to rumors that HCFA has already decided to reject the waiver, reiterated that “we have not made any sort of formal decision. We haven’t even given the state thumbs down informally.”

• Massachusetts is preparing to submit its own HIV waiver, an addendum to an existing 1115 (a) waiver that would essentially expand Medicaid eligibility to pre-disability people with HIV before they develop AIDS.

• Congress, meanwhile, is considering a provision that would allow some states to extend early pre-disability Medicaid eligibility to people with progressive illnesses. The provision, contained in a bill introduced by Senator Jim Jeffords (R-VT) and Senator Edward Kennedy (D-MA), S.331, would provide a limited amount of money on a demonstration basis for some states to expand Medicaid coverage to people with disabilities whose condition would become worse if left untreated. Congress, though, would have to opt for Medicaid coverage of working disabled persons as opposed to the non-working disabled in the bill language in order to cover conditions like HIV and AIDS.

The investigatory arm of Congress is conducting an audit of all federally financed HIV programs to determine whether the programs are operating appropriately, a process that could jeopardize reauthorization of the Ryan White CARE Act next year by generating Republican opposition to HIV programs, according to Jeff Jacobs, Government Affairs Director for AIDS Action Council in Washington, D.C.

The General Accounting Office (GAO), which is conducting the audit at the request of House Republicans, is basing the audit on a series of questions that primarily address the Ryan White CARE Act.

“The GAO serves Congress and is to some extent bipartisan,” said Jacobs, who discussed the politics surrounding Ryan White reauthorization. “Having said that, the GAO is an arm of Congress and they are well aware of who is in control and who has requested this audit.”

“We are concerned that the [GAO] will serve their masters with a negative spin,” he added. Jacobs described the questions in the GAO audit as politically motivated. He acknowledged, however, that the “questions are not all bad.” The first audit question, for example, asks if there is “evidence of abuses or misuses of federal AIDS funds.”

“It is a good question,” Jacobs said. “It is a question we should all be concerned about. I don’t have any problems with this question at all.”

The GAO also plans to list the salary levels of top administrators in AIDS service organizations (ASOs) receiving large amounts of federal grant money, comparing those salaries with state and civil servants in the immediate ASO areas.

Jacobs describes the GAO’s intent in this matter as “somewhat fair. . . but I hope that they will also go and look at some of the salaries of some of
the other voluntary health organizations,” he said. Elizabeth Dole, for instance, made more than $500,000 a year as head of the American Red Cross, he noted.

Jacobs expects the GAO to carry out a “fair audit.” But even if the report is favorable, there are concerns that congressional Republicans will use one or two negative paragraphs in the overall report to rail against the CARE Act on the floor of the House, thereby undermining support for the program and threatening reauthorization. The CARE Act, enacted in 1990 and re-authorized in 1996, is up for reauthorization again in fiscal year 2000. Without reauthorization, Congress is not under any obligation to fund the Ryan White CARE Act.

**Representative Coburn Leads Audit Charge**

Three House Republicans requested the audit — House Majority Leader Richard Armey (R-TX), Commerce Committee Chairman Thomas Billey (R-VA), and Representative Thomas Coburn (R-OK) also a member of the Commerce Committee, which is responsible for Ryan White reauthorization. The GAO is expected to release the audit late this year. To an extent, the audit questions reflect support for the ADAP but a lack of understanding for other CARE Act services that support ADAP, according to Jacobs. Jacobs, in fact, describes Representative Coburn as a “friend of ADAP who doesn’t understand the CARE Act.”

One question, for instance, asks the GAO to “provide an estimate of the percentage of CARE Act program funding that directly supports treatment and medical care for HIV and AIDS patients.” Another question instructs the GAO to “estimate the percentage of CARE Act program funding, support services and welfare not directly related to treatment such as housing, counseling and other services.”

“We are talking with the GAO, trying to make sure the importance of support services is not left out of the audit,” Jacobs said.

