

pls review:

1) Bobby - NAPWA dues. paid?

Ben ~~X~~
Bobby ~~X~~
Hiroko —

THW File

February 13, 1995

Mr. Mike Shriver
Executive Director
Mobilization Against AIDS
584-B Castro Street
San Francisco, CA 94114

2) Ben-Ho

fy letter to NAPWA on quality of report.

Done

Dear Mr. Shriver: Mike

The National Association of People with AIDS (NAPWA) is pleased to send you the enclosed 1995 Public Policy and Legislative Agenda. In recognition of our on-going partnership, we would like to further strengthen your involvement with NAPWA by asking you to advocate on behalf of the issues we have outlined. More detailed policy statements on the topics highlighted are also available upon request.

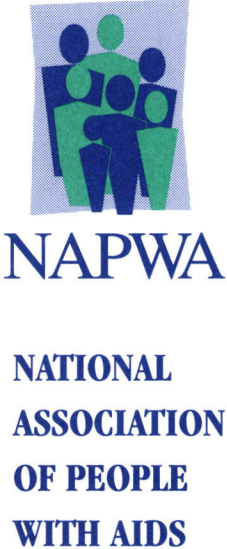
As our nation is considering fundamental changes in the relationship between individual citizens and various levels of government, we believe that meeting the needs and addressing the concerns of people living with HIV disease depends on focused action. We realize that we could never be effective if we attempted to take on every worthwhile cause or issue. For that reason, we have identified the key areas where our public policy department will concentrate its efforts in 1995. Under the direction of A. Cornelius Baker, Deputy Executive Director for Policy, our Policy staff will educate the Congress, the media, the public, and our own communities about key issues that effect us. They will also work in coalition with a broad assortment of individuals and organizations nationwide to advocate for reasoned and effective public policies.

NAPWA will continue to bring the voice of people living with HIV disease to important national policy issues that range from reauthorization of the Ryan White C.A.R.E. Act, to welfare reform, to HIV antibody testing. I know that we can count on your continued support.

Sincerely,

William J. Freeman
Executive Director

Enclosure



the
National
Association
of **People**
with
AIDS

1995
Public Policy
and
Legislative
Agenda



NATIONAL ASSOCIATION OF
PEOPLE WITH AIDS

Bartholomew T. Casimir
President, Board of Directors

POLICY COMMITTEE

Valerie P. Setlow, Ph.D.
Chair

Rubén García
Kathleen M. Gerus
Maureen A. Homenick

• • • • •

William J. Freeman
Executive Director

DEPARTMENT OF PUBLIC POLICY
AND EDUCATION

A. Cornelius Baker
Director of Public Policy and Education

Gary R. Rose, J.D.
*Associate Director for Legislative and
Regulatory Affairs*

Christina U. Lewis
*Community Education and Technical
Assistance Coordinator*

Lisa J. Ragain, M.A.T.
Program Assistant

• • • • •

Jeffrey S. Crowley, M.P.H.
Assistant Executive Director

Troy D. Petenbrink
Communications Coordinator

NAPWA PUBLIC
POLICY MISSION:

To bring an end to the AIDS epidemic by advocating for effective national policies in prevention, care for the infected, and research towards a cure; by working to affect change in the political and social systems that impede individuals in their attempt to lead long, healthy and meaningful lives; and to improve the lives of people living with HIV disease by activating the diverse communities affected by the epidemic.

OUR PRINCIPLES:

America must recognize HIV disease as a major health challenge affecting everyone and we all must respond appropriately.

The President of the United States MUST lead the nation's response to the HIV epidemic.

We can care for those who are already infected.

It is possible to live with HIV.

We can end the epidemic.

PERSPECTIVE

AIDS is the leading cause of death among men and the fourth leading cause of death among women aged 25-44 years in the United States. It is the primary cause of death for African-Americans aged 25-44 years. Since 1981, over 250,000 Americans have died from AIDS. Currently, more than one million people in the United States are believed to be infected with HIV.

