The NAPWA/TAEP HIV/AIDS Policy Report

Securing the Legacy of Ryan White: Lessons From a (Nearly) Forgotten Report

September 1, 2008 By David Ernesto Munar

How might the United States get more bang for its buck in HIV/AIDS services? Pondering this question, members of Congress added a provision to the Ryan White CARE Act legislation in 2000 to commission a blue-ribbon panel to investigate the issue and report their findings.

Over the course of three years, a panel of experts—including some of our nation's leading doctors, lawyers, social workers, service providers and policymakers—deliberated and developed what would become one of the most important, and yet summarily ignored, federal recommendations ever to emerge in the history of HIV/AIDS policy in America.

With its congressional mandate, the Institute of Medicine—a branch of the National Academy of Sciences—empowered a group of experts to evaluate and recommend how federal safety-net HIV/AIDS services might be better organized and delivered to achieve the best possible value for the cost. The group began its work in early 2002 by defining the scope of its inquiry, establishing parameters for evaluating various options, and testing different ideas against established criteria.

As the study was conducted discreetly, few in the AIDS advocacy community had any hint of the magnitude of the panel's ambitious recommendations. That is, until the report, titled *Securing the Legacy of Ryan White*, was unveiled in May 2004. To the surprise of many, the report called for a radical reorganization of federal HIV services by creating a new, national entitlement program for low-income Americans living with HIV/AIDS.

The new plan, as envisioned by the panel, would offer beneficiaries a standardized benefits package consisting of primary care, prescription drugs, inpatient services, substance-abuse treatment, mental health services, case management, obstetrics and family planning, and prevention services. The program, which would be entirely federally funded, would be administered by those states that elected to offer it; those states' administrative costs for the plan would then be covered by the federal government.

Low-income Americans with HIV would automatically qualify for the program with-out having to meet disability or other categorical requirements currently imposed on Medicaid applicants.

Services would be free for HIV-positive Americans with annual incomes at or below 250 percent of federal poverty. Otherwise-eligible applicants at higher incomes would be permitted to use medical expenses or pay premiums to become eligible.

While increasing federal HIV spending by $5.6 billion over 10 years, the plan is intended to reach an additional 60,000 people who currently lack access to needed HIV medical care. Better negotiations with pharmaceutical companies and other offsets—including a partial redirection of Medicaid, Ryan White and other federal funds—would lower the overall cost. By reducing new infections and inpatient expenses, the program will eventually "pay for itself," the report says.

Report authors argue that a degree of Ryan White CARE Act services would still be needed, despite development of the new program, to meet the health and social service needs of noncitizens who would be ineligible for the entitlement program. In addition, the Ryan White CARE Act could provide supplemental services including community outreach to ensure everyone eligible gains access to the new system.

The report explains the many options the panel evaluated and subsequently rejected as ill-suited to rationally and cost-effectively improve health outcomes for low-income and uninsured HIV-positive Americans. While recognizing the potential benefits of scaling up the Ryan White CARE Act, extending Medicaid to nondisabled HIV-positive people or building enhanced HIV services onto Medicare, the panel wrote that geographic variation, inadequate provider reimbursement and steep cost-sharing requirements made each option inferior to a new entitlement program.

"The health care delivery system as offered in the IOM report would pro-vide enormous benefits in lives saved, health maintained, and medical and socioeconomic costs deferred or avoided," wrote 30 AIDS organizations in a 2004 letter to the CDC/HRSA AIDS Advisory Committee. "It would also result in significant public health benefits by removing barriers to HIV testing and reducing infectivity and new HIV infections. Finally, it would help to alleviate existing strains on the Ryan White CARE Act, allowing it to fill gaps in care and provide the range of essential support services required to meet the complex challenges created by HIV disease."

While originally intended as a guide for the 2005 reauthorization of the CARE Act, the report had little to no influence in the heated congressional negotiations that shaped the 2006 Ryan White CARE Act law. Instead, a disunited AIDS advocacy community and an equally divided Congress pieced together a complex legislative package that is reshaping CARE Act services across the country. But the wisdom of the IOM report need not be lost. Achieving rationality in the organization and delivery of HIV services can and indeed must be brought to bear as Congress revisits the Ryan White law again in 2009. In addition, the report contains important lessons for a national debate on health care reform.

Lessons From the IOM Report

A rational health system for low-income people with HIV must provide access to continuous, uninterrupted and high-quality health services that are portable and accessible across the country.

A minimum benefits package is necessary to address the health needs of low-income people with HIV.

Adequate and standardized reimbursement rates (set at Medicare levels) must be provided to ensure a sufficient supply of HIV health care providers across the country.

A national HIV health care plan must leverage savings from aggressive negotiations with pharmaceutical companies and factor cost-savings from decreased emergency and institutional care and averted new infections.

Delaying health care coverage until an individual becomes disabled by HIV/AIDS is inconsistent with U.S. public health guidelines, costly and irrational.

Of course, the IOM proposal does have one significant and obvious flaw: It envisions the development of a national health care system designed entirely for low-income Americans living with HIV/AIDS. As national health care reform gains political traction, one can only hope decision makers look to HIV service systems and other networks serving people with chronic health conditions for innovative models and ideas that will serve all low-income populations in the United States. We must do everything we can to reverse current trends, as there are 6 million more uninsured Americans today than there were in 2000, with close to 50 million people currently uninsured in the country.

Short of demanding national health care reform, HIV advocates and policymakers must be guided by the 2004 IOM report in developing future HIV health care policy. “Current programs are characterized by limited state budgets, limited services and a confusing array of eligibility requirements—all of which undermine the nation’s goals for preventing and treating HIV/AIDS,” said Lauren LeRoy, president of Grantmakers in Health and head of the panel that drafted the report. “Failing to provide these cost-effective, lifesaving drugs to all Americans who need them, including individuals who lack insurance or cannot afford them, is indefensible.”

Several studies have established that implementation of the IOM recommendations can reduce new HIV cases, improve health outcomes of those living with HIV and lower HIV-related deaths in the U.S. by as much as 50 percent. A new administration in Washington, DC, provides an important opportunity to advocate for implementation of the IOM recommendations and finally achieve guaranteed health care for everyone.

Learn more about the 2004 IOM report, Securing the Legacy of Ryan White, by downloading the fact sheet at napwa.org/resources/.

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