

**MARCH 2005:**

**WELCOME TO HHSWATCH:** This is the first issue of *HHSWatch*, a new watchdog newsletter from CHAMP that will monitor and report on activities related to HIV prevention at Health and Human Services agencies, including CDC, NIH, HRSA and SAMHSA.

*HHSWatch* will be a resource for community members, policy advocates, researchers and anyone interested in more fully understanding and tracking the committees, panels and administrators whose recommendations and decisions affect our work.

*HHSWatch* is committed to providing an outlet for those concerned about infringements upon science-based HIV prevention and treatment, and will respect your wishes for confidentiality. If you are interested in contributing information or suggesting a story, please contact [champ@champnetwork.org](mailto:champ@champnetwork.org).

**ONGOING CONCERNS ABOUT DEBI PROGRAMS AND IMPLEMENTATION:** Community groups and policy advocates continue to raise concerns about the implementation of CDC-funded HIV prevention programs known as "DEBI projects" -- Diffusion of Effective Behavioral Interventions. Health departments and CBOs say they are getting inconsistent or incorrect information, which includes the following misstatements:

- DEBIs must be given priority consideration over non-DEBI programs;
- a certain portion of funded programs must be DEBIs; and
- any use of non-DEBI programs must be justified.

In addition, there has been little guidance on adapting the DEBIs to account for specific cultural and community needs while retaining "core elements." The 12 funded Capacity Building Assistance organizations (CBAs) can be contracted, through your CDC program officer, to provide assistance in making these adaptations. *For a list of CBAs, go to [www.effectiveinterventions.org](http://www.effectiveinterventions.org).* The National Association of State and Territorial AIDS Directors (NASTAD) has requested additional clarifications on behalf of health departments. *For more information, contact Leo Rennie at [rennie@nastad.org](mailto:rennie@nastad.org).*

*HHSWatch* will continue to track reports of conflicting or incorrect directions given by CDC. We encourage providers and public health leaders to contact us if you have anything to share; all identifying information will be kept confidential at your request.

**TELL CDC WHAT YOU THINK OF PEMS:** CDC continues to push community-based organizations (CBOs) and health departments to implement Program Evaluation and Monitoring System (PEMS), with a target date to begin data collection by January 2006. But they are proceeding with very limited community consultation. Many groups are concerned that PEMS -- which may link sexual behavior and other intrusive information to identity and HIV names reporting -- will impede their ability to reach at-risk clients. *It's not too late to let CDC know how this system will impact you, your clients, and your community.* E-mail Rob Janssen at [rxj1@cdc.gov](mailto:rxj1@cdc.gov) with your concerns.

**VERMONT ORGANIZATION JUST SAYS NO TO CDC RESTRICTIONS:** Vermont Cares, founded by volunteers in 1986, prioritizes peer outreach (both by those living with, or at risk of, HIV) as an effective way of reaching out in their largely rural state, allowing them to cover 10 out of Vermont's 14 counties with HIV testing, safer sex information and tools. In addition, they operate the state's only residential facility of people living with HIV, offer oral HIV testing from three offices, and provide needle exchange. In a state that provides no funding for HIV prevention services, Vermont Cares has benefited from many years of CDC funding channeled through their state Department of Health. *However, this vital organization has decided to decline prevention funding from CDC under new requirements.*

Outgoing Executive Director Kendall Farrell explained: "As with any federal dollars there have always been certain mandates or strings attached that we have had to weave into incorporating our programs. We have been fairly successful at that. But this year, as they started to talk about the new PEMS program and all the mandates that were coming down, after many discussion with board, staff, and our partners in the community, we realized there was no way we could continue to accept this money without totally shifting our programming, which would then compromise our mission."

Reasons for this decision cited by the organization include:

- After nearly two decades of honing their work on HIV prevention in a rural state, they do not believe that the DEBI models adequately address the dynamics of rural HIV prevention issues or provide room for innovations developed by Vermont CARES and peer organizations.
- Concerns that PEMS data collection requirements do not take into account the high level of stigma that makes people reluctant to take an HIV test; they believe that some of the PEMS questions are unnecessarily invasive and that unique identifiers are not a reliable system for tracking data in their region.

Farrell said, "You have one chance, one window of opportunity to gain someone's trust, to have a conversation where you are not asking invasive questions about how many anal encounters you have had in the last month. If you gain their trust, they will come back and yes, some of this PEMS

information is definitely helpful. But I think it is the approach that is everything with the initial contacts, and it has to be totally non-judgmental... You can word those questions as sensitively as you can, but they are just too invasive of questions to be seeking on the first date. And in rural states, even with unique identifier, if you have an African American woman from Swanton, Vermont, you may have disclosed right there or narrowed it down to 2 people."