The magnitude of the HIV epidemic, however, cannot be measured by counting the number of cases. HIV continues to cut a tragically wide swath across our society, adversely impacting a multitude of families, communities and social systems. Whereas many cancers and other disorders disproportionately impact the elderly, HIV largely strikes at people in the prime of their lives. This amplifies the devastating affects of the epidemic by depriving society of its most productive members. Sadly, the deaths of large numbers of men and women of childbearing age is also creating a substantial increase in the number of orphans. By the year 2000, it is estimated that 100,000 children will have been orphaned as a direct result of the HIV epidemic.

“Each month I decide either to eat or buy medicine.”

Since the beginning, the epidemic has been identified with gay men, hemophiliacs, and injection drug users. Increasingly it is concentrated in communities of color and among the poor. This, in turn, has fostered a fierce complacency among the many Americans who believe that HIV is not a factor in their lives. Despite these grim realities, a constructive and positive national response to the HIV epidemic can and must be mounted; centering on the needs and concerns of people living with HIV disease and the use of their experiences with discrimination, compassion, victimization and empowerment to assist the uninfected to remain uninfected. There has yet to be a sufficient mobilization of public will to mount a credible effort to end the HIV epidemic in the United States.

In 1992, NAPWA conducted a national needs assessment of people living with HIV disease in the United States. *HIV in America: A Profile of the Challenges Facing Americans Living with AIDS*, a baseline survey of approximately 1,800 individuals, documented that a central result of HIV disease is the financial devastation it wreaks upon nearly all those who become infected. When asked to identify their current unmet needs, nearly 60% of respondents expressed a strong need for financial assistance. Moreover, approximately one-third had

inadequate access to medicines, health insurance, legal assistance, and mental health services; one-quarter required better access to health care and transportation; and one-fifth needed assistance with employment and housing. Whatever their source of income, a large proportion of people with HIV live on very little money with 27.7% of respondents surviving on less than \$500 per month.

In addition to lack of financial resources, the study highlighted the chronic difficulty respondents had in accessing health care, benefits and entitlements. Other adverse experiences cited by respondents included system-wide acts of discrimination by health care workers, and a high level of personal violence experienced in all areas of life by people with HIV disease. In particular, the survey indicated that:

- Nearly one-half of respondents have had problems qualifying for group health insurance. Substantial numbers of people have had problems qualifying not only for health insurance, but Medicaid (30.8%), Social Security Disability Income (29.1%), private disability insurance (23.7%), and Supplemental Security

“I now have a one bedroom apartment where I do not have to pay rent. I have been here for two years, but I worry it will not continue.”

Income (28.3%). From 25-35% found themselves at risk of losing their coverage due to a variety of circumstances, the most basic of which was an inability to maintain premium payments. In addition, over 32% of the fully employed were unable to access health insurance and medicines, while 16.7% needed access to adequate health care.

- Many persons have experienced discrimination as a result of their HIV status, particularly when receiving health care (36.5%). Nearly one-quarter of respondents say that health workers seem afraid of them because they have HIV. These results support the findings of a study published in the *Journal of the American Medical Association* that concluded that 23% of young American resident physicians would not care for AIDS patients if they had a choice¹. The same study also noted that 39% of surgeons or other medical specialists have refused care to at least one of their HIV-infected patients.

- A high proportion of people reported being victimized by violence as a

result of their HIV status, both in the home (12.3%) and in the community (21.4%). Of particular grave concern is the level of violence experienced by women (17%) versus men (11.8%), especially among women of color — Latinas (25%) and African Americans (18.7%).

NAPWA's public policy agenda for improving the lives of people living with HIV disease is based on efforts to eliminate these circumstances. These broad areas pose major challenges to all people living with HIV disease. We recognize, also, the importance of expanding federal resources to combat HIV among heterosexuals and in the Hispanic and Black communities where the disease is now spreading rapidly.

