

# Withdrawal/Redaction Sheet

## Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. list	List of Invitees to Health Care Task Force meeting (partial) (6 pages)	nd	P6/b(6)
002. list	List of Invitees to Health Care Task Force meeting (partial) (1 page)	nd	P6/b(6)

**COLLECTION:**

Clinton Presidential Records  
 Domestic Policy Council  
 Carol Rasco (Meetings, Trips, Events)  
 OA/Box Number: 4591

**FOLDER TITLE:**

AIDS Provider Groups 4-16-93 11:15 a.m.

rw137

**RESTRICTION CODES**

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
- P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
- P5 Release would disclose confidential advise between the President and his advisors, or between such advisors [a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

- b(1) National security classified information [(b)(1) of the FOIA]
- b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
- b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
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- b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
- b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

April 15, 1993

To: Carol Rasco  
Ira Magaziner  
Alexis Herman

MEETING WITH AIDS HEALTH CARE PROVIDERS

DATE OF EVENT: April 16  
LOCATION: Roosevelt Room  
TIME: 9:00 a.m.-12:00 p.m.  
From: Christine Heenan (x2929)  
Molly Brostrom (x2936)

1. PURPOSE

This meeting serves as an opportunity for representatives of the Task Force and the working groups to hear from AIDS health care providers, advocates, and activists.

The HIV Subgroup of the Task Force's Underserved Populations Cluster group has already met with many of the attendees several times. This meeting provides an additional opportunity for these concerns to be raised and to be heard directly by more senior White House officials.

2. BACKGROUND

Attached are Tollgate papers prepared by the HIV subgroup of the Working group called "Health Policy Initiatives for Underserved Populations."

Bob Hattoy put together the attached list of invitees. Bob will attend the entire meeting. Note: Some of the members of the group he has assembled will have concerns that have not been addressed by the Task Force (e.g. NIH clinical trials, research funding).

3. AGENDA

The meeting will be three hours long and will be attended by leaders and members of working groups looking at aspects of health care reform of concern to AIDS providers and advocates-- Long-Term Care, New System Organization, Underserved Populations, and New System Coverage (benefits).

Note: two of the Congressional staff who are members of the HIV subgroup, Tim Westmoreland (Waxman) and Michael Iskowitz (Kennedy), were key architects of the Ryan White CARE Act.

9:00 - 9:15      Opening Remarks  
Carol Rasco, Domestic Policy Adviser  
Mark Smith, MD, HIV subgroup leader

9:15 - 9:30      Overview of New System Organization  
Roz Lasker, a physician on the group looking at  
the overall organization of the new system

9:30 - 10:00     Issue: Long-Term Care  
Discussion Leader: Robyn Stone, cluster leader

10:00 - 10:30    Issue: Benefits  
Discussion Leader: Linda Bergthold, head of  
benefits working group

10:30 - 11:00    Issue: Financing, Capacity, and Prevention  
Discussion Leader: Mark Smith, MD

11:00-12:00     General Discussion/Closing Remarks  
Ira Magaziner

#### 4. REMARKS

Talking points for the meeting prepared by Mark Smith, head of  
the HIV Subgroup.

# Withdrawal/Redaction Marker

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For a complete list of items withdrawn from this folder, see the  
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TO: IRA MAGAZINER  
CAROL RASCO  
ALEXIS HERMAN  
MOLLY BROSTROM  
CHRISTINE HEENAN

FROM: BOB HATTOY

RE: Invitees to Health Care Task Force meeting with AIDS organizations and service providers.

(This meeting is scheduled for Friday, April 16, 9am - 12 noon in the Roosevelt Room in the West Wing of The White House).

---

1). REGINA ARAGAN: San Francisco, CA

P6/b(6)

\*State policy director for The San Francisco AIDS Foundation

2). BILL BAILEY: Washington, DC

P6/b(6)

\*American Psychological Association

\*Legislative analyst and lobbyist for HIV prevention issues

3). CORNELIUS BAKER:

Washington, DC

\*Director of National Association of People With AIDS

4). TERRY BESWICK:

Washington, DC

\*HRCF-largest Gay & Lesbian political organization in the U.S.  
\*AIDS research policy analyst  
\*AIDS treatment activist

5). LEONARD BLOOM:

Los Angeles, CA

\*CEO of AIDS Project Los Angeles  
\*support and maintain quality of life for people living with AIDS  
\*provide vital human services to people with AIDS  
\*works to decrease the number of HIV cases, the level of fear and discrimination related to AIDS issues and to focus on education and prevention.

