

Ryan White Reauthorization: Losing the Sense of Community

HHSWatch first reported on the controversies surrounding reauthorization of the Ryan White CARE Act over a year ago (see the August, 2005) issue, when we critiqued the set of reauthorization principles enunciated by HHS Secretary Mike Leavitt. The \$2 billion-plus Ryan White CARE Act provides critical treatment and care services for needy persons living with HIV. Besides direct medical care, its funds pay for a number of client support services. Ryan White also covers early identification of people with HIV through testing and counseling – its only direct connection to HIV prevention.

Congress has considerably moderated Leavitt's principles since they were announced. Meanwhile, a major controversy erupted concerning how Ryan White funds are distributed to states and municipalities. The Act as passed by the House establishes essentially flat funding for the next five years, with some of the money shifted from the huge established epidemic in states like California and New York, to areas where HIV rates have been raising quickly, mainly Southern and rural states. The new funding formula has split AIDS service organizations and governments according to whether their areas are winners or losers.

A central change in the funding formula involves a shift to counting states' total HIV population rather than only people with AIDS. The states' report on their HIV population was supposed to go into effect by 2007, according to the year 2000 Ryan White reauthorization. The new reauthorization bill gives states extra leeway by establishing a transition period through 2010. But there is a tradeoff: by the end of the transition period,

all states will have to report the count of "living names-based cases of HIV/AIDS." The states will need to record the name of each known resident living with HIV. This is a new requirement – the previous version of the Act did not specify how the HIV population was to be counted. The switch to names reporting has received little comment although it has a long, contentious history.

The CDC has strongly promoted names reporting in recent years as the only way to keep an accurate count of the epidemic. In a letter sent to state health departments in July, 2005 CDC director Julie Gerberding strongly criticized HIV reporting that assigned a unique numerical code for each individual (code-based reporting). She wrote, "HIV reporting using coded identifiers has not been shown to routinely produce equally accurate, timely or complete data to that produced using confidential name-based surveillance methods." Yet 17 states, including California, Illinois and Massachusetts had not implemented names-based reporting by the end of last year. In the past, many AIDS advocacy organizations have opposed names-based reporting as a governmental intrusion on privacy rights and a threat to confidentiality. It may discourage many persons from requesting HIV testing. The new Ryan White funding formula effectively ends the argument.

More discussion has revolved around a provision of the reauthorization bill requiring that at least 75% of the \$2 billion in annual Ryan White grants must be devoted to specifically designated "core medical services." These include outpatient and ambulatory health services, pharmaceuticals, oral health care, health insurance premiums, mental health and substance abuse treatment, and medical

case management. The core medical services requirement could restrict local communities' ability to provide support services such as food, housing, transportation, health education, client advocacy and legal assistance. The amount of money taken away from support services turns out to be small. Still, this new inflexibility reinforces the tendency to shift funds from AIDS service organizations to medical facilities. For one thing, prevention services directed at the CDC's priority target, HIV positive persons, will have to look elsewhere for any expansion of funds.

Prevention activities could be more directly impacted by a section of the bill that rewards states for instituting "opt-out" HIV testing of pregnant women (with "universal" testing of newborn babies) and/or opt-out testing in STD clinics and drug treatment centers. Opt-out testing is part of the new CDC recommendations for testing in medical facilities (see below). It allows HIV testing of patients as part of their overall medical care. Although patients may refuse testing, no special, explicit consent or pre-test counseling is required. (The "universal" testing of newborns mentioned in the bill would involve essentially mandatory testing for babies whose mothers are of unknown HIV status.)

This provision shifts \$30 million dollars per year from established CDC HIV prevention programs to a new "Early Diagnosis Grant Program." Pregnant women are supposed to be the target of two-thirds of this money, with STD and substance abuse programs receiving the rest. The states receiving these grants may use them for HIV prevention, but are not required to. Other allowable uses include HIV testing programs, efforts to link persons testing positive to treatment and care, and treatment of HIV-positive mothers and their babies. It is notable that this section of the bill contradicts the other section pertaining to funding for testing. The bill's Early Intervention Services title contains the classic requirements for confidentiality,

informed consent and counseling. For good measure the current bill adds hepatitis B and C to the required counseling topics.

The reauthorization bill passed the House by a lopsided vote of 325 to 98. Seventy-three of the "nay" votes came from California, New York, Florida and New Jersey. The Senate was not able to vote on reauthorization before the current electoral recess due to objections by the senators from New York and New Jersey, all Democrats. The senators are objecting to the loss of funds to their states. Unless the bill's supporters can muster 60 votes to override the objecting senators, reauthorization will have to wait to the next Congress, which could well witness a shift in power to the Democrats. Senators Clinton (D-NY) and Lautenberg (D-NJ) are meanwhile sponsoring a bill to extend the current year 2000 authorization through 2007.

New CDC Testing Guidelines: Leaving the Future to Take Care of Itself

Taken together, the names-reporting and opt-out testing provisions put new teeth into the CDC testing guidelines. States will have a strong financial motive to increase testing since the size of their HIV population will determine their Ryan White funding.

The pursuit of testing will largely take place in doctor's offices, clinics and hospitals. According to a Kaiser Family Foundation survey conducted last March, 93% of persons tested for HIV in the previous 12 months had their tests in medical centers. These facilities fall under the new CDC guidelines for HIV testing in healthcare settings. They recommend HIV testing as part of general healthcare and recommend an opt-out consent process with little counseling for those who test negative. The agency issued the final version of these guidelines on September 21.

