

Confidentiality, Consent Remain Central as Policymakers, Activists Address Changing Face of HIV/AIDS

By Lisa Kaeser

Scientific advances are fundamentally changing perceptions about HIV/AIDS. Although a cure is not yet in sight, new treatments are permitting HIV-infected individuals under some circumstances to live longer, “healthier” lives; in the case of a pregnant woman infected with the virus, treatment very often also can prevent transmission of the disease to her fetus. Yet, the social stigma of having AIDS—or even being HIV-positive—and the pervasive, extreme discrimination that can result by no means have been eradicated in this country.

These dual realities are challenging policymakers and activists alike as they confront the changing face of the HIV/AIDS epidemic half-way into its second decade. Because the disease is beginning to be seen as chronic and treatable rather than inevitably and imminently fatal, calls increasingly are being heard to “regularize” it from both a clinical and public policy viewpoint. For example, the historic position taken by most AIDS activists that people need to be extensively and carefully counseled before being tested for HIV—and that for many a decision not to be tested may be realistic and entirely appropriate—is being challenged by the notion that HIV-infected people have not only a right but also an obligation to know their status so that they can obtain treatment for themselves and protect others from infection.

This shift is leading to stepped-up calls for “routine,” if not mandatory, HIV testing—not only of individuals

deemed to be at high-risk on the basis of their behavior, but all people under certain circumstances, such as pregnant women or newborns. Similarly, greater attention is being paid to the issue of partner notification, on the grounds that HIV/AIDS now should be treated as any other communicable disease. In light of the changing demographics of the disease, the federal government and the states, recognizing the need for reliable information with which to plan, are also debating ways to gather data on those who are infected.

These efforts, however well-intentioned, raise major concerns around issues of confidentiality and informed consent. Given the ongoing stigma of HIV infection, many people’s willingness to be tested may largely depend on whether they trust that the results will remain confidential. Accordingly,

Amid calls to “regularize” it from both a clinical and public policy viewpoint, the social stigma of HIV/AIDS persists.

moves toward routine or mandatory testing, heightened emphasis on partner notification and the possibility of reporting HIV infections *by name* to state authorities raise alarm bells for many in the AIDS community. AIDS advocates are concerned that people who believe that they may face negative consequences—such as domestic violence or loss of home, job or health insurance—from the knowledge that they are HIV-positive will forgo seeking needed health care rather than risk an HIV test.

Testing Pregnant Women

In general, the health of a person with HIV can be maximized with earlier treatment. For a pregnant woman, early therapy may not only extend her health but also prevent transmission to her fetus. A breakthrough study published in 1994 showed that administering zidovudine (ZDV, formerly known as AZT) to pregnant women could reduce the transmission of the virus by about two-thirds. (It is estimated that 6,000–7,000 HIV-infected women give birth annually in the United States, and that 14–33% of infants born to untreated HIV-positive women contract the virus perinatally.) These findings revolutionized the accepted standard of care for pregnant women with HIV; guidelines were quickly developed by the Centers for Disease Control and Prevention (CDC) that urged universal counseling of pregnant women, followed by voluntary testing and treatment with ZDV if indicated.

The vast majority of states have moved to implement the 1995 guidelines to some extent through new laws or policies. According to CDC, rapid implementation has helped decrease the rate of perinatally acquired HIV by 43% between 1992 and 1996. *Acceptance* of treatment by HIV-positive pregnant women following voluntary testing apparently is not a problem: CDC reports that in some states the percentage of pregnant, HIV-positive women who were offered ZDV increased from 27% to 85%, and that fewer than 5% of women offered the treatment refused it. However, some AIDS advocates caution that significant barriers remain to being *tested* during pregnancy—carryovers from the earlier days of the AIDS epidemic when testing often seemed superfluous in the absence of meaningful treatment.

