AIDS and Health Scare Reform

October 1, 1994 By Bruce Mirken

Larry Day's death certificate says he died from a barrage of AIDS-related infections that finally wore out his weakened body. But friends say what killed him was nothing less than the U.S. health care system. Day's private health insurance ran out six months before he qualified for Medi-Cal (California's version of Medicaid, the government-funded health insurance for the poor). He spent the last part of his life in a sort of health care Twilight Zone. When he needed good care the most, he spent a day-and-a-half lying on a gurney in a hallway of overcrowded, underfunded Los Angeles County Hospital, a public facility with conditions the *Los Angeles Times* onced described as "third world."

Day's condition was misdiagnosed, his pleas for tests were ignored and his health went into a tailspin from which he never recovered.

Larry Day's plight is far from unique, however. While politicians talk about people falling between the cracks in the health care system, people living with AIDS often experience those cracks as gaping holes. One study found that PWAs are eight times more likely to have lost their health coverage than those without AIDS. A full 40 percent of Americans with AIDS rely on Medicaid, while another 30 percent have no health coverage at all.

People with HIV have a life-or-death stake in the battle over health care reform but lobbyists for AIDS organizations have been vastly outgunned by the insurance industry, drug companies, the American Medical Association and other health-industry interests. As the political war reached a climax in Washington, it remained far from clear whether a bill that achieves even the bare minimum that AIDS lobbyists and activists consider essential would ever reach President Clinton's desk.

Although AIDS organizations have sometimes used different phrasing when enumerating their health care reform priorities, AIDS activists have generally agreed on broad principles they consider crucial. While more nuts-and-bolts concerns regarding the details of any health package are also important, AIDS lobbyists have generally agreed that those details will have very little relevance unleess several big-picture items are firmly in place.

Because PWAs are generally considered undesirable risks by insurers, AIDS activists are most adamant that any proposal must guarantee universal coverage. They fear a weakened definition of universal coverage: The bill proposed by Senate Majority Leader George Mitchell and endorsed by President Clinton would accept coverage of 95 percent of Americans as universal. People with HIV,

says San Francisco AIDS Foundation lobbyist Paul DiDonato, are “disproportionately represented in terms of people who are uninsured, underinsured and at the bottom end of the health care ladder.”

“When you talk about 95 percent coverage,” says AIDS Action Council lobbyist Christine Lubinsky, "I think that [the other] five percent is our people with AIDS. Damn it, everybody means *everybody*.“ Most advocates also agree that employers should pay the majority of the cost for their employees’ coverage, with subsidies to help small firms and government funding to take care of the unemployed. This example of employer-based mandates, AIDS advocates believe, are essential to providing universal coverage, since there is no political support for broad-based tax increases. Without mandates, Lubinsky says, ”there just isn’t the money to do it." Out-of-pocket costs -- such as co-payments and deductibles -- should be based on income and structured to avoid punishing those who happen to be sick.

To cover the spectrum of needs of people with AIDS, the basic benefits package of a health care reform law should include all medically necessary home health care: Inpatient and outpatient services, home health care, long-term care, hospice care, prescription drugs and substance abuse and mental health treatment. The fine print will be crucual, since details such as off-label use of prescription drugs and expenses associated with experimental treatments are vital in AIDS care. Henry Waxman, a California Democrat, is fighting to include these benefits. “It’s critically important that people with HIV know they’re getting a guaranteed benefits package and that the package includes prescription drugs and home- and community-based care. Without a guaranteed package, these benefits might not be covered,” Waxman says.

Freedom to choose a physician is crucial to getting state-of-the-art care, as anyone with HIV who has suffered under an AIDS-ignorant physician can attest. Some reform proposals would coerce low-income people into health maintenance organizations (HMOs) or managed-care plans that often limit choice of providers.

AIDS lobbyists consider it imperative that Congress not interfere with state experiments. States must be given freedom to enact a more comprehensive health care plan than one likely to be passed on the federal level. Hawaii already has in place a system more sweeping than one that would be created by any of the bills now before Congress. California has an initiative on this November’s ballot, Proposition 186, that would set up a Canadian-style single-payer plan -- an approach in which the federal government replaces private insurers and that many AIDS activists consider the only sure way to provide comprehensive care to all at a reasonable cost.