The final version is only slightly different from the draft reviewed by HHSWatch in September. Among the significant changes is

that the agency has backed off a little in its position against pre-test counseling. Now, such counseling is merely “not required” instead of “not recommended.” The final draft does recommend making “informational materials” available to patients.

The basis for the CDC’s anti-counseling position continues to be based mainly on one 1999 article. That article contends counseling elicits no significant effect in HIV-negative persons (LS Weinhardt et al., American Journal of Public Health, 1999). Not only does that study actually come to the opposite conclusion, but researchers from the CDC itself later dismissed it for looking at only out-dated, information-based counseling methods (ML Kamb et al., American Journal of Public Health, 2000). Ironically, these are the same simplistic methods that the CDC is now advising healthcare facilities to adopt.

The final recommendations also clarify how often retesting should occur. Everyone in the United States from age 13 to 64 is supposed to be tested at least once. Even if heterosexual, people who change sex partners (or whose partners change partners) are included in the high-risk category that requires retesting at least annually. Also, anyone seeking care for a new STD should receive an HIV test as part of his or her work-up.

If the new guidelines are ever fully implemented, medical facilities will see a huge leap in the amount of testing they perform. According to a CDC survey in 2002, over 20,000,000 men and women aged 15 to 44 had had more than one sex partner of the opposite sex in the 12 months prior to the survey. Only about a quarter of them had been tested for HIV during that period. And only 38% of gay men and 23% of bisexual men had been HIV-tested in the previous 12 months. (These figures are from CDC’s 2002 “National Survey of Family Growth.”)

The guidelines may be intended to make HIV testing regular part of health care, but local health departments have realized that this is not just another test. Washington, DC is one place that already has started a program to routinely test everyone of a sexually active age. The coordination is a mammoth task. Marsha Martin, head of the District of Columbia’s HIV/AIDS division, told a Kaiser Family Foundation symposium in early October:

“I’m not sure that the CDC has fully appreciated what it has taken to even begin it here. Industry is involved in this conversation. The pharmaceutical companies and viral test companies are involved in the conversation... Our hospitals are on it. Our private industry is on it. Our community providers are on it, and this implementation of routinizing HIV screening is in the context of a task force that’s working specifically on implementation, and then that task force is engaged in discourse with the mayor’s [HIV/AIDS] task force, and then all of this is in conversation with the mayor. And so this is not just the health department and we’re implementing CDC’s guidelines. This is a comprehensive citywide health systems effort.”

There is considerable federal money to support testing programs, but little of it is new. The Ryan White reauthorization bill calls for \$219 million for the testing and counseling programs, an increase of \$25 million over 2006, but the House version of the HHS budget has cut this amount back to last year’s level. Also, the informed consent and counseling requirement in this section of the bill are stricter than the new CDC guidelines. Then there is the \$30 million in Ryan White grants given to states that allow opt-out in the circumstances described above. But with nothing in the bill requiring that this come from new funding, the money would likely be transferred from other CDC funds devoted to prevention and testing.

The one really new support for expanded testing is the president's "Domestic HIV/AIDS Initiative," a package of measures that includes \$93 million for purchasing rapid HIV test kits, plus care and prevention counseling for those who test positive. This amount was supposed to provide for the testing of 3 million Americans. Three million tests seems like a drop in the bucket given the CDC goal to test everyone once, and tens of millions of people annually, but it might be especially productive if targeted to high-prevalence populations. Indeed, the proposal focuses on African Americans in general, MSM of color and young MSM. It has special provisions for testing in prisons and drug abuse treatment centers. The proposed budget currently before the House of Representatives whittles this testing appropriation down to \$60 million.

Testing is just the first step in the process, though. The CDC estimates that there are a quarter million Americans who have HIV but don't know it. What would happen if routine testing identified most of them? Identification does not guarantee treatment: Another 250,000 Americans know they have HIV yet receive no care for it. Then there are the 40,000 Americans who acquire HIV every year, a number that so far has resisted reduction. The care costs for all these people depend on their stage of disease. Sooner or

later, they will all need anti-HIV drugs, and treatment then will cost over \$20,000 per year. The total medical bill is very large; it rivals the current total federal government expenditures for HIV care (about \$12 billion in 2006 including the Ryan White CARE Act grants). Still, it is manageable if there were sufficient planning.

In her symposium talk, Marsha Martin said, "It's not just about the test... [W]hen you screen for HIV, you have to talk about your risk for HIV. You have to talk about how you prevent it. You have to talk about what it means if you are positive. And so it's a way for us on the advocacy side to have our conversation reach areas that haven't been reached."

But that kind of discussion is precisely what the new CDC guidelines discourage. The guidelines advise healthcare centers to test patients and send them on their way – to a world that is ill-prepared to receive them. Under the finalized guidelines, those who test positive or negative may well miss an introduction to the education and empowerment necessary for navigating such a world.

This HHS Watch was written by David Gilden.

HHSWatch, a watchdog newsletter from CHAMP, monitors and reports on activities related to HIV prevention at Health and Human Services agencies, including CDC, NIH, HRSA and SAMHSA.

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