6). ANNE BROOMFIELD:

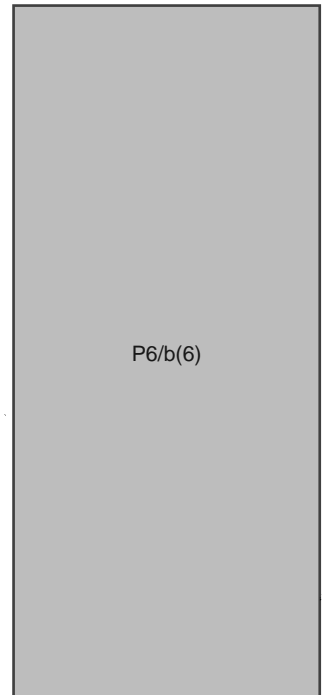
Baltimore, MD

\*Greater Baltimore HIV & Health Services Planning Council  
\*recipient of Ryan White Title I funding  
\*African-American

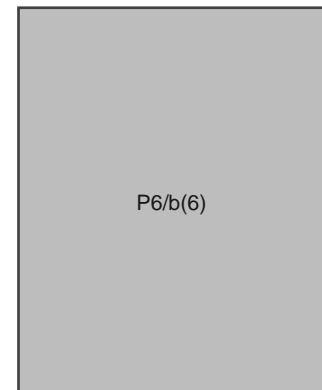
7). DICK CHASEN:

Baltimore, MD

\*Johns Hopkins Medical Center



P6/b(6)



P6/b(6)

SS:  
DoB:

8). MARTIN DELANEY:

San Francisco, CA

- \*Executive Director, Project Inform in San Francisco
- \*Founding Director in 1987
- \*former businessperson
- \*AIDS treatment and research issues

P6/b(6)

9). SONDRA ESTEPA:

New York, NY

- \*Executive Director of The Latino Commission on AIDS
- \*focuses primarily on outreach to the Latino community
- \*AIDS prevention, education, research and treatment services
- \*provide policy analysis and advocacy on AIDS issues effecting Latino community

10). DR. RUTH FINKELSTEIN:

New York, NY

- \*Director of Public Policy at the GMHC in New York
- \*AIDS research issues

P6/b(6)

11). JIM GRAHAM:

Washington, DC

- \*Executive Director of The Whitman Walker Clinic
- \*clinic is the primary community-based AIDS service provider in the DC area

12). DAVID HARVEY:

Washington, DC

\*Coordinator of policy analysis for The National Pediatric HIV Resource Center

\*strongly recommended by Elizabeth Glaser to take her place

P6/b(6)

13). DEBRA FRAZER-HOWZE:

New York, NY

\*Executive Director/CEO of Black Leadership Commission on AIDS

\*promote leadership and education on AIDS-related issues within the African-American community

\*enhance service providers and input on public policy & funding

\*African-American

14). DR. BILLY JONES:

New York, NY

\*Executive Director of Health and Hospitals Corporation

\*African-American

P6/b(6)

15). PAUL KAWATA:

Washington, DC

\*Executive Director of The National Minority AIDS Council

\*provides leadership for people of color and Asian-Pacific Americans

\*provides technical assistance and training on public policy



16). JEFF LEVI:

Washington, DC

P6/b(6)

\*Director of Public Policy for The AIDS Action Council

\*represents community-based organization issues from research, drug development and regulation, health care financing and public health response

\*lobbying, policy analysis, research and grassroots organizing

17). CHRISTINE LUBINSKI:

Washington, DC

P6/b(6)

\*Deputy Executive Director for Programs for The AIDS Action Council

\*DC-based lobbying organization represents over 900 community-based AIDS services providers

18). JANE SILVER:

Washington, DC

P6/b(6)

\*American Foundation for AIDS Research (AmFAR)

\*Highly recommended by Dr. Mathilde Krim to take her place at meeting in her absence

19). PETER STALEY:

New York, NY

P6/b(6)

\*Treatment Action Group (TAG)

\*small activist group, spinoff of ACT-UP

\*focus on AIDS research issues

20). TODD SUMMERS:

Boston, MA

P6/b(6)

- \*Executive Director of The AIDS Housing Corporation
- \*advocacy on housing, legislation, funding for AIDS health care needs and issues
- \*Boston AIDS Consortium
- \*Project ABLE

21). SANDY THURMAN:

Atlanta, GA

P6/b(6)

- \*Executive Director of AID Atlanta
- \*responsible for planning and administering all programs and services for the Southeast's largest and oldest community-based service organization

22). PHIL WILSON:

Los Angeles, CA

P6/b(6)

- \*National Minority Gay & Lesbian Association
- \*AIDS Project Los Angeles
- \*African-American

**AIDS MEETING  
TALKING POINTS**

**PREVIOUS MEETINGS**

In addition to numerous individual contacts, Cluster Group 22 has held 3 meetings with AIDS groups, including a number of those expected at the 4/16 meeting.

The first was with Cluster Group leaders and consultants, at which a number of representatives of advocacy groups concerned with AIDS, public health, infant mortality and other issues discussed their general outlook on health care reform.

The second was a 5-hour meeting of representative of 12 AIDS organizations (including 6 of those invited to the 4/16 meeting) with the HIV subgroup of Cluster Group 22. The meeting was a detailed discussion of AIDS groups' concerns, principally those listed below.

