Dissing Disability Queens

Big-name activists are breaking ranks to blow the whistle on gay HIVers' riding the disability gravy train into the fast-lane lifestyle. But up ahead the insurance industry has set a speed trap.

October 1, 2001 By Lawrence Goodman

Robin Lambert leads a good life. Each morning he wakes up in his two-bedroom colonial in Portland, Maine, and takes his hound dog, Harley, for a walk. He regularly heads off to the gym for an hour-and-a-half workout and on weekends swims in the Atlantic. "I push myself as much as I can," he says. He's 51, tested positive in 1992, volunteers as a speechwriter for a local congressional candidate and is on the market for a husband. Every month or so, he has a date, hits a nightclub to dance. Then there's the cushiest part of Lambert's life -- he pulls in $70,000 a year without having to work.

No matter how buff and busy Lambert may be, he says that the side effects from all his anti-HIV meds -- daily bouts of diarrhea, nausea or fatigue -- prevent him from holding down a 9-to-5 job. In 1996, overcome with fatigue, a viral load over 1 million and a CD4-cell count of 10, and convinced that he was on his way out, Lambert abandoned the long hours and high pressure of a human-resources executive and filed for private disability benefits. Since then, he concedes, triple-combination therapy has dramatically improved his health to the point where he has enough energy for a rich, full life. "Some people say, 'You look great. There's nothing wrong with you,'" Lambert says. "But I'm really not capable of going back to what I was doing. I wish it was different, but it isn't."

In a 1999 sign of increasing industry crackdown, Lambert's insurance company tried to cut off his benefits, claiming he was no longer disabled. But the HIVer fought back and won his case. Still, Lambert's disability-supported days may be numbered. As a significant number of back-to-health HIVers -- many of them affluent gay men in their 30s and 40s -- resist the back-to-work ethic and spend their disability checks less on Lambert-like volunteerism than on fast-lane hedonism, a bitter backlash is brewing. What's most surprising is that the shots are being fired not by the chronic right-wing cranks but by big guns right here at home. New York City's Howard Grossman, MD, a leading AIDS doc whose bona fides include ACT UP, GMHC and Visual AIDS, was the first to go public to *POZ*, decrying a change in the community whereby the hard-won benefits of the late '80s are now seen by some gay men as privileges owed them simply because they have HIV, ill or not. "There's a sense of entitlement: 'I'm going to get sick, so I should get and get and get," he says. "They are creating this weird leisure class -- summers on Fire Island, days at the gym, nights on drugs, dancing, you name it."

Martin Delaney, founding director of Project Inform, an AIDS treatment and advocacy center in San Francisco, has even harsher words. “There are plenty of people who either never warranted disability in the first place or warranted it for a time but should have come off when the new therapies came along,” the gay activist says. “You see guys with 800 T cells and healthy as could be. Under what justification are they receiving disability?” Delaney has spent much of the last two decades helping PWAs get a full array of benefits and government services. But now, seeing how having HIV has become an excuse to accept handouts and services, he wonders if he went too far. “You get the sense that there is a population of gay men for whom having AIDS is an excuse for never growing up,” Delaney says. “Instead of getting their lives together, their answer to their problems is: The government or somebody else should take care of me.”

Though the “cocktails” have stabilized plummeting CD4-cell counts and spiraling viral loads, they have done little to increase the number of HIVers going back to work. While there are no hard stats available (neither the feds nor the industry keeps close tabs on disability numbers), benefits counselors and HIV docs report that most HIVers who did disability in the dark, old days are still on the dole. Alvin Fisher, associate director of the Brown University AIDS Program, says that many on disability fall into a “gray zone -- it’s not clear they should go back to work and it’s not clear they are disabled.” And yet Fisher acknowledges that since the late ’90s he has expected to see his office busy with Lazaruses eagerly waving résumés. It isn’t.