For people who live each day with HIV as part of their lives, bad news and overwhelming challenges often seem unrelenting. Nonetheless, the past two years have brought many changes that form the foundation for a new national assault on these problems. Of special note is a \$100 million increase in prevention funding, without the regressive content restrictions that had previously been tied to AIDS education materials. And while it remains insufficient, funding has significantly increased for the Ryan White C.A.R.E. Act and for biomedical research.

The 103rd Congress also enacted the NIH Revitalization Act, which made significant changes in federal AIDS research including the establishment of the NIH Office of AIDS Research. The director of this office now coordinates all AIDS-related biomedical and behavioral research supported by NIH. The Congress has also taken steps to ensure that clinical trials are opened to women and people of color. Previously, women had been excluded from many AIDS clinical trials, thereby making it more difficult to assess the efficacy of drugs in treating their conditions.

In the past year, the Centers for Disease Control and Prevention (CDC) has taken a large step forward by creating the HIV prevention community planning process. The intent of this new prevention process is to better direct funding through the states to individual communities. These communities then have significant involvement in planning the type of prevention services that are most appropriate and effective for their specific needs.

In other areas, the Food and Drug Administration took a large step toward the prevention of HIV and other sexually transmitted diseases (STDs) among women by approving Reality™, a female barrier protection (condom) device, for commercial distribution. In addition, the NIH and CDC have expressed a renewed commitment to developing

microbicides, that will allow women to protect themselves from infection. At the end of 1994, the FDA finally gave approval for the marketing of Orasure™, a saliva-based HIV antibody test for which NAPWA has long advocated and that we believe will be extremely useful, in limited circumstances, for reaching people who will not or cannot initially avail themselves of the global-based system.

In January 1994, NAPWA worked with the Agency for Health Care Policy and Research to release guidelines on Evaluation and Management of Early HIV Infection. Although these guidelines are not comprehensive, they do provide a manual of selected protocols of particular use to primary care providers and consumers. We are now assisting the CDC in preparing guidelines on the prevention of opportunistic infections and disease progression for people with HIV infection. While these activities do not represent a cure, they are important steps toward crucial goals.

Of special note, in June 1993, President Clinton appointed Kristine Moore Gebbie as the nation's first National AIDS Policy Coordinator. In her position, Ms. Gebbie served as the senior coordinator of our government's response to the AIDS epidemic.

NAPWA strongly supported the creation of this office and attempted to work closely with Ms. Gebbie until May 1994, when her inaction compelled us to call for her resignation. Ms. Gebbie resigned and has been replaced by Patsy Fleming as the Director of National AIDS Policy. NAPWA remains committed to advocating for strong national leadership, and working with Ms. Fleming and the President toward our common goal of ending this epidemic.

“Help is not available in small communities.”

During much of 1994, the nation focused considerable attention on reform of our health care system. While reform legislation was not passed by the Congress, the need for change remains. The number of uninsured people in the United States has increased to almost 39 million; many of whom are people with HIV. This exercise, in which NAPWA and the HIV community was involved, was not necessarily a wasted opportunity. The states, the insurance industry and the biomedical research community are all beginning their own reform initiatives, and NAPWA has been following much of this activity. The work of NAPWA and other HIV advocates has also been strengthened by working in coalition with a broad array of disability and health activists. Whether change comes through a single piece of legislation or over an extended period of time

through incremental reforms, we remain committed to advocating for a more sensible and efficient health care system, as well as one that better serves the needs of people living with HIV disease.

The challenges before us remain great. The public appears to be growing extremely weary and tired of AIDS, and some people have begun to respond to HIV as a chronic, endemic health care problem that has been granted an inappropriately large measure of resources and attention to the detriment of other health problems. We are committed to reemphasizing the epidemic as a public health crisis in order to stir the nation's commitment to wiping out HIV disease. Unfortunately, we still face a health care system under great stress, and a community afflicted with increased rates of violence, depression, and trauma. Fiscal austerity and a public backlash against social spending, embodied in welfare and immigration reform, makes our work more difficult.