Lastly, the HIV subgroup met with representatives of the Sheridan Group, which lobbies for the high-impact cities which are recipients of money from Title I of the Ryan White Care Act. They were principally concerned with continuation of Ryan White funding.

**I. ISSUES WHICH ALL ATTENDEES WILL WANT TO HEAR ABOUT**

**A. Universality of coverage**

*Will everyone in the country be insured?*

**B. Insurance underwriting reform**

*Will pre-existing conditions be prohibited?*

*Will health plans have to accept all who apply?*

**C. Benefits package**

*Will the standard package be comprehensive?*

*The group will be particularly concerned about coverage for the following:*

1. prescription drugs
2. home care
3. long term care
4. mental health
5. substance abuse

**D. Choice of provider**

*Because press coverage of the Task Force's work has (erroneously) claimed that "everyone will be forced to be in HMO's", there will be concern that AIDS patients continue to be able to choose their personal physician.*

#### **E. Reimbursement rates to AIDS providers**

*AIDS patients cost far more than the average payment. The group will want to be assured that plans will receive adequate reimbursement for the costs of AIDS care, either as adjusted premiums or in some other way.*

#### **F. Concerns about managed care**

*Since the new system relies heavily on managed care, concerns will be expressed about the possible incentives to under-treat patients. In particular, the following issues have been raised in previous meetings:*

1. quality assurance/certification of AIDS expertise
2. anti-discrimination provisions
3. ombudsperson function
4. protection against denials care, including "off-label" uses of FDA-approved drugs

#### **F. Transition issues**

*Assuming that there will be a period of several years of transition to the new system, the group will want to see some tangible gains for people with HIV during this period. Options discussed are:*

1. Ryan White funding – Increased funding for care through increased appropriations to the Ryan White Care Act.
2. Medicaid eligibility reform – The cluster group has proposed changes in Medicaid eligibility (with 100% Federal payment) to include anyone with HIV infection, who would be covered for outpatient care and prescription drugs.

## **II. OTHER ISSUES**

Some members of the group will have particular concerns in these areas:

A. Access to and payment for experimental therapies

B. Research : NIH budget and priorities

*We have not discussed this issue; do they have suggestions?*

C. Preference for single-payer approach to health reform

D. Need for greater capacity for care, particularly in low-income urban areas

*We agree; there are proposals for capital investment, personnel placement, and technical assistance to increase capacity in underserved areas over the*

*transition period.*

**E. Importance of prevention**

*The developing proposal places high emphasis on prevention and includes innovative ways of securing funding for it.*

**F. Appointment of an AIDS Czar/Czarina**

*We have not discussed.*

FOR OFFICIAL PURPOSES ONLY  
MARCH 8, 1993

### TOLLGATE 3

## OPTIONS FOR CARE OF PEOPLE WITH HIV INFECTION

### INTRODUCTION

Over the past 10 years a network of AIDS-specific funding streams and programs has grown up to fill some of the gaps in care available to people with HIV infection. This has been the case for three reasons:

- **Lack of health insurance.** People with HIV are more likely to be uninsured than the general population (29% vs. 11%), both because of their demographic characteristics and because of the impoverishing effects of the disease.
- **The health care system's lack of orientation towards needs of people with chronic disease.** For AIDS patients who have health insurance, the system's imbalance towards preferential coverage of acute care (ER visits, hospitalizations) rather than chronic disease (long-term prescription drugs, ambulatory and home care) is apparent.
- **Problems unique to AIDS.** The biological and social realities of AIDS (e.g., dementia, social stigma) create special needs, such as mental health care and housing assistance.

Patients with HIV infection are in some respects like others with chronic disease, in that they have some special needs and concerns and require skilled and expensive care. In addition, though, AIDS regrettably continues to carry social stigma, rendering AIDS patients potentially unattractive for reasons other than direct financial ones. Providers may fear that their presence in a physician's waiting room or hospital ward may impair the provider's ability to attract other patients who are AIDS phobic. In this regard people with HIV infection are unlike patients with diabetes or emphysema, and will require special measures to assure high-quality care.

The handling of AIDS depends in large part on decisions made on system questions such as insurance underwriting reform (to eliminate exclusion of pre-existing conditions), quality assurance measures, and HIPC governance. A major issue is adequate coverage of prescription drugs and substances abuse treatment. If these are not present we will need to add them to our options.

Also important will be the existence and adequacy of a risk adjustment in HIPC payments to AHPs or providers to cover the higher expected use of AIDS patients.

#### OPTIONS

Option 1 - Each HIPC pays for all services to AIDS patients from premiums. All services, whether in the benefit package or not, are provided the regular HIPC-health plan structure with increased capitation in payments by HIPCs to plans for their patients with AIDS. (Note: This and other options envision the potential establishment of health plans specializing in AIDS and targeting that "market" in areas large enough, and with a high enough AIDS prevalence, to economically support their development.)

