

MEDICAID MATTERS TO PEOPLE WITH AIDS

March 7, 2003

Dear Members of Congress,

The undersigned organizations are writing to express our opposition to the President's proposal to restructure Medicaid. Medicaid is the largest source of funding for health care for people with HIV/AIDS. Any action to limit the ongoing commitment of the federal government to Medicaid will seriously affect people living with the disease, as well as those health care providers who care for them. We urge you to oppose the inclusion of any of these proposals in any legislation and, instead, to support temporary additional federal assistance for states for their Medicaid programs.

Background:

People with HIV/AIDS rely on Medicaid for a vast array of services. It is the major source of the prescription drugs that can forestall their illness and disability. It is also the major source of diagnostic and preventive care, as well as treatment for those who become sick. Overall, state and federal governments provided roughly \$7.7 billion for HIV/AIDS care in FY 2002 through the Medicaid program, serving well over 200,000 people with HIV/AIDS. While many people with HIV/AIDS benefit from other federal programs—most notably Medicare and Ryan White—these other programs cannot take the place of Medicaid. The need for services is too large for these other programs to compensate for lost Medicaid coverage—and these other programs do not provide all of the Medicaid covered services that are critical to people living with HIV/AIDS. Therefore, weakening Medicaid would seriously harm the HIV/AIDS care infrastructure.

The President's Proposal:

The President's Budget proposes to restructure Medicaid by inviting states to create a block grant. The essence of the proposal is to replace the open-ended federal commitment of funds with a pre-set formula of federal spending that is hard and fast over ten years. Under the existing Medicaid system, if the costs of the state's program go up, so does the federal commitment. However, under this proposal, if the costs of the state's program were to go up unexpectedly (because of a recession, an epidemic, medical inflation, or changing technology), the federal contribution would stay the same.

HIV/AIDS History and Medicaid:

Having dealt with HIV/AIDS over the years, we know why Medicaid matters for the more than 200,000 HIV positive beneficiaries. The arrival of the epidemic in the 1980s was obviously unpredicted and could not have been built into a pre-set formula. Because of the epidemic, there was a dramatic increase in the number of Medicaid beneficiaries. Many people became sick and disabled; many lost their jobs and their health insurance. Under the existing Medicaid system, the federal government shared the expense of increased enrollment with states automatically. If the block grant had been in place, states would have been left on their own to cope with the costs of this epidemic-related growth in enrollment.

Generally, states must treat all Medicaid beneficiaries equally. While they have freedom to cover or not cover a wide range of "optional" services, they are not permitted to pick winners and losers, by covering services for one group and not for another. In the 1980s, this core principle was tested when a few states tried to deny coverage for the first HIV medication—even though they had elected to cover prescription

drugs for other beneficiaries. Eventually, the requirement that states must treat all beneficiaries in a comparable way was upheld.

Likewise, when protease inhibitors—the drugs that fight HIV and postpone illness and death—were discovered and approved in the mid-90s, the cost of HIV/AIDS pharmaceuticals rocketed from \$1,500 per person per year to more than \$10,000 per person per year. This, too, could not have been planned and budgeted for in a ten-year formula. Under the existing Medicaid system, the federal government shared that expense with states automatically. If the block grant proposal had been in place, states would have been left with huge shortfalls with no federal assistance. These medications have made a huge difference. Before these effective therapies were available, HIV had become the leading cause of death of Americans aged 25-44. Because of the availability of these drugs—to which Medicaid contributes mightily—there has been a dramatic reduction in HIV-related deaths.

Conclusion:

In short, because of the open-ended, uncapped nature of the federal program, Medicaid was there when people with HIV/AIDS and their home states needed it. Under a block grant, that would not be true.

We hope that health care for people with HIV/AIDS and all people with chronic illnesses and disabilities will continue to improve. But we fear that a proposal like the President's block grant will make it impossible for low-income and uninsured people to benefit from improvements in care and treatment. Without a continued federal commitment, states will not be willing or able to provide new therapies and innovations to sick, poor people.

Many Members of Congress and Governors have supported increased federal matching payments; such increased payments would help states and the people who depend on Medicaid. We urge you to oppose the President's proposal and, instead, to work to enact these other efforts.

Thank you for considering our comments. If you have any questions, or need additional information, please contact Lei Chou, Director of the Access Project of the AIDS Treatment Data Network at (212) 260-8868, Michael Kink, Legislative Counsel of Housing Works at (518) 449-4207, or Laura Caruso, Policy Associate at Gay Men's Health Crisis at (212) 367-1228.