NAPWA's mandate is clear. We will refuse to allow despair to overwhelm our feelings of hope. People living with HIV disease are already leading longer and lives while our collective efforts are having an impact on improving the systems which affect our lives.

¹Shapiro, M.F. (July 1992). "Residents' experiences in, and attitudes towards, the care of persons with AIDS in Canada, France, and the U.S." *Journal of the American Medical Association* 268 (4): 510-515.

1995 POLICY & LEGISLATIVE AGENDA

Following are the key issues to which NAPWA's policy department staff and resources will be dedicated in 1995. This agenda does not reflect NAPWA initiatives on treatment and regard issues. Please contact us for individual papers describing our position or to learn more about our work on any issue.

- **Ryan White C.A.R.E. Act Reauthorization**

The Ryan White Comprehensive AIDS Resources Emergency (C.A.R.E.) Act has led to a profound increase in access to health care and other services for tens of thousands of persons living with HIV disease. In 1995, NAPWA will work to reauthorize and strengthen the C.A.R.E. Act.

- **Welfare Reform**

NAPWA recognizes that broad support exists for curbing public spending on social welfare programs and that many of these program mechanisms effectively create disincentives to productivity and self-determination. Nonetheless, NAPWA believes that we cannot address any of our great social challenges, whether we are talking about HIV, poverty, or racism, simply by turning

our back on the most vulnerable people and communities in our society. In 1995, NAPWA will advocate for creative solutions to reforming welfare that enable human development and self-reliance, yet which constantly guard the interests of our constituents currently receiving support from social welfare programs, especially those who are poor or were made poor by their health condition.

- Safe Drinking Water/Clean Water Act Reauthorization

An outbreak of cryptosporidiosis in Milwaukee that claimed the lives of more than one hundred people, the majority of whom were people living with HIV disease, focused attention on the need for stricter monitoring of our nation's water supply. NAPWA will continue its leadership role within the HIV community by working with environmental coalitions to strengthen rules protecting safe drinking water and by advocating for clean water legislation.

- HIV Antibody Testing

Some people seem to be losing hope because a cure for HIV appears to be increasingly unlikely in the near future. Nonetheless, people with HIV infection

are not helpless against their condition. Because early intervention allows people to live longer and with a greater quality lives, NAPWA strongly believes that every American should know his or her HIV status. In 1995, NAPWA will conduct a national campaign on the benefits of HIV antibody testing.

- Discrimination

Despite enactment of the Americans with Disabilities (ADA) Act and efforts to educate the public about HIV, discrimination against people with HIV disease remains pervasive in our society. NAPWA continues to work for greater enforcement of the ADA while advocating for individuals who have been denied fair treatment based on their HIV status.

- Violence

HIV in America, NAPWA's 1992 survey, highlighted the pervasive problem of HIV bias-related violence. In the spring of 1995, NAPWA will address this problem by convening, with the Anti-Violence Project of New York City, a workshop on the link between HIV status and violence in the home and community.

"I pray every night to stay healthy. My family does not know about me."

- Right to Die

A fundamental principle of NAPWA is that people living with HIV disease must have maximum control over their lives. In our view, this includes the right to choose to die with dignity. In 1995, NAPWA will work to expand laws which allow people to actively end their lives and will monitor state-based initiatives addressing this issue.

- HIV Prevention Community Planning

NAPWA hails the efforts of CDC to empower local communities with greater control of their HIV prevention planning process. In 1995, NAPWA will continue to provide technical assistance to state and local health departments and local prevention planning councils in an effort to address issues of inclusion, parity, and representation of people living with HIV disease in the prevention community planning process. NAPWA will also continue to advocate for greater resources in the federal budget for community prevention efforts.