#### PROS

- Does not isolate AIDS patients in a separate, and possibly inadequate, financing system.
- Provides access to mainstream providers, especially tertiary centers.
- Administrative simplicity.
- No cross-subsidies from other geographic areas -- internalizing all costs increases incentives for prevention, in the case of preventable diseases.

#### CONS

- Patients with HIV are not simply a "risk" of higher-than-average expenditures by providers, they are a certainty. Additional payments might have to be prohibitively high, especially as AIDS patients are concentrated in some metropolitan areas.
- Does not promote development of specialized centers of care or community-wide AIDS services available to member of various plans.
- May compromise patient confidentiality because of identification of patients as those with "special needs" or funding not only within the clinical system, but within the financial/accounting system as well.
- May yield inefficiencies in provision of specialty services if AIDS-specific plans are not developed and if AIDS patients are dispersed across numerous plans.

Option 2 - Separate pool, established and financed by HIPCs, which could be augmented by Federal and State funding. HIPCs would pay capitated payments to health plans, but would reserve a pool based on health plans' reporting of actual costs of care. This pool could be used partially to augment health plans' payments, and partially to establish special services (through contracts with outside vendors or providers) which are more efficiently delivered on a wider basis than individual plans, such as transportation.

**PROS**

- Would allow the most efficient organization and funding of specialized services.
- Would help to overcome financial disincentives for health plan acceptance of AIDS patients.
- Might promote centers of excellence in AIDS care with enriched funding.
- Internalizes some cost of care to HIPC with possibility of outside subsidy.

**CONS**

- Plans might feel funds needed for extra costs of clinical care are being diverted for "non-essential" services.
- Requires a great deal of expertise in HIPC.



**Option 3 - Inclusion in regular HIPC-health plan structure with normal or increased capitated payments, with supplementation from Federal, State, and/or local non-HIPC funds such as special grants.**

**PROS**

- Spreads payment burden more widely, reducing regional variation.
- Allows targeting of State and Federal funds for high-need areas and services while still mainstreaming AIDS patients.
- Compatible with existing specialized funding streams which allow independent TA, creative service mechanisms, quality oversight, and increased confidentiality.
- Easier to coordinate with special services for non-HIPC AIDS patients (workers for companies which opt out of HIPCs).
- Might promote centers of excellence in AIDS care with supplemental funding.

**CONS**

- Does not internalize full cost of care to HIPC funds-collection and payout system.
- Requires some external government bureaucracy.
- Reduces flexibility of plans because of imposition of the guidelines which must accompany separate grant structure.
- Requires substantial HIPC expertise.

**Option 4 - Financing outside of normal HIPC structure - this might take either of two forms:**

**Modification of capitation; payment for HIV care on a partial or total fee-for-service basis; or:**

**Separate contracting for care; transmittal of payments collected for AIDS patients to an independent group (perhaps like the current Ryan White Planning Councils) which would independently arrange for their care.**

#### **PROS**

- If HIPCs are passive entities, they may not have the expertise to recognize and plan for special services. An outside body would have a better understanding of AIDS patients' needs.
- Fee-for-service option may be reassuring to providers who might not want to assume risk for high-cost disease whose standard of care is changing rapidly.

#### **CONS**

- Possible segregation of AIDS care.
- Removal of capitation would remove some incentives for prudent, efficient and innovative care.
- Separate funding may be politically vulnerable and might wind up being inadequate.
- The creation and operation of an independent body would add another layer of administrative expense, politics, and potential conflicts of interest - all criticisms which have been made of the Planning Councils.
- The history of high-risk pools has not been encouraging about the financial viability of such arrangements.

#### **PHASING**

##### **Short Term Improvements**

These approaches are intended to improve the system's ability to meet the needs of AIDS patients prior to full implementation of Health Care Reform. Depending upon decisions regarding implementation of Health Care Reform, some of these may be more appropriate short-term approaches than others, or the mix may change.

1. **Expand Ryan White funding.** Title I emergency grants and Title II grants to States were originally authorized at \$275 million each. They have only been funded at about half that amount. Increased Ryan White funding would expand availability of supplemental services for HIV patients. If there are short term improvements in Medicaid, the Ryan White funds could be adjusted accordingly and focussed on non-insured services.
2. **Reform Medicaid with eligibility changes.** While Medicaid currently covers 48% of adults and 98% of children with AIDS, it pay for only 25% of the costs. Eligibility provisions are restricted and many services needed by AIDS patients (e.g. home and community based care) are not available in all states. This options fits best with a phasing plan for Health Care Reform that assumes limited change in Medicaid in the near term.
3. **Include HIV-infected patients in the first group to be phased into the new system.** Private insurance covers approximately 29% of individuals with AIDS. The link with employment limits eligibility, and many private plans do not cover needed services. Bringing HIV-infected patients into the new plan early would expand their coverage in the context of the new system structure.