Critics ask why. For some HIVers like Lambert, the answer is simple: chronic drug side effects and HIV symptoms such as peripheral neuropathy and fatigue can often be debilitating. Others blame the private-disability insurance industry for its Byzantine policies that often seem devised to make a PWA’s workplace return as difficult and risky as possible. But the perception remains that a very visible subset of gay HIVers are bilking the system. Private-disability insurance, which you either buy for yourself or get as a benefit through your employer, typically pays around 60 percent of your annual salary. Because it often comes free of federal income taxes, your net take-home can almost equal your former paycheck. For those who can persuade their doctors to sign off, disability is an alluring option.

The indignant blasts of Grossman, Delaney and AIDS leaders who spoke to *POZ* off the record echo, of course, Reagan-era attacks on single-mother welfare recipients. But not every gay HIVer on disability is floating from the golden parachute of private insurance. Those on the fed’s dole are lucky to scrape by, stitching a safety net with such entitlements as Medicaid for health care, ADAP for AIDS meds, food stamps and city rent subsidies.

All of this sounds off base, even offensive, to many in a community that has circled the wagons against prevailing “AIDS is over” indifference. David Franks, a financial-benefits supervisor at the San Francisco AIDS Foundation, insists that abuse of the disability system is rare. It’s the system, he says, that keeps people stuck on disability. “Most people with HIV want to re-enter the work force,” he says. “Work -- being a productive member of society -- provides meaning to their lives.”

Joseph Sonnabend, MD, a pioneering community doctor, slams this talk of gay “disability queens” as “discriminatory. Of all HIV-infected Americans, these people represent a small minority.

Focusing on fast-lane gay men suggests that women and current or ex-IV-drug users are not also ripping off the system." Certainly, exaggeration, deceit and fraud are endemic to the culture of entitlement programs; even civil-service systems, such as city police and firefighters, plan their disability claims years in advance. What may be new is that not only are gay white men now doing the disability jive but it is their fellow gays -- particularly HIV negatives -- who are most vocal about their disapproval. Other communities have had generations in which to assimilate and accept the the time-honored practice.

Once upon a desperate time, the ethic of HIVers working the system was different. During the Reagan-Bush years, when government was widely viewed as criminally negligent in their AIDS policies, there was a community consensus that HIVers had every right to take whatever reparations they could get from the feds. Few had long to live. Most were already sick. Devoting yourself to "the cause" -- from street activism to healing circles -- was what the crisis demanded. It is this war memory that makes Grossman's stridency about post-protease princessess strike some as slightly antigay. Still, Grossman is quick to deny that his anger has a touch of sour grapes -- or burnout. Most docs report happy days now that they can offer their HIVers long-term, effective drugs.

One of his patients is a fortysomething world-class business executive who went on what Grossman viewed as well-deserved disability. But after Grossman adjusted his patient's regimen, the man rebounded -- more energy, less pain -- and started going on vacations to exotic locales like Central America and weight-training six days a week. The man, says Grossman, was "215 pounds of sheer solid muscle." He was also renovating a country house in upstate New York, showing the doctor plans for a tennis court, swimming pool and state-of-the-art kitchen. "It was hard sitting across the table from someone with AIDS thinking I'm going to die before him from a heart attack from trying to run my practice," Grossman says. Soon after this appointment, Grossman recalls, he got a call from the man's insurance company. "Can the patient work?" the investigator asked. "He says no," Grossman said. "What are his symptoms?" the company rep asked. "He says he's fatigued and in a lot of pain," Grossman said. Asked for the man's prognosis, Grossman gave the boilerplate: "His disease is expected to progress to death."

Grossman's semantic game, which saved him from having to lie about his patient's actual health status, is the M.O. for most docs when dealing with disability issues. Physicians say that their role is not to question patients who claim to be sick enough to need disability. And they wash their hands of any responsibility for pushing their patients back to work. Grossman allows that challenging patients will result in his losing their business. "I'm not going to lie, but it's not my place to tell them how they feel, either," he says. Adds Frank Spinelli, an HIV specialist in New York City, "I never confront anybody."