- Increased Secondary Prevention Efforts

Secondary prevention is crucial to the effort to aid people with HIV to remain healthy for as long as possible. Additionally, individuals who adopt sec-

ondary prevention behaviors may be more likely to engage in behaviors that reduce their risk of transmitting HIV to others. In 1995, our community education and technical assistance program will focus on primary and secondary prevention issues for people living with HIV disease.

- Needle Exchange

Recent studies conducted in New York City by the American Foundation for AIDS Research suggest that needle exchange programs can be effective at reducing the spread of HIV. NAPWA supports the expansion of needle exchange programs, but also believes that needle exchanges cannot ethically be made available to individuals without also providing for substance use/injection use counseling and treatment. In 1995, NAPWA will advocate for Federal funding of needle exchange programs.

- Health Care Reform

In 1994, the nation witnessed Washington's failure to create fundamental changes in our health care delivery system. While there appears to be little current support for dramatic reform, economic realities will continue to drive efforts to change the system. In 1995, NAPWA will monitor national reform efforts and trends among states in order to continue our advocacy for expanded access to health care for all

Americans in the belief that the treatment of people living with HIV disease in any health care system will be a good measure of how successful that system is for the public as a whole.

- **Viatical Settlements**

NAPWA has a longstanding position of supporting the right of people with life insurance to viaticate or sell their policies. While we are cognizant that this does not affect the majority of people living with HIV disease, it does provide a godsend for many people with life insurance and mounting medical cost and other expenses. NAPWA will continue to advocate for protecting the ability of all with life threatening illnesses to exercise this option and to the creation of tax-free status.

- **Gay and Lesbian Civil Rights**

NAPWA continues to call attention to the spread of the HIV epidemic into

many diverse communities in the United States. We believe that everyone should recognize that they are at risk for infection. Nonetheless, the majority of cases of HIV infection are among gay and bisexual men. Homophobia and life lived in the closet foster shame and ham-

per behavior change efforts that prevent new HIV infection. Therefore, in 1995, NAPWA will advocate for gay and lesbian civil rights as the most efficient means to effectively assist people at risk.

- **Endangered Species Act**

The search for new therapies and cures for chronic diseases has often ended in rain forests and exotic plant and animal life. To protect natural resources that could harbor a treatment or cure for HIV, NAPWA will continue to work with environmental organizations to ensure reauthorization of the Endangered Species Act.

"I was just cut off from Medicaid without a hearing - I worry about this."

NAPWA'S PUBLIC POLICY & EDUCATION PROGRAMS

Public Policy and Advocacy:

NAPWA identifies, researches and generates positions on critical issues that impact the lives of people with HIV disease. NAPWA produces change by disseminating information and educating people living with HIV disease, the general public, the media, and our national leaders. The department publishes a quarterly publication, The Active Voice.

Legislative and Regulatory Affairs:

NAPWA monitors and works closely with the executive and legislative branches of the federal government. Occasionally, when a precedent-setting issue is involved, we also work at the state or local level. NAPWA's role is to make government responsive to the needs of its citizens and residents living with HIV disease.

Community Education and

Technical Assistance:

NAPWA builds the capacity of local communities of people with HIV disease to advocate for, operate, and participate in effective and responsive programs. A particular focus of the technical assistance program is to enable people with HIV disease to participate in the decision-making processes for programs that affect their lives.

Grassroots Development:

NAPWA's grassroots development seeks to recruit and enhance the capacity of individuals to advocate for policies that meet the needs of people living with HIV disease on the national level. Of particular note, NAPWA will coordinate AIDSWatch '95 which is a collaboration of AIDS service organizations across the nation that brings hundreds of people with HIV to Congress to advocate for federal resources.