**Transition**

1. Develop technical assistance and training for HIV service providers to enable them to integrate with new AHP structures, if an integrated option is chosen.
2. If the option chosen combines supplemental Federal funding with HIPC structure, change the structure of Ryan White to coordinate with HIPCs.

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HIU/AIDS - Tollgate 4: page 1

TOLLGATE 4  
ASSURING APPROPRIATE HIU/AIDS CARE

I. DESCRIPTION OF SERVICES

A. Medical Services

As the introduction to our workgroup's paper states, we expect the vast majority of straightforward medical services for HIU infected patients (inpatient and ambulatory care, prescription drugs, limited mental health benefits, etc.) to be covered by the normal employer/government > HIPC > health plan insurance arrangements, albeit with stop/loss arrangements and/or risk-adjusted premiums. The actual operation of such mechanisms for AIDS patients will, however, require considerable work to develop.

In an environment of capitated price-competition around a standard package of benefits, adverse selection is likely to be a serious problem for any health plan which makes a substantial commitment to HIU care by recruiting expert HIU providers, seeking special AIDS grant funds, and developing appropriate programs. Stop/loss arrangements alone may reduce disincentives to enroll HIU infected patients, but provide no positive incentive to do so; furthermore, they may reduce the plans' interest in instituting innovative and cost-effective modes of care because their downside risk is limited.

Adequate premium adjustment, on the other hand, may provide a positive incentive to enroll HIU patients, but does not limit risk. Furthermore, the "science" of risk-adjusting premiums is primitive, at best, and leaves a majority of cost variation unexplained. As care for late stage HIU-infected patients can be confidently predicted to cost at least 10-20 times the normal premium, this difference dwarfs the magnitude of premium adjustments which would be made for "high-risk" patients.

2

At least initially, financing of these services should probably include elements of both strategies: substantially augmented premiums (with a Federal role in providing extra funds to high-incidence areas) to promote enrollment, adequately reimburse expensive care, and promote flexibility, and stop/loss mechanisms to protect providers from unpredictable changes in therapy, new medicines, etc.

B. Other Services

As with other special groups of patients there is a range of other services which need to be provided for. They include:

1. Long-term substance abuse treatment
2. Mental health services (both therapeutic services and care of dementia)

Preliminary staff working paper for illustrative purposes only

FOR OFFICIAL PURPOSES ONLY; March 18, 1993  
HIU/AIDS - Tollgate 4; page 2

3. Housing assistance

4. Supportive outpatient services which reduce institutionalization and promote independence (eg. adult day care, home care skilled nursing and chore workers)

II. OPTION 1: MAXIMUM HIPC FLEXIBILITY

HIPCs would receive supplemental AIDS funding from Federal, state, or local government on the basis of regional HIU prevalence data or by reporting numbers of HIU-infected participants.

1. FINANCING

HIPCs would be largely responsible for setting standards for AIDS care and assuring that health plans meet them. Such standards might include demonstration of adequate numbers of sophisticated HIU clinicians, appropriate home care and outpatient capacity, and links with social service and support agencies. HIPCs would also establish mechanisms to prevent plans from avoiding enrollment (or promoting disenrollment) of HIU-infected individuals.

Under this scenario HIPCs would be free to organize and/or fund community-wide as they saw fit, and to make decision about the integration of those services with publicly-funded programs (such as those serving those insured outside of the HIPC structure)

2. PHASING

One of the principal issues in phasing of HIU care (as for other public-sector spending, as on public health infrastructure) is the assurance of maintenance of state and local efforts. The pressures of budget constraints will, unless counteracted, lead to a withdrawal of non-Federal dollars, raising the possibility that no more (and possibly fewer) people will be served.

Of the 3 principal options for transition outlined in Tollgate 3, the group's preference is #2: expansion of Medicaid eligibility.

Main Points:

1. Medicaid eligibility would be for all HIU -infected individuals up to 200% of poverty level.
2. 100% Federal contribution (no state share)

3. Coverage would be for outpatient services and prescription drugs.

**Pros:**

1. Relies on an existing mechanism with accountability and audit structures in place.

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HIV/AIDS - Tollgate 4; page 3

2. Does not saddle HIPCs early with financially complex and politically sensitive group.

3. Produces some savings from current Federal and state categorical AIDS spending (eg. about 35% of Ryan White).

4. Targets resources to those most in need - something difficult to do with programs such as Ryan White.

5. Would automatically integrate HIV patients into HIPC structure as Medicaid is integrated.

**Cons:**

1. Low rates of Medicaid reimbursement mean continued access problems for beneficiaries unless adjusted

2. Builds up the Medicaid program, which is presumably in the process of being phased out.

3. A few individuals (those with incomes over 200% of poverty but lacking health insurance) would remain uncovered.

Cost projections for this approach are being developed

**B. OPTION 2: STANDARDIZED REQUIREMENTS**

**1. FINANCING**

The Federal government would retain a strong role in determining standards of care for HIV, and might require HIPCs to certify that participating health plans meet those standards (in part through the practice guidelines process). HIPCs might have to report annually on AIDS statistics and care.