To get a clearer picture of how effective the states have been in reducing perinatal HIV transmission, Congress in 1996 amended the Ryan

White CARE Act to require the Institute of Medicine (IOM) to conduct an evaluation of state efforts and an analysis of existing barriers. In October 1998, the panel convened by IOM released its report, documenting the ongoing tension between the reluctance on the part of many women to be tested and the urgency of preventing perinatal HIV transmission. The panel recommended what is widely viewed as a compromise between purely voluntary and outright mandatory testing of pregnant women: that “universal” HIV testing with patient “notification” (but without pretest counseling) become “a routine component of prenatal care.”

The goal of encouraging all pregnant women to be tested is to provide treatment opportunities at the earliest possible moment and, if advisable, further reduce the likelihood of transmission by allowing for a planned cesarean delivery. Laudable though this goal may be, the IOM panel’s recommendation raises a number of concerns. Chief among them is the panel’s strong emphasis on routine testing of all pregnant women with mere notification of their right to opt out. Absent counseling followed by written informed consent, AIDS advocates say, women might not fully understand the implications of being tested for HIV or even the meaning of a positive result.

Further, in place of the comprehensive, individual pretest HIV counseling that traditionally has included a major risk reduction component, the panel suggests that “outreach” and “group education programs” could provide similar information in a more efficient way. Advocates for low-income groups have reacted strongly to this recommendation, saying that health care providers who serve these groups—already pressured to reduce the time spent with their patients—will not feel compelled to continue what has been viewed as standard pretest counseling.

Moreover, the issue of access to treatment, or the lack thereof, following an HIV test that may not have been fully voluntary raises real ethical dilemmas, especially when uninsured and impoverished pregnant women are concerned. Recognizing that the current mix of public- and private-sector health care services and insurance coverage varies enormously from state to state—and is completely inadequate in many—the IOM panel recommends that regional perinatal testing and treatment centers, and “appropriate resources,” be established to facilitate care. Whether those resources will ever become available, of course, is an open question.

Newborn Testing

A major, related HIV controversy concerns testing newborns. Prior to the 1994 publication of the ZDV study, newborns were tested for HIV only for surveillance purposes, but more recently, testing newborns has come to be seen as a diagnostic tool in its own right.

AIDS activists and many ethicists have long opposed newborn testing, pointing out that it only permits *maternal* antibodies to HIV to be

As a “compromise” between voluntary and mandatory HIV testing of pregnant women, the Institute of Medicine has called for “universal” testing as a routine component of prenatal care.

measured; the child’s independent HIV status cannot be determined for weeks or longer following birth. Thus, they argue that what is termed “newborn” testing is in reality a backdoor approach to testing the woman *without her consent*—opening the door for her potential prosecution in states that criminalize transmission. They also traditionally

have argued that, with the notable exception of counseling women not to breastfeed, little can be done after birth to prevent the infant from acquiring the virus. Proponents of newborn testing have countered that a woman whose infection was not diagnosed prior to delivery at least needs to know whatever can be known about her newborn’s HIV status at the time of birth so as to be prepared to provide care should the infant become ill.

The momentum for mandatory newborn testing may increase in light of new research demonstrating that ZDV treatment can significantly reduce mother-to-infant HIV transmission if it is administered within 48 hours—or even more—following birth. (So far, New York is the only state to mandate testing of *all* newborns, but Indiana moved this year to allow physicians to test newborns without the consent of their parents in some circumstances.) At the same time, if prenatal testing actually becomes near universal—as IOM recommends—the perceived need for newborn testing may diminish over time.

Partner Notification

One reason commonly cited for why women do not seek HIV testing for themselves or their babies is fear that their sexual partners will be notified. Since the early 1930s, when antibiotics first became available, and diseases such as syphilis became curable, state governments have required that the sexual partners of infected individuals be notified to prevent further spread. However, partner notification for HIV has been a more difficult matter for a number of reasons: The disease is still not curable—and meaningful treatment is not yet universally available; social stigma and the potential for discrimination—and even criminal prosecution—are still associated with it; and its long incubation period often inhibits a person’s memory or ability to locate a partner.