Project Inform’s Martin Delaney puts it this way: “The only way you’re going to get health care reform without coming fown on services is to squeeze out administrative costs. And no matter what route you take, it always leads you back to the single-payer plan.” AIDS advocates hope that the U.S. might eventually follow the example of Canada, which adopted its single-payer system one province at a time.

In the early glow of optimism surrounding President Clinton’s January introduction of his health

care proposal, AIDS advocates were upbeat. But by the time August began and the make-or-break Congressional votes approached, that optimism had eroded, replaced by growing concern over that DiDonato calls “a dramatic slide to the right” in the health care debate. The original Clinton plan was no longer on the table and speculation centered on how severely the final package would be scaled back. AIDS lobbyists began to ponder a once-unthinkable possibility -- what finally passes may actually make things worse for people with HIV.

Only House Majority Leader Richard Gephardt has written a bill that meets PWAs’ needs and has any chance of passage. Gephardt’s bill included a mandate that employers pay 80 percent of their workers’ premiums, a major expansion of Medicare to take care of the unemployed and a solid benefits package largely based on current Medicare benefits with prescription drugs added. “There are a lot of good things for PWAs in the House bill,” says Steve Morin, senior legislative aide to San Francisco Democrat Nancy Pelosi. AIDS lobbyists generally agree. A staffer with the House subcommittee on Health and the Environment who has been actively working on health reform points out that Gephardt’s bill is really quite good for people with HIV. “It pays for the ancillary expenses of experimental drugs and it pays for off-label drugs,” the staff member says.

But Morin and others are furious that Clinton undercut the Gephardt bill’s already-tenuous chances by indicating no preference between it and a far less complete bill proposed by Senator Mitchell. “Clinton,” Lubinsky says glumly, “has sent a message that he’ll sign anything.”

Mitchell’s bill, they argue, is defective -- starting with the fact that it fails the universal-coverage test. Employer mandates that would require businesses to pay just half of their workers’ premiums would kick in only if 95 percent of Americans remained uncovered by the year 2002, and only in states that failed to meet the 95 percent standard. And though the language wasn’t entirely clear, it appears that people would be counted as insured if they purchased a very-high-deductible policy that would effectively give them no coverage at all except in the case of catastrophic illness.

Worse, the Mitchell bill includes no guaranteed package of benefits. Instead, a commission would be appointed to define what coverage would be offered -- a prospect Bill Skeen of AIDS Project Los Angeles calls “kind of scary” -- with no promise that the needs of people with HIV would be met. Although Mitchell promises states the ability to adopt single-payer plans, Lubinsky cites fine print that she fears would have a chilling effect on such efforts. And deductibles and co-payments would be set up in a way that would effectively force moderate-income people into HMOs or managed-care plans.

PWAs being shoved into HMOs? Treatment advocates around the country often butt heads with HMO-type plans. Jeff Getty of ACT UP/Golden Gate describes a recent encounter with HealthNet in which, he charges, the HMO only agreed to authorize a prescription for combination therapy with AZT and ddI when Getty threatened them: “I have a crystal ball and in it I see people from ACT UP chaining themselves to your furniture.”

But Washington, D.C., is a strange world. AIDS activists have to hope Mitchell’s plan, inadequate as it is, will pass relatively intact. Expected amendments would likely strengthen the plan rather

than weaken it and if the Senate doesn't pass *something* the whole process will die. If the House passes the Gephardt bill, the stage is set for a House-Senate conference committee to iron out the differences, from which something acceptable might emerge.

But as mid-August approached, things looked increasingly shaky in the House. By most counts, Gephardt remained at least 50 votes short of the total needed for passage and a worried Democratic leadership put off floor debate on health reform while reportedly keeping a much weaker bill on hand as a possible substitute.

The Republicans are not sitting on their thumbs through all of this. The GOP leadership, joined by some conservative Democrats, continues to maintain that a major overhaul of health care is unnecessary and that it would be foolish to tamper with what Senate Republican leader Robert Dole insistently calls "the greatest health care system in the world."

The only real problem, Republicans say, is one of availability; and that problem can be solved, they say, by a package of insurance reforms coupled with limited subsidies and incentives to help the poor buy insurance.

AIDS advocates actually strongly support a number of provisions put forth by conservatives in their plans. Some proposals bar insurers from denying coverage to people with pre-existing conditions, for example, or establish community rating schemes under which everyone pays the same premium, regardless of age or health status. But often, as in Senator Dole's bill, the reforms are offered in watered-down form. For example, Dole would have allowed insurance companies to refuse a claim for a pre-existing condition for up to six months under group policies and up to a year for individuals.

