Economic Meltdown: Staying Healthy During the Recession

The economy is in the worst recession in decades. Health care costs are soaring while incomes are shrinking. Many people living with HIV/AIDS are already feeling the financial pain. Benefits experts explain how to access the health care we need to stay healthy during these tough times.

January 13, 2009 By David Evans

Just last month the federal government finally acknowledged something that most Americans have known for some time: We are in a recession, and our economy will likely worsen before it gets better. While the U.S. government maintains programs such as Social Security, Medicaid and unemployment insurance to catch those most vulnerable in a bad economy, experts at frontline AIDS organizations are warning that many of those safety nets, even for people living with HIV, are already stretched to the breaking point. They worry that the money simply won't be there to meet the growing volume of people who will likely need public assistance in the coming year.

The San Francisco AIDS Foundation (SFAF) has already seen a significant increase in the number of people seeking assistance due to lost jobs and shrinking incomes. Debra Holtz, SFAF's media relations manager, says they're doing everything possible to connect people with benefits, but that with huge city and state funding cuts looming, they've been forced to take a watch-and-wait approach with some clients.

All is not lost, however. Experts agree that many benefit options are available to people with HIV experiencing financial hardships. The key, however, is figuring what's out there and knowing how to work the system. AIDSmeds checked in with a few benefits specialists for some helpful tips.

Don't Go It Alone

Ann Fisher, executive director of the AIDS Legal Council of Chicago, says that all kinds of people with HIV have been contacting her organization during the past six months. These include people currently on disability, who've seen their expenses balloon without a corresponding increase in income, as well as those who have recently lost their jobs or benefits (or fear losing them). She offers everyone this common piece of advice: Seek professional help from a case manager, lawyer, budgeting expert or benefits counselor.

Alexandra Remmel, who has counseled clients for more than 12 years at Gay Men's Health Crisis

(GMHC) in New York City, says professional help is essential. “There’s no way you can state it strongly enough,” she says.

Remmel says rules and regulations—not to mention the paperwork—of most public and private benefits programs are often so complex that it takes a professional with years of experience to sort them out. Fortunately, there are case managers in most states to help people access benefits no matter where they are. (See POZ’s ASO Finder for help locating a case manager near you.)

Professionals can also help prevent difficult-to-undo mistakes. Fisher recounted a recent case where a man had lost his job and couldn’t afford his health insurance premium. A federal law called the Consolidated Omnibus Budget Reconciliation Act (COBRA) allows people to continue their health insurance, on their own dime, provided that they sign up soon after losing their jobs. Unfortunately, the man didn’t know that Illinois uses federal AIDS funding to help HIV-positive people cover their COBRA payments, and waited until his COBRA offer had expired before seeking help at Fisher’s organization.

Know What’s Available

Darrell Phillips, the director of housing and client services at the Pittsburgh AIDS Task Force, says people with HIV are often unaware of the benefits available to them, even people who may already be on disability. “Living on that fixed income,” Phillips says, “and trying to maintain your co-pays for medications and doctors’ appointment, as well as trying to pay for utilities, can be a little overwhelming.”

What people don’t often know is that there may be programs, some specifically for people with HIV, that can help ease the burden in small ways. These include free groceries and coupons for food, assistance with transportation costs and help with utility bills. Anything that reduces overall expenses can ultimately help people cope with rising medication co-payments and other costs. Some pharmaceutical companies also offer programs to help struggling individuals with the cost of their prescription co-payments. People should ask their health care providers and pharmacies about these programs.

Build a Paper Trail

That pile of clutter on your kitchen counter—pay stubs, insurance claims, medical bills, bank statements, etc.—may contain your golden ticket to the benefits you need, provided you can find it. Not only should you keep these papers, experts recommend, but you should also keep them organized.

Remmel advises people to keep their paperwork handy and in good order. You don’t want to wait, she says, “until after the fact, when you’re upset because you just got a letter from Social Security asking what you’ve been doing for the past year.”

She says you can’t count on your workplace, former employers or health care providers to just

hand over months of paperwork or personnel files when you need them. Such paperwork is often required to document your employment, income, medical claims and benefits stats. When filing for Social Security Insurance (SSI), for instance, the state or federal government may have incorrect information on file and either deny your claim or terminate existing payouts. The only way to correct the information is good documentation, Remmel says.

Patience Pays

Remmel recommends thoroughly investigating your options before making a big financial decision like changing jobs or going on or off disability. This is where a professional, including people who assist others in preparing budgets and spending plans, can be vital, especially now. “In an economy that’s in a state of trauma, people need to be as secure as possible. They need to keep their access to health care. First and foremost, if you don’t maintain access to your meds, what’s the point?”

When it comes time to apply for benefits, explains Ken Fornataro, executive director of the AIDS Treatment Data Network (ATDN) in New York City, persistence may be necessary. Even when you’ve done your homework and followed all the rules, he says, there can be setbacks. For instance, it’s not uncommon for people to be denied disability benefits the first time they apply, or to be told that paperwork has gotten lost or never showed up.

But along with persistence, Fornataro says, it’s vital that people not lose their cool when dealing with bureaucracies and red tape.

Fornataro agrees with the old adage: if you want to make sure you get good health care, bring your nurses cookies. That’s doubly true, he explains, when it comes to personnel such as receptionists and employees at government offices and large corporations responsible for benefits. Treating key point people with respect and patience, no matter how many times you’re put on hold or transferred to somebody else, may ensure that you get the help you need. Getting agitated can result in roadblocks and delays.

ATDN operates the Access Project for people who have experienced difficulties accessing health care and medication, even with the help of their local benefits counselor. Though Fornataro says that they’re now getting up to 3,000 requests for help every month, ATDN is still devoted to helping those in dire straits.

Gain Skills

Job training and education are excellent goals during difficult economic times. Despite the rough economy, some of Remmel’s clients would like to go back to work after being on disability, or to move from part-time or temporary work to a full-time job. She points out that most government disability programs offer back-to-work assistance and suggests people ask their case managers to help them determine whether they qualify. Some programs cover the cost of tuition or books at colleges and trade schools.

Beyond formal training, Remmel agrees that volunteering for a nonprofit organization can be an excellent way to learn new skills and gain hands-on experience that can make a résumé shine. There are organizations that serve every aspect of society looking for help, especially during rough economic times. Beyond the skills and experience you may acquire through volunteerism, she says, other benefits include opportunities to network, gain support from your peers and boost your self-esteem from knowing that you're helping others.

As rough as things are and may become, however, Chicago's Ann Fisher feels hopeful that most people with HIV will get the help they need. "Together we've gotten through a lot before—and people with HIV have faced up to a lot, and dealt with a lot—and I think people are going to get through this," she says, adding, "The challenges we have now are significant, but for people with HIV who've already faced the challenges of living day to day with this disease…you know, it's a pretty resilient group."

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