**Medical Advancements Outpace ‘Antiquated’ Medicaid Eligibility Rules**

Recent medical advancements have made Medicaid eligibility rules and regulations obsolete for some chronic diseases, creating a need for a new federal program that provides care for people with HIV/AIDS and other long-term illnesses who are not disabled or sick enough to qualify for Medicaid, said Tim Westmoreland, Senior Advisor for HIV/AIDS with the Henry J. Kaiser Family Foundation.

As a society, the United States has “built a system around the needs of acute care, responding quite poorly to people with chronic health care disabilities and chronic illnesses,” Westmoreland said. That situation, he added, is probably best exemplified by Medicaid’s coverage of people with HIV and AIDS.

Medicaid serves as the largest payer for AIDS-related services, comprising 57 percent of all federal and state AIDS funding, making it “an incredibly important source of health care financing” for people with HIV disease, Westmoreland commented. More than 50 percent of the people with AIDS in this country end up as Medicaid beneficiaries; at the same time Medicaid pays for the health care services of 90 percent of children infected with the virus.

Yet, people with HIV disease cannot qualify for Medicaid, in many cases, unless they are sick and disabled, conditions associated with late stage disease progression. With the combination regimens, many people are no longer becoming sick and disabled, thus precluding Medicaid eligibility and access to the combination therapies.

“We are going to have a parallel paradox here,” Westmoreland warned. “Research is going to produce products that keep you healthy but the only people who can get through our current Medicaid finance system are people who are truly sick and disabled.”

Moreover, the federally endorsed HIV guidelines recommend early treatment with the three drug cocktails, well before the onset of AIDS-related conditions. The guidelines are, in fact, “180 degrees in opposition to the eligibility policies of Medicaid,” Westmoreland pointed out.

“The only people who will be so disabled that they will qualify for Medicaid in the future are people who didn’t follow the treatment guidelines or who didn’t have access to the drugs in the first place,” said Westmoreland. “A few will continue to qualify but not many of those newly infected people are going to be eligible for Medicaid.”

This paradigm has, in turn, created an inevitable “collision” between Medicaid’s antiquated eligibility rules and the “research progress of the pharmaceutical industry,” Westmoreland said.

The use of combination therapies has led to dramatic decreases in AIDS-related deaths during the past few years but new HIV infection rates have remained steady. As a result, many newly and chronically infected people will have to rely on programs such as the Ryan White CARE Act for care and treatment, discretionary programs that are not adequately funded to carry additional case loads, Westmoreland observed.

“We are going to have to find another source of payment for those [AIDS-related] services,” Westmoreland commented. He proposed a health care program for “people who are chronically ill—people who need ongoing health care but who don’t need inpatient hospitalizations.”

James C. Arvantes may be contacted at Martin Medical Services, Inc., (202) 518-7768. (Look for Part II in the next issue of The Voice.)

**The 1999 AIDS Drug Assistance Program National Educational Forum** was sponsored by the following pharmaceutical companies:

- Bristol-Myers Squibb Company
- Hoffmann-LaRoche Inc.
- Merck & Co., U.S. Human Health Division
- Agouron Pharmaceuticals, Inc.
- Roxane Laboratories
- DuPont Pharmaceuticals Company

This year’s meeting was facilitated by The Title II Community AIDS National Network (T**II CANN**) and PAREXEL International.
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living, going off public assistance and back into jobs. Of course, it’s especially important that those jobs have health insurance benefits and an accommodating environment. A little bump in the road can derail your health more than it would somebody else.

T•II CANN: What other issues are folks concerned about?

SW: There has been a lot of focus on New York State’s HIV positive names reporting. We are looking at the draft regulations on that. People are very concerned about their privacy, obviously, and there is also concern about how this system will be paid for and where the money will come from. We are certainly hoping money won’t be cut from services for people, that’s the whole irony of this—we’re going to spend a lot of money and not guarantee that we can provide people with the services they will need if they are HIV positive. There’s a real misguided sense of what the real need out there is. The new regulations out there go far beyond the intent of the legislation into very punitive areas. I’m not sure it’s constructive.