Continued Federal support for non-core package services could flow through a variety of mechanisms - some to HIPCs, some perhaps directly to high-prevalence health plans, and some to local and state health departments and community-based organizations. HIPCs (or health plans) would be required to establish relationships with federally-funded resources in their area.

**2. PHASING**

The preferred phasing option under this scenario continues to be Medicaid expansion, although there would be greater need for continued categorical Federal funding.

Preliminary staff working paper for illustrative purposes only



Field memo  
Research

Intro priced

- System of indep. accounting  
showing actual deal.  
costs, utilization of  
a formula by Fed.  
govt.

Research

Education of pri. care MD's



## **Health Care Reform Statement of Principles**

The following are the criteria against which the HIV/AIDS community will measure the various proposals for health care reform. HIV/AIDS poses the same challenges to the health care system as any chronic disabling condition. The reformed health care system must be able to meet the needs of all Americans -- and all Americans are at risk of becoming disabled, whether the cause of their disability is HIV, Alzheimer's, stroke, multiple sclerosis, or any other condition.

To be acceptable, any proposed administrative structure must meet all of the following criteria:

### **UNIVERSAL COVERAGE**

Coverage should be universal and uniform. All U.S. residents should be covered by the health plan and receive the same set of benefits. Whether or not coverage and benefits are tied to employment; the method for accessing health care and the scope of benefits should be the same regardless of employment status.

### **COMPREHENSIVE COVERAGE**

All medically necessary health care should be part of any benefits package, including coverage for in-patient and out-patient primary health care services, including full gynecological services, preventive health services such as prenatal and well-baby care, prescription drugs (including off-label use of approved drugs and ancillary and actual costs of experimental treatments), hospice care, long- and short-term home and community-based services, substance abuse treatment, mental health services, outpatient rehabilitation services, dental care, vision care, and the healing arts. Case management should be provided to link people with appropriate health and social services.

1875

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Tel 202 986 1300

**FREEDOM OF CHOICE**

Individuals should be free to choose their own health care provider. Individuals should not be required to join a plan or delivery system if the individual does not believe that program will meet his or her needs. In addition, individuals should be allowed to change providers if they are not satisfied with the care provided. This is particularly important for people with HIV infection, given that a relatively small number of physicians are experienced in treating people with HIV and there is no credentialing process that identifies those qualified or experienced with HIV disease.

**NO FINANCIAL BARRIERS TO CARE**

Payment for coverage should be based on ability to pay, not based on a flat premium schedule. Out-of-pocket payments should also be based on income. If there is a system of copayments or deductibles, it should be designed so as to prevent sick people from being disproportionately burdened. (For example, if copayments are based on a per visit or a per prescription basis, sick people will pay a larger portion of their income for health care coverage.)

**GOVERNMENT RESPONSIBILITY**

The federal government must exercise its authority to assure that health care is delivered equitably and cost effectively through the following:

- Global budgeting, which sets targets for health care spending by sector and is the most effective way of assuring appropriate distribution of scarce health care resources while reining in inflation in the health care field.
- Undertaking initiatives to redistribute the availability of health care (especially health care practitioners) to underserved areas and populations, including appropriate education and financial incentives to increase the number of primary care providers.
- Guaranteeing the involvement of consumers in all aspects of decisionmaking associated with any new health care system.

**AIDS Action Council health care reform statement of principles/Page 3**

- **Guaranteeing the confidentiality of all aspects of patient involvement with the health care system.**
- **Achieving quality assurance through establishment of federal standards of care and minimum standards for quality assurance methods.**
- **Requiring nondiscrimination in accessing the health care insurance system, whether demographic or based on preexisting medical conditions.**
- **Assuring that appropriate care is given to all Americans, meaning that the appropriate services are given for the appropriate level of need.**
- **The government must assure access to care under existing mechanisms *during a transition to the new health care system.***
- **The government must not "de-institutionalize" the traditional public health programs even after a new system of health care delivery is established.**
- **The government must assure full disclosure to and appropriate education of all participants regarding access and options within the new system.**

## **MEDICAL INNOVATION AND RESEARCH: AN INTEGRAL COMPONENT OF HEALTH CARE REFORM**

The administration's 1994 budget proposes reduced investment in research at the NIH, resulting in many missed opportunities in biomedical and behavioral research. As a part of a growing coalition (contact list attached), we propose that the Task Force consider the following measures:

Convene a new Research Issues Working Group to consider the potential impact of reform proposals on biomedical and behavioral research and, conversely, to consider the potential impact of increased investment in research on health care reform.

Convene a series of meetings with NIH intramural and extramural researchers and health care economists (suggestions attached) to discuss their findings relating to the historic and potential cost-effectiveness of research as a means of controlling health care costs.