Coalition Participation:

Strength lies in numbers and among a diversity of opinions and outlooks. NAPWA's centrist, non-partisan position within the HIV community allows us to work constructively with a broad range of groups and individuals. NAPWA participates in coalitions with other AIDS organizations and with other advocacy groups to broaden the impact of our advocacy work and maximize the possibilities for positive change.

The following are key coalitions in which NAPWA participates:

- National Organizations Responding to AIDS (NORA)
- Coalition on Consumer Health & Safety
- Prevention Action Group (PAG)
- National HIV/Immigration Working Group
- Consortium for Citizens with Disabilities

NAPWA

The National Association of People with AIDS is dedicated to improving the lives of people with HIV disease at home, in the workplace and in the community. Since 1983, when a group of people with AIDS from across the nation met in Denver, Colorado and produced the Denver Principles — a statement of self-empowerment for people with AIDS — NAPWA has served as the “voice” for the needs and concerns of all people infected and affected by HIV/AIDS in the United States.

The magnitude and challenges of the HIV epidemic are often masked by statistics and often ignored or overly dramatized by the media. NAPWA works to focus national attention on the realities faced by people living with HIV disease. We support all communities affected by the AIDS epidemic with information and educational resources, technical assistance and advocacy.

In an effort to facilitate a richer quality of life for HIV-infected individuals and to create a unified national response to the epidemic, NAPWA fosters coopera-

tion among people with AIDS, professionals, organizations, businesses and government.

For more information on NAPWA's programs, please contact us at:

**National Association of
People with AIDS**

1413 K Street, NW
7th Floor
Washington, DC 20005
202.898.0414 - Voice
202.898.0435 - Fax

We gratefully acknowledge the support of the following who make our public policy and education work possible.

AT&T Foundation

Aetna Life & Casualty Co.

The Body Shop

Paul Rapoport Foundation

and

The U.S. Centers for Disease Control and Prevention (for technical assistance on HIV Prevention Community Planning)

May 3, 1995

MEMORANDUM FOR: WILLIAM FREEMAN
MICHAEL SHRIVER

FROM: A. CORNELIUS BAKER *AKB*

SUBJECT: CANDLELIGHT AGREEMENTS

Attached is a final draft copy of the agreement of partnership between NAPWA and Mobilization to coordinate the 1995 candlelight observance. If it is okay, Mike should sign his copy and return it for Bill's signature. Please do this by Friday.

Also, for Bill's information, attached is a copy of the agreement between Mobilization and Gregory Adams (as the consultant) and a copy of the draft budget. I think the consultant's agreement is fine and adequately reflects NAPWA's understanding of his duties. The budget presents no real problems, but please note that there is a current shortfall between pledges and budget which we will monitor. This should not present a problem and solicitation of other contributions continues.

Gregory has requested payment and because he is not working I get the impression that this is urgent for him. I informed him today that as soon as all the agreements are signed I will submit a check request for his first payment. We have received a thousand dollar contribution from NASTAD which would cover this expense.

Please
send
to NAPWA
mjb

AGREEMENT OF PARTNERSHIP
BETWEEN THE
NATIONAL ASSOCIATION OF PEOPLE WITH AIDS
AND MOBILIZATION AGAINST AIDS

The National Association of People with AIDS and Mobilization Against AIDS agree to co-produce the 1995 International Candlelight Memorial & Mobilization (the candlelight) observance in Washington, D.C. on May 21, 1995. The terms of this agreement are as follows:

The National Association of People with AIDS

Agrees to the following:

1. To serve as the Washington, D.C. coordinator of the candlelight.
2. To serve as the fiscal agent for the local observance, including the receipt and distribution of all funds as defined in the agreed upon budget.
3. To provide workspace, telephone, and other resources to the project manager (consultant) designated by Mobilization Against AIDS.
4. To assist the consultant in solicitation of local co-sponsors for the candlelight, including in-kind contributions.
5. To assist the consultant in arranging speakers and soliciting volunteers for the candlelight.