Bruce Olmscheid, the director of AIDS education at Saint Vincent's Medical Centers in New York City, says that his job is to advocate for patients, even if getting them what they need involves misrepresenting the true state of their illness. "It's not necessarily lying, but it might be stretching the truth," he concedes. Such accommodation is a common medical practice. In the age of HMO profiteering, physicians ranging from podiatrists to psychoanalysts tailor a patient's symptoms to

fit a diagnosis, entitling the patient to as many HMO benefits as possible.

Insurance companies are far from blameless for the number of apparently healthy HIVers on disability. Policies often put people in a Catch-22: If they go back to a part-time job -- either to get their feet wet or because that's all their health can handle -- they risk losing their benefits. Advocates charge that often insurance companies immediately cut off re-employed PWAs with no contingency plan for paying for meds, or doctor visits. Other times, insurers begin asking why a positive policyholder can't just go back to work full-time. And HIVers often worry that they will take a full-time job only to fall sick again. Then they will have to re-process the labyrinthine paperwork and wait six months-plus for the first check -- often with no income. And there's always the risk that, given the increasingly stringent eligibility regs, they won't be approved.

For its part, the insurance industry denies that it penalizes once-sick HIVers from going back to work. Reps say that most policies contain clauses that guarantee an income supplement, so that if they take a part-time job, they will bring in as much as their disability check. Terri Sorota, a senior counsel for the American Council of Life Insurers (ACLI), the industry's trade group, also points out that their carrier is more likely to scrutinize them if they're not working.

Consider the case of Andrew Mean, a high-powered San Francisco attorney until 1994, when AIDS forced him to abandon his beloved career and settle for disability. Today, at 42, this Lazarus is desperate to go back to lawyering. "The whole time I was dying," he says, "the prospect of sitting around the house didn't seem so bad. But now that I expect to live -- I can't imagine going on like this." But after recently notifying his disability carrier that he was searching for a job, he says, the company immediately gave notice that if he didn't find work soon, his case would be extensively reviewed to see if he still deserved benefits. Yet even his own doctor has warned him that he is not well enough to work. "This is all a lot of risk and worry," Mean says.

A decade ago, insurers rubber-stamped virtually every HIV-related disability claim. It was both a no-brainer -- PWAs were desperately ill -- and a bottom-line calculation -- paying benefits until the HIVer died was cheaper than a court battle. But now that easily verifiable symptoms like PCP and CMV have given way to the more subjective fatigue or nausea, not to mention that HIVers are living much longer, the carriers have an easier case to make and more incentive to do so. They have stepped up investigations, interrogating patients' doctors, reviewing medical records and using their own physicians to assess claims. They even admit to dispatching private eyes to secretly videotape claim filers. The new view of disability for HIVers, according to ACLI's Sorota, is simply as a short-term crutch. "We're looking at AIDS not as a terminal illness but a chronic disease like some cancers," she says. "Many folks are now able to work."

While the industry's efforts have yet to hit critical mass, advocates expect an upcoming Waterloo that will eclipse the "disability queen" flap. They fear that insurance companies may even use the issue to tap into festering ill will toward "AIDS exceptionalism" and then succeed in forcing not only the able-bodied but many disabled off the HIV rolls. "In a lot of ways, I hate to even start this conversation," Grossman says. "The insurance companies are looking for any way to screw people with HIV. On the other hand, as a community we've created some very serious problems for

ourselves by keeping people from going back to work."

For Grossman and Delaney, the point ultimately is less the scamming than the community toll. With fading recall of the crisis era combined with the illusion that HIV can be "managed" -- not to mention a gay culture that values physical and sexual perfection above all other ambitions -- a one-way ticket to a Fire Island of the mind may seem, especially to the young, worth the price of being positive. "The model is becoming the hot guy on disability who has lots of free time to 'be gay,' not the normal guy who is working hard and making a contribution," Grossman says. "It's one more way we are making having the virus seem like a desirable condition."