Sincerely,

ACT UP Atlanta, Atlanta, GA

ACT UP Philadelphia, Philadelphia, PA

AIDS Action, Washington, DC

AIDS Action Baltimore, Baltimore, MD

AIDS Action Project Northwest, Portland, OR

AIDS Alliance for Children, Youth, and Families, Washington, DC

AIDS Foundation of Chicago, Chicago, IL

AIDS Legal Council of Chicago, Chicago, IL

AIDS Project Los Angeles, Los Angeles, CA

AIDS Rochester, Rochester, NY

AIDS Services of Dallas, Dallas, TX

AIDS Survival Project, Atlanta, GA

AIDS Treatment Activists Coalition (ATAC)

AIDS Treatment Data Network, New York, NY

AIDSmeds.com, Brooklyn, NY

American Academy of HIV Medicine, Los Angeles, CA
Asian and Pacific Islander Wellness Center, San Francisco, CA
Baltimore Commission on HIV/AIDS, Baltimore, MD
Boulder County AIDS Project, Boulder, CO
Care for the Homeless, New York, NY
Cascade AIDS Project, Portland, OR
Catholic Charities AIDS Services, Albany, NY
Center for AIDS, Houston, TX
Community HIV/AIDS Mobilization for Power (CHAMP), New York, NY
Critical Path AIDS Project, Philadelphia, PA
Doorways, an Interfaith AIDS Residence Program, St. Louis, MO
Elizabeth Glaser Pediatric AIDS Foundation, Washington, DC
Fenway Community Health Center, Boston, MA
Florida AIDS Action, Tampa, FL
Florida Keys HIV Community Planning Partnership
Foundation for Integrative AIDS Research (FIAR), Brooklyn, NY
Gay, Lesbian, Bisexual, and Transgender Community Center of Baltimore and Central Maryland
Gay and Lesbian Medical Association, San Francisco, CA
Gay Men's Health Crisis, New York, NY
Harm Reduction Coalition, New York, NY
Health Education Resource Organization, Inc. (HERO), Baltimore, MD
Hemophilia Association of New York
Hep-C Alert, North Miami, FL
Hepatitis C Action & Advocacy Coalition (HAAC-SF), San Francisco, CA
Hepatitis C Caring Ambassadors Program, Oregon City, OR
Hepatitis C Outreach Project, Vancouver, WA
HIV/AIDS Alliance for Region Two, Inc., Baton Rouge, LA
HIV Medicine Association, Alexandria, VA
Housing Works, New York, NY
HUG-ME Program, Orlando Regional Healthcare, Orlando, FL
International Foundation for Alternative Research in AIDS (IFARA), Portland, OR
Iris House, Inc. New York, NY
Latino Commission on AIDS, New York, NY
Latino Organization for Liver Awareness (LOLA), New York, NY
Lifelong AIDS Alliance, Seattle, WA
Long Island Association for AIDS Care (LIAAC), Huntington Station, NY
Metro St. Louis HIV Health Services Planning Council, St. Louis, MO
McAuley Health Center, Grand Rapids, MI
Minnesota AIDS Project, Minneapolis, MN
Montrose Clinic, Houston, TX
Movable Feast, Inc., Baltimore, MD
NAMES Project Foundation, Upper Ohio Chapter, Wheeling, WV
Nashville CARES, Nashville, TN
National Association of People With AIDS (NAPWA), Washington, DC
National Health Law Program
National Healthcare for the Homeless Council, Baltimore, MD
National Minority AIDS Council (NMAC), Washington, DC
New York City AIDS Housing Network, New York, NY
Persons Living with HIV Action Network of Colorado, Denver, CO

Philadelphia FIGHT, Philadelphia, PA
Positive Employment Options, San Diego, CA
Project Inform, San Francisco, CA
Project Open Hand, Atlanta, GA
Providence Rhode Island Miriam Hospital Community Advisory Board, Providence, RI
Provincetown AIDS Support Group, Provincetown, MA
Rochester Area Task Force on AIDS, Rochester, NY
San Francisco AIDS Foundation, San Francisco, CA
San Mateo County AIDS Program, San Mateo, CA
SAVE ADAP Committee of the AIDS Treatment Activists Coalition
Seattle Treatment Education Project (STEP), Seattle, WA
Siouxland and Local Area AIDS Project, Sioux City, IA
St. Louis Effort for AIDS, St. Louis, MO
T.H.E. Clinic, Los Angeles, CA
Tennessee AIDS Support Services, Inc., Knoxville, TN
The Health Association, Rochester, NY
Title II Community AIDS National Network, Washington, DC
Treatment Action Group, New York, NY
Treatment Access Expansion Project (TAEP)
Vermont People With AIDS Coalition, Montpelier, VT
Visionary Health Concepts, New York, NY
West Virginia HIV Care Consortium
Williamsburg/Greenpoint/Bushwick HIV CARE Network, Brooklyn, NY
Wilson Resource Center, Arnolds Park, IA