The Task Force should also carefully consider a number of other issues related to both health care reform and research, including education and training of physician specialists and researchers, strengthening the economy and creating jobs through increased research investment, technology transfer, maintaining international competitiveness in biotechnology, decreasing lost productivity, outcomes research, and reimbursement for health care costs associated with clinical trials.

As a part of its proposed reform package, the Task Force should consider utilizing new revenue to increase the NIH biomedical and behavioral research budget in phases, with a goal of doubling the budget to \$21 billion by the year 2000. New funds would be targeted at research on chronic, debilitating and life-threatening diseases currently most expensive to treat, including basic research, clinical research, training, etc.

### **RATIONALE FOR INVESTMENT IN RESEARCH**

Containing Health Care Costs: A primary goal of health care reform is access to high quality care at reasonable cost. Medical research is an important strategy for containing and in many instances reducing health care costs, while improving quality of care.

Small investments in research have paid billion dollar dividends in terms of decreased utilization of health care resources and restoration of productivity for those otherwise disabled by illness. A recent NIH report estimated that approximately \$800 million invested in NIH-supported clinical and applied research had the potential to realize a one-year savings of between \$5.2 billion and \$6.7 billion based on 1989 prices.

Chronic and debilitating diseases contribute increasingly to the nation's health care bill. For example, the Agency for Health Care Policy and Research has estimated that \$10.4 billion may be spent in 1994 in the United States for the care of people with HIV/AIDS; this number is estimated to increase 21% annually.

The NIH cites many examples of the savings which have resulted from biomedical and behavioral research. With the advancement of technology, the potential for development of more effective, cheaper treatments increases. A few examples:

Vaccine Development: The cost effectiveness of vaccines has been widely accepted and demonstrated throughout history with polio, smallpox and measles. Now, a conjugate H. influenza type b vaccine has also been developed. If every infant were to be immunized, the total direct and indirect savings are estimated to be approximately \$400 million a year.

Cancer: Research to establish the effectiveness of a two-stage breast cancer procedure cost the National Cancer Institute \$10.6 million over a 15 year period. The potential one-year savings from this research is estimated at \$169 million.

Kidney Disease: NIH-supported research has identified the metabolic abnormalities which underlie the formation of kidney stones. This led to the development of a relatively simple treatment, potassium citrate, for the prevention of recurrence of kidney stones. About \$680 thousand was spent on the research grant to study this problem. The estimated annual savings, in treatment and lost work days, is approximately \$300 million.

Stroke: The overall cost of stroke is estimated to be about \$25 billion annually. An NIH-supported trial has shown that an aspirin and a drug called warfarin lowered the risk of stroke by 50 to 80 percent in people with atrial fibrillation. To date, the cost of the trial has been \$8 million; it is estimated that 100 to 150 strokes per day could potentially be prevented with this simple treatment - saving more than \$200 million a year.

Eye Research: The development of laser photocoagulation treatment of diabetic retinopathy has been shown through clinical trials to be effective in reducing the risk of severe visual loss from advanced stages of diabetic retinopathy and other eye complications of diabetes. The total NIH investment for the clinical trial was \$48 million. The potential one-year savings is over \$2 billion.

Just two potential areas of future research which exemplify the important relationship between medical research and health care reform:

Antecedents of Adult Disease: Research over the past few decades has indicated with ever increasing clarity the causal relationship between events occurring during childhood and the development of the major disease processes compromising health in adults. Continued research is needed in areas such as: Type II diabetes; Juvenile onset of Type 1 diabetes; Hypertension; and behavioral prevention research.

Gene Therapy: One of the clearest demonstrations of the inseparable relationship between research and patient care is in the approach to both conceptualizing and implementing somatic gene therapy as the primary or only viable method of clinical management. Many disease processes, requiring the expenditure of huge amounts of funds and extracting an immense toll in human suffering, will come under control - in time - through the extension of gene therapy.

Bill Steen Chair  
Physgen + CEO  
Physgen  
212-573-3116

Jai Gons

Jordan  
Lauterbach  
Bradley

Physgen  
J&J  
Mensch

Donna  
& Yuhay Nale

Readers - comment device  
against ARE

put in a file for my 11:15a.m.  
meeting on Fri.

TO: IRA MAGAZINER  
CAROL RASCO  
ALEXIS HERMAN  
MOLLY BROSTROM  
CHRISTINE HEENAN

FROM: BOB HATTOY

RE: Invitees to Health Care Task Force meeting with AIDS organizations and service providers.

(This meeting is scheduled for Friday, April 16, 9am - 12 noon in the Indian Treaty Room).

(If you have any problems, additions or comments regarding these choices call me at 456-2866 by 12:00 noon on Wednesday.