T•II CANN: I have found one of the best things pulling people into the “system” are the new treatments themselves.

SW: That’s right—when you have something to offer people, like we do now, it brings them in. People have more sense of hope and engagement when there is positive news. We have found that creating a sense of community and peer to peer exchanges have also made people feel more welcome.

T•II CANN: So it’s building people’s comfort level first?

SW: Absolutely. It leads me to the artificial separation between prevention funding and treatment funding. We want to be able to move people seamlessly to the services they need, regardless of what they may be. Transportation is a big issue for us as well. We use bus systems in the cities, there are some intercounty connections, but otherwise the focus is on taxis and vouchers for designated drivers—friends or relatives of PWA’s. There are many places where you just can’t get around without a car. Also we need to get people to other services which are not funded by Ryan White. How do we get people to them without Ryan White money for transportation?

T•II CANN: What other things are you finding?

SW: We are finding an increasing disproportionate impact on communities of color. It continues to be difficult to involve people in leadership roles in this community—people in the faith community and the NAACP and Urban League, with some exceptions, haven’t really stepped forward yet. There are lifestyle and morality issues, a failure to address substance abuse, gender issues and a strong dose of denial.

T•II CANN: What sort of support would you like to get from a national Title II group?

SW: I would like to see a good hard look taken of program administration at the local level. I think there needs to be more flexibility from the federal government on designing responses so that organizations in rural areas have more administrative support. I would like to contribute through an organization to continued advocacy on harm reduction issues. There ought to be federal money for needle exchange programs. I have a concern that too much focus is on the bottom line of “what you have produced” rather than tying together the continuum of education, prevention, outreach, case management, and treatment. We need to continually look at what we are doing since this epidemic is constantly changing. The new medications are great, but some people develop resistance or have side effects. Who knows all of this success could crash and we’d be back at square one, so we need to remain flexible in our responses.

T•II CANN: Talk to me more about getting people involved in designing a flexible response to the epidemic.

SW: As we have become more committed to getting people involved in our process, planning is fairly alien to most people. So we have spent time educating people about the issues involved and what the options of responses are. Often people felt alienated from the process thinking that once anything got done they would be dead, so now we educate them about the process so they better know how to make an impact on it. The New York State’s AIDS Institute has leadership training institutes on regional levels to teach people process, planning, advocacy, and skills building. It has been a terrific boon to people.

T•II CANN: So people have a better idea of how to advocate for their own needs and concerns?

SW: That’s the point, exactly.

T•II CANN: Thanks Steve.
Issues For Reauthorization

Across the country, non-profit organizations are beginning to plan for the second decade of the Ryan White CARE Act. Since the first year of Ryan White appropriations, the service system has changed but the epidemic remains. The federal program has helped to establish and develop a health and social service system for persons living with HIV/AIDS that is respected worldwide. Though the struggles with HIV/AIDS continue, virtually all health systems are in better shape today than a decade ago. Improved treatment modalities and the use of combination therapies have provided tremendous hope and success in the combat against AIDS. Deaths due to HIV/AIDS-related illness have dropped dramatically during the past few years. This should sound like good news right?

Yes and No. Disease is a tricky thing in the non-profit world. If an organization is too successful in fighting a disease, it can be dangerous to the organization. The American Lung Association (ALA) is currently struggling to reinvent itself despite its historical success. As the risk of lung disease became less of a concern due to the successful outreach and prevention programs, government and private foundations have dropped support for the ALA in recent years. Some may argue that this same “disinterest” may hamper the efforts to reauthorize Ryan White. The success of the Ryan White CARE Act could be its worst problem.