"People who are engaged with HIV prevention work and services have not only an enormous amount of work but also the tremendous amount of bureaucracy we have to claw through. It's no wonder people are burned out so quickly," she concluded.

**CONGRESSIONAL HEARINGS TARGET HARM REDUCTION:** Rep. Mark Souder (R-Indiana), chair of the Government Reform subcommittee on Criminal Justice, Drug Policy and Human Resources, held hearings on February 16 titled "Harm Reduction or Harm Maintenance: Is There Such a Thing as Safe Drug Abuse?" Souder has led past attacks on comprehensive sex ed programs, and the witnesses he called testified against harm reduction programs -- including needle-exchange programs, which can only receive local, state or private funding in the U.S. due to the ongoing federal ban on funding. Democrats on the committee, including Rep. Elijah Cummings (D-Maryland) and Rep. Henry Waxman (D-California), demonstrated strong support for harm reduction programs, and clients of Housing Works attended, wearing buttons to protest the attacks.

But this hearing is likely to be just the beginning of a renewed attack on harm reduction. Drug Free America Foundation -- a 501(c)(3) group unaffiliated with the Partnership for a Drug-Free America folks who brought you "Just Say No" -- announced a conference at the European Parliament on the subject, and commended Souder, saying, "This hearing is extremely important because a number of young people are dying daily while thinking they can use deadly drugs such as heroin safely." Souder is also leading a proposal to make all US-based groups that support international drug treatment sign a pledge condemning harm reduction strategies. The *Washington Post* and the *New York Times* both strongly criticized these political attacks.

With the exception of Africa, one in three cases of HIV transmission are injection-related, making harm reduction a vital part of sound HIV prevention strategies. We need your help to defend and expand harm reduction and sterile syringe access -- please sign up for the CHAMP Alert list at [www.champnetwork.org](http://www.champnetwork.org) and also check out the Drug Policy Alliance's website, [www.dpa.org](http://www.dpa.org).

**CDC/HRSA ADVISORY COMMITTEE NAMES NEW MEMBERS:** HHS replaced six members on the CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment (CHAC) and named new co-chair in January. The committee, which is officially charged with assessing the two agencies' HIV

and STD activities, also makes recommendations about major policy decisions at CDC and HRSA. Former members Beny Primm, Dorothy Mann, Cornelius Baker, Gale Grant, Antonia Villarruel and Bob Fullilove have been replaced by the following people:

- Dr. Jean McGuire, Northeastern University and the former state AIDS Director for Massachusetts, will now serve as co-chair
- Teresa "Tiny" Devlin, Alaska Native Health Board and planning group
- Dale Anthony Edmonston, Dale House, Hempstead, NY
- Dr. Lydia R. Temoshok, University of Maryland School of Medicine, did early research on HIV in the military and secondary prevention
- Dr. Nathan M. Thielman, Duke Medical Center and a member of NIAID's advisory board
- Leuga A. Turner, LBJ Tropical Medical Center Social Services Department, American Samoa
- Dr. Priscilla L. Young, preventive medicine research consultant

The committee's next meeting is May 11-12. Public comment is accepted in person and in writing. *For more information about submitting comment, contact Ron Valdiserri at CDC, [rvaldiserri@cdc.gov](mailto:rvaldiserri@cdc.gov). HHSWatch will continue to monitor the committee's actions and recommendations.*

**SAMHSA BOWS TO PRESSURE, REINSTATES 'LGBT' TO WORKSHOP TITLE:** A workshop examining the risk of LGBT people for suicide was attacked by Substance Abuse and Mental Health Services Administration (SAMHSA) officials in February, who pressured the researchers to use more general language about "sexual orientation," and to avoid using the term "gender identity." Ron Bloodworth, one of the presenters, wrote an email to colleagues in which he called the censorship "intolerable" and cited fear of reprisals from federal funders. *"We have been timid about speaking out for fear that suicide prevention funding would be jeopardized," he wrote, "but failure to do so sends a dangerous message of complicity to the decision-makers in government who are responsible for this situation."* After the researchers' protest garnered attention from Rep. Barney Frank (D-Massachusetts) and major news outlets, government officials said they would support the original workshop title.

*HHSWatch is helping to collect information about this and other threatened censorship. Send your stories to [champ@champnetwork.org](mailto:champ@champnetwork.org)*

**SEEKING PRISON TESTING STORIES:** In response to the possibility of CDC forming a working group about routine HIV testing for prisoners, Barry Zack of Centerforce is seeking stories from people about their testing experiences inside prisons or jails. Please contact Barry Zack at [bzack@centerforce.org](mailto:bzack@centerforce.org) or (415) 456-9980.

*This issue of HHS Watch was reported and edited by Shana Krochmal and Julie Davids*