Nonetheless, since 1988 CDC has required states receiving HIV prevention funds to have partner notification programs in place. As of 1996, the Ryan White CARE Act requires the states to make “good faith” efforts to notify spouses of infected individuals. The majority of states have already acted by strengthening their programs, increasing funding for partner notification activities and improving confidentiality protocols. However, some in Congress feel that the states are not moving quickly enough. Pointing to reports showing that a majority of infected individuals do not tell their partners, Reps. Tom Coburn (R-OK) and Gary Ackerman (R-NY) introduced federal legislation last year that would place new requirements on states and health care entities to carry out partner notification programs.

Coburn and Ackerman argue that HIV/AIDS should now be treated much as any other communicable disease, and that the importance of notifying partners in order to help them seek treatment and prevent further spread of the disease far outweighs concerns about discouraging testing and confidentiality. Opponents of the bill argue that partner notification should not be the subject of federal law—at least not without waiting to judge the impact of similar measures in the states. Reproductive rights advocates are also concerned about the precedent the bill might establish for federal regulation of other health services such as abortion.

HIV Reporting

A key goal of public health efforts around HIV/AIDS is to accurately monitor the extent of HIV infection. This information, long tracked for full-blown AIDS cases, is essential in many aspects of planning, from developing prevention programs aimed at reaching special populations to the actual distribution of service dollars. While there is general agree-

ment that collecting such information is important, there also is burning controversy over how it should be done: whether the *names* of infected individuals should be reported to the state—and whether states have the ability to keep such information confidential—or whether a *unique identifier* system can be used to gather sufficient information without revealing individual names to the state.

Supporters of the unique identifier system (for example, a 12-digit code made up of the last four digits of a person’s social security number, a six-digit date of birth, and one digit codes for race/ethnicity and sex) say that the system gathers information that is perfectly adequate for making funding allocations and related decisions. The fact that the data collected may be somewhat less precise than actual names is a small price to pay, they claim, for the decreased risk of violating individuals’ confidentiality; they also point out that even the strictest confidentiality laws carry penalties that hardly suffice for disclosure of a person’s status in certain situations. Unique identifier proponents further argue that merely knowing that a state list of names exists may be enough to discourage testing among those who already distrust government, especially among the low-income or minority groups that might be at highest risk.

Proponents of names reporting disagree, saying that the states need better information, as well as the ability to follow up on reports, in order to make efficient funding and policy decisions. They contend that numerous protections have long been established within state public health systems to ensure individuals’ confidentiality and that there have been few, if any, breaches. In fact, they argue, the unique identifier system is far from foolproof since health care providers are required to keep backup “logs” so that a surveillance officer can double-check the

information reported, thus increasing the chances of inadvertent breaches of confidentiality.

The CDC is scheduled to take a formal position on HIV information collection early in 1999. In the meantime, agency representatives have been forthright about promoting the names reporting approach while, at the same time, arguing that *anonymous* testing sites should also be maintained so that those who distrust “the system” will not be deterred from seeking testing.

Anonymous testing permits individuals to be counseled and tested for HIV without even the health care provider being able to link a name

Should the names of HIV-infected individuals be reported to state governments, or is a system of “unique identifiers” sufficient?

with a test result. Although follow-up is not possible and little useful demographic information can be gathered (since some people are tested more than once), research indicates that the availability of anonymous testing encourages people to seek testing earlier. (Home tests, while promoted because they are anonymous, do not carry the benefits of immediate, personal pretest and posttest counseling.)

Most of the 29 states that currently require names reporting (only two use unique identifiers) also permit anonymous testing, a position likewise strongly supported by the IOM panel. Nonetheless, the Coburn-Ackerman bill would require all states, in order to continue to receive federal AIDS funding, to establish names reporting systems and prohibit anonymous testing. ☹