Mobilization Against AIDS

Agrees to the following:

1. To hire and designate a Washington project manager (consultant) for the candlelight, including establishing salary and terms of contract.
2. To monitor the activities of the consultant.
3. To develop and provide to NAPWA a budget for the candlelight (attached).

The primary duties of the consultant shall be as follows:

1. To develop and implement the program for the candlelight.
2. To obtain all necessary permits and government assurances for the candlelight

ID:

MAY 03 '95 17:35 No.042 P.03

Page 2 - Partnership Agreement for 1995 Candlelight Observance

observance.

3. To coordinate publicity and promotion for the candlelight, including local community participation and media..
4. To coordinate production of the event, including negotiating contracts with vendors. All contracts will be reviewed by NAPWA prior to signing. The consultant will be responsible for all non-approved expenses.

This agreement will become effective April 28, 1995 and terminate on June 15, 1995, subject to the renewal of the executive directors.

William J. Freeman
Executive Director
National Association of People with AIDS



Michael Shriver
Executive Director
Mobilization Against AIDS.

January 20, 1995

Michael D. Shriver
Mobilization Against AIDS
584-B Castro St.
San Francisco, CA 94114

Dear Mr. ^{Mike} Shriver:

If we are to be successful in our efforts to combat HIV related diseases and eliminate transmissions, it becomes apparent that secondary prevention must move into the forefront of prevention and treatment strategies. Yet very little is understood about this strategy and there is even less agreement as to how to implement comprehensive secondary prevention.

The National Association of People with AIDS invites you to participate in a discussion on secondary prevention. Entitled, "Creating a Framework for Secondary Prevention," the purpose of the meeting is to discuss and summarize secondary prevention issues for people living with HIV disease. The group will work to make recommendations on the integration of these service needs through Ryan White CARE services, HIV Prevention programs, and other programs.

Enclosed, you will find the agenda for the workshop. It would be appreciated if you could comment during Session I on perspectives of secondary prevention. This should be a five minute presentation on secondary prevention from the constituent perspective.

This meeting will be held on February 9, 1995, 9:00 am to 4:00 pm, in Washington, DC. The location is the American Psychological Association at 750 First St., NE, in Room 4054.

Please confirm your participation by FAX to 202.898.0435 by Monday, January 30, 1995. If you have any questions, please contact Lisa Ragain at 202.898.0414, ext. 11. We look forward to your participation.

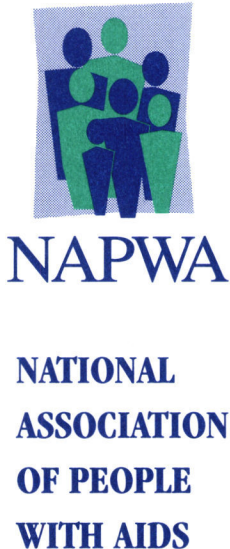
Sincerely,

Conroy

A. Cornelius Baker
Director, Public Policy and Education

Enclosure

*Send reports. There...
can't be there...
John*



1413 K Street, N.W.,
Washington D.C. 20005
Phone: (202) 898-0414
FAX: (202) 898-0435

CREATING A FRAMEWORK FOR SECONDARY PREVENTION

Purpose: A roundtable discussion on the design and integration of secondary prevention services for people living with HIV disease through Ryan White CARE services, HIV Prevention programs and other services.