But AIDS activists point with alarm to New York State's experiment with similar reforms. In 1992, the state put into effect a sweeping community rating plan that was strongly supported by the HIV community. Many activists are now convinced that such reforms can only work if everyone is brought into the system, creating a large enough pool to spread the costs of the sicker individuals who were previously locked out. New York's reforms made no such attempt at universal coverage.

The reform wasn't a complete disaster. Karen Timour of ACT UP/New York's Insurance and Health Care Access Committee points out the positive. "A lot of people who couldn't buy insurance before now have the opportunity." The downside is that their choices are now severely limited. "We got community rating and open enrollment," Timour says, "and the insurance industry left the state." Most commercial health insurers stopped selling policies altogether, she explains, leaving only Mutual of Omaha and Empire Blue Cross/Blue Shield. The lowest deductible available from Blue Cross is now $1,000 while Mutual of Omaha offers no deductibles below $5,000.

"Conservatives are espousing community rating and open enrollment as all we need," says Timour. "New York's experience is an example of how that's completely false."

"Money," the late California politico Jesse Unruh once observed, "is the mother's milk of politics."

AIDS lobbyists learned that quickly this summer, as they were vastly outgunned and outspent by business, insurance and health-industry interests fighting to keep health reform from touching their particular piece of the $7 trillion health care pie.

It wasn't for lack of trying. AIDS Action Council devoted one quarter of its roughly $2 million annual budget to health reform efforts and several major AIDS service organizations, including Gay Men's Health Crisis in New York City, AIDS Project Los Angeles and the San Francisco AIDS Foundation, committed significant resources as well.

But the HIV community's effort was dwarfed by the big-money interests involved. All have blanketed the Capitol with hundreds of lobbyists, DiDonato says. "We'll have four or five of us while everybody else is roaming the halls in packs."

Campaign contributions -- the mother's milk Unruh referred to -- tell a similar story. From January 1993, when the current session of Congress opened, to May of this year, political action committees (PACs) representing physicians and other providers gave $4.8 million to congressional campaigns. Pharmaceutical and health-equipment company PACs chipped in $2.2 million. Insurance PACs coughed up $5.3 million. But the only national AIDS PAC, the recently formed American AIDS Political Action Committee (AIDSPAC), was too new to have made any contributions at all during that period. AIDSPAC has now begun disbursing what it expects to be a total of $50,000 in contributions for this election.

One of the key difficulties AIDS lobbyists have faced is the need to focus on big-picture items such as universal coverage while still keeping an eye on the huge number of nuts-and-bolts details that can be crucian for people with HIV. The tiny number of lobbyists further frustrates their ability to keep track of mammoth bills that sometimes run to $1,400 pages or more of intensely technical language.

Details of the benefits package -- if the final bill in fact specifies one -- are particularly crucial. Virtually any one area of care, from diagnostic and lab services to home health, hospice and long-term care, can be critical to both survival and quality of life.

One example frequently cited by AIDS advocates is coverage for prescription drugs. Coverage must be adequate, without high co-payments or deductibles that could keep people with HIV from getting needed medicines. That's just the beginning.

Use of drugs off-label -- that is, for conditions other than those for which they have been officially approved by the Food and Drug Administration (FDA) such as using fluconazole to prophylax against thrush -- is a constant source of tension between PWAs and their insurers. One survey of 387 physicians found that fully 40 percent of their HIV-related prescriptions were for off-label uses; 81 percent of study participants were on at least one off-label drug. Although virtually everyone, including the FDA, acknowledges that its labeling does not necessarily reflect the best clinical practice, insurers regularly balk at paying for off-label uses. So far, only California has a law requiring insurers to pay for off-label treatments as long as there are published studies to back up

such use. Inclusion of similar language in a national health plan could literally become a life-and-death issue for many PWAs.

What does this all mean? We may not know for a year. Clinton, dramatically altering his priorities, spent the make-or-break week of health care reform debate strong-arming Comgress into passing his crime bill -- an issue more likely to preserve Democratic Congressional seats as most Americans cool to the idea of radical health reform. In the meantime, Congress is hinting that it will pass on a major health care overhaul -- and opt for exactly the New York State-style insurance reform that many PWAs are now decrying as a failed experiment.

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