---

1). BILL BAILEY: Washington, DC

- \*American Psychological Association
- \*Legislative analyst and lobbyist for HIV prevention issues

2). TERRY BESWICK: Washington, DC

- \*HRCF-largest Gay & Lesbian political organization in the U.S.
- \*AIDS research policy analyst
- \*AIDS treatment activist



3). LEONARD BLOOM:

Los Angeles, CA

- \*CEO of AIDS Project Los Angeles
- \*support and maintain quality of life for people living with AIDS
- \*provide vital human services to people with AIDS
- \*works to decrease the number of HIV cases, the level of fear and discrimination related to AIDS issues and to focus on education and prevention.

4). ANNE BROOMFIELD:

Baltimore, MD

- \*Greater Baltimore HIV & Health Services Planning Council
- \*recipient of Ryan White Title I funding
- \*African-American

5). DAN BROSS:

Washington, DC

- \*Executive Director of The Whitman-Walker Clinic
- \*Clinic provides AIDS care, testing, counseling and prevention

6). PAT CHRISTEN:

San Francisco, CA

- \*Executive Director, San Francisco AIDS Foundation
- \* she has been involved with organization for over 6 years, started as volunteer

7). MARTIN DELANEY:

San Francisco, CA

- \*Executive Director, Project Inform in San Francisco
- \*Founding Director in 1987
- \*former businessperson
- \*AIDS treatment and research issues

8). SONDRA ESTEPA:

New York, NY

- \*Executive Director of The Latino Commission on AIDS
- \*focuses primarily on outreach to the Latino community
- \*AIDS prevention, education, research and treatment services
- \*provide policy analysis and advocacy on AIDS issues effecting Latino community

9). DR. RUTH FINKELSTEIN: New York, NY

- \*Director of Public Policy at the GMHC in New York
- \*AIDS research issues

10). ELIZABETH GLAZER: Los Angeles, CA

- \*Director of The Pediatric AIDS Foundation
- \*issues directly related to children with AIDS

12). DEBRA FRAZER-HOWZE: New York, NY

- \*Executive Director/CEO of Black Leadership Commission on AIDS
- \*promote leadership and education on AIDS-related issues within the African-American community
- \*enhance service providers and input on public policy & funding
- \*African-American

13). JIM GRAHAM: Washington, DC

- \*Executive Director of The Whitman-Walker Clinic
- \*clinic is the primary community-based AIDS service provider in the DC area

14). MARK HARRINGTON: New York, NY

- \*Treatment Action Group (TAG) leader, 5 years
- \*small activist group, spinoff of ACT-UP
- \*focus on AIDS research issues

15). MARK ISHAUG:

Chicago, IL

- \*Director of Public Policy for The AIDS Foundation of Chicago
- \*involved with state and local lobbying effort on AIDS-related issues
- \*National Care Coalition to increase funding for the Ryan White Care Act
- \*Illinois Gay & Lesbian Task Force Policy Committee

16). MATHILDE KRIM, PhD.:

New York, NY

- \*Chair, the American Foundation for AIDS Research (AmFAR)  
-one of the original founders over 6 years ago in New York
- \*former cancer researcher

17). DR. BILLY JONES:

New York, NY

- \*Executive Director of Health and Hospitals Corporation
- \*African-American

18). JEFF LEVI:

Washington, DC

- \*Director of Public Policy for The AIDS Action Council
- \*represents community-based organization issues from research, drug development and regulation, health care financing and public health response
- \*lobbying, policy analysis, research and grassroots organizing

19). TODD SUMMERS:

Boston, MA

- \*Executive Director of The AIDS Housing Corporation
- \*advocacy on housing, legislation, funding for AIDS health care needs and issues
- \*Boston AIDS Consortium
- \*Project ABLE

20). SANDY THURMAN:

Atlanta, GA

- \*Executive Director of AID Atlanta
- \*responsible for planning and administering all programs and services for the Southeast's largest and oldest community-based service organization

# Withdrawal/Redaction Marker

## Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
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002. list	List of Invitees to Health Care Task Force meeting (partial) (1 page)	nd	P6/b(6)
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**This marker identifies the original location of the withdrawn item listed above.  
For a complete list of items withdrawn from this folder, see the  
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**COLLECTION:**

Clinton Presidential Records  
 Domestic Policy Council  
 Carol Rasco (Meetings, Trips, Events)  
 OA/Box Number: 4591

**FOLDER TITLE:**

AIDS Provider Groups 4-16-93 11:15 a.m.

rw137

**RESTRICTION CODES**

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
- P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
- P5 Release would disclose confidential advise between the President and his advisors, or between such advisors [a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]


- b(1) National security classified information [(b)(1) of the FOIA]
- b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
- b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
- b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
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- b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
- b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

20). REGGIE WILLIAMS:

San Francisco, CA

\*Executive Director of The National Task Force on AIDS Prevention based in San Francisco

\*multi-racial AIDS prevention organization-targets gay men of color

 with organization for over 6 years

\*African-American

21). PHIL WILSON:

Los Angeles, CA

\*National Minority Gay & Lesbian Association

\*AIDS Project Los Angeles

\*African-American