Concerns raised by a representative of an AIDS Service Organization serving the Hudson Valley New York region indicate that, although the medical system has improved, prevention efforts are struggling. Complacency is taking over. The increase in life expectancies has created a decrease in concern for infection. In recent studies of the local service system, the at-risk group, Men-Who-Have-Sex-With-Men, has seen an increase in unprotective sex. In some areas, the death rate due to AIDS may be decreasing, but the cumulative incidence (total number of new cases) is increasing. In addition, the continuing advances in treatment modalities is coming with an increase in resistant HIV viral strains. Many feel that the country is heading towards a massive increase in AIDS cases, despite the successes of Ryan White funding.

And what about the funding? Though advocates have successfully secured increases in federal appropriations for the Ryan White CARE Act in recent years, not all Ryan White funded (and dependent) agencies see increases in their grants. Many organizations must respond to stricter application guidelines and documentation requirements. Demonstrating continuing and/or developing need for Ryan White funding in light of service improvements is becoming more and more difficult and frustrating. Is there any end to this application trial? Not likely. Perhaps certain considerations could be addressed in the Ryan White Reauthorization.

According to agents of the Lower Hudson Network, Ryan White grants need built in a way to maintain services. Categorical grants are limited to a specific service for a restricted period of time. Ryan White grant funding should account for the increasing cost of providing care and for cost increases during the contract period and beyond. Lead agencies which administer the Ryan White contracts should provide assistance to recipients

The Internet As A Coalition Building Tool

The extent to which PWA’s can have an effective voice in legitimate grievance or complaint processes is a direct relationship to the local HIV/AIDS “network” and how active it is. That can start with individuals organizing and then making other links to really evolved statewide, or countywide groups of PWA’s willing to advocate. Usually AIDS service organizations have some mechanism to help with this process. As a group, a unified voice can speak out and will be listened to.

The lone client has a much rougher (and usually less effective) time of it. However - NEVER UNDERESTIMATE THE POWER OF THE INTERNET. Access to your computer will find you chat rooms, other local HIV concerned individuals, and “groups” can be formed in cyberspace - even in rural & isolated areas. If you haven’t already done so - make every effort to find out who near you shares your interests and concerns. A letter of complaint signed by one person is interesting. The same letter signed by 18 people is suddenly a “must respond now” tool. There are about 3,000 counties in the US. There are about that number of AIDS programs. Your state has many, and several may be active in or near your area. Find them. Become a client, meet the other individuals in person (or via the Internet) involved with these organizations. Then - make organized noise for changes, when needed.
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It is T•II CANN's position that the CARE Act has been one of the most effective emergency response programs ever created by Congress and that audits and reviews will show thousands of individually successful community-level programs and hundreds of thousands of individual success stories as a direct result of funding HIV care, medicines, and support in every State, District, and Territory. Should any irregularities not already being addressed appear during the audit, we believe they should be addressed and corrected immediately— as a matter of course.

T•II CANN will cooperate with the GAO and will lend it’s expertise (as we have in the past) upon request. Any improvement, however small or large, in Title II CARE act programs will extend scarce resources to additional people with HIV and AIDS who rely on community-based services for access to care, support, increased quality of life, and extended lives.

We will, however, strongly oppose any effort to subject any HIV programs to an agenda from any party whose central interest is not the care and support of people living with HIV.

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for building upon supplemental funding sources to increase program viability.

And then there’s prevention. Although the CDC provides support for prevention initiatives for HIV/AIDS and many other diseases (worldwide), the Ryan White CARE Act needs to foster integration among primary and specialty health care service programs and outreach and prevention efforts. The Lower Hudson, as well as the country, needs to revisit policies for disease prevention. Hopefully, by the end of the next decade of Ryan White, the success stories in the prevention community will be as bright as the those in the medical community.

CORRECTION
The toll-free number for Warmline was omitted from the article, “Rural Situations and Others Where Phone Access May be the Only ‘Safe’ Private Way to Get HIV/AIDS Information,” in the Mar/Apr issue of The Voice. The toll-free number is (800) 933-3413.

The Voice Editorial Board apologizes for any inconvenience this omission may have caused our readers.