Breakfast - 9:00 - 9:30

I. Introductions (9:30 - 10:00)

- A. Around the table
- B. Statement of purpose, - historical perspective - epidemiological and sociological profiles, how needs and delivery of services have changed

II. Session I (10:00 - 11:15)

- A. Perspectives of Secondary Prevention
- B. Discussion

Break - 10 Minutes

Summary of morning topics (11:30 - 12:00)

III. Lunch (12:00 - 1:15) on your own

IV. Session II (1:15 - 2:00)

- A. Implementation of Secondary Prevention programs
- B. Discussion

V. Session III (2:00 - 2:50)

- A. Improved delivery of Secondary Prevention
- B. Discussion

Break - 10 Minutes

VI. Summary of afternoon discussion (3:00 - 3:30)

VII. Conclusion (3:30 - 4:00)

Adjourn - 4:00

CREATING A FRAMEWORK FOR SECONDARY PREVENTION

FEBRUARY 9, 1995

9:00 AM - 4:00 PM

MIKE SHREWER, EXECUTIVE DIRECTOR
MOBILIZATION AGAINST AIDS

YES, I WILL ATTEND THE WORKSHOP: _____

NO, I WILL BE UNABLE TO ATTEND: X

WITH REGRETS.

PLEASE FAX ATTENTION TO LISA RAGAIN AT 202.898.0435, BY **JANUARY 30, 1995.**

February 3, 1995

Attention: Bobby Rosenthal, Administrative Director

Bobby, thanks for taking the time to check out the availability of the MAA Offices for the following days:

Monday Evening
beginning February 6, 1995
6:45 p.m. to 9:15 p.m.
5 weeks

Wednesday Evening
beginning February 8, 1995
6:45 p.m. to 9:15 p.m.
10 weeks

In our conversation of last week, I believe that we agreed that you would add \$10.00 a week per class to our "gift" to MAA. If this is not so, please discuss this with Andy Lisac and then I will speak with you later to bring closure to our deal.

Thanks,

Bill Macatee

OK
MS
2/3/95
2/3/95
for Monday
for Sun 3/4 - Sun 2/5



**New York City
Gay and Lesbian
Anti-Violence Project**

June 14, 1995

Michael Shriver
Mobilization Against AIDS
584-B Castro Street
San Francisco, CA 94114

Dear Mr. Shriver,

On behalf of the New York City Gay and Lesbian Anti-Violence Project (AVP) and the National Association of People with AIDS (NAPWA), we welcome your participation in the upcoming **National Workshop on HIV and Violence**. We are so pleased that you have agreed to share your expertise. This letter will provide you with further information and logistic instruction.

As earlier registration materials indicate, the Workshop will be held at the **Gramercy Park Hotel on Thursday, June 29 and Friday, June 30**. If you have not yet reserved your room for Wednesday and Thursday nights, we urge you to do so by calling the Gramercy Park Hotel at **1-800-221-4083**. Identify yourself as a National Workshop on HIV and Violence participant and you will be booked at the discounted rate of \$95.00 for a room with one double bed (single or double occupancy) or \$125.00 for a room with two double beds (double, triple or quadruple occupancy). The hotel is located at 2 Lexington Avenue at 21st Street, on the northern edge of Gramercy Park, a lovely landmark neighborhood and private park.

Travel arrangements may be made through your own agent, or by contacting Pat Dasent at Omega Travel in New York City at (212)867-7009. Anyone requesting scholarship assistance for travel and/or lodging should have received confirmation and instruction by the time you receive this letter. If you have not received confirmation, please contact Leslie Herzik at (212)807-6761.

The Workshop begins promptly at 8:30 am on Thursday. All Workshop events will take place in the **Park Suite**, on the hotel's second floor, and in the adjoining **Gramercy Room**. There will be a **check-in table** open in the **hotel lobby on Wednesday night from 6:00-8:30pm**, and in the **Park Suite on Thursday morning from 7:45-8:30am**.

When you check in, you will receive your focus group assignments, updated agenda materials, and a literature packet. Coffee, fruit and danish will be provided on Thursday and Friday mornings. Both Workshop days include a **working luncheon**, with both vegetarian and non-vegetarian options. Additionally, a **reception** will be held in the Roof Garden on Thursday evening, featuring a reasonably-priced cash bar and beautiful Manhattan views. Dinner Thursday night is on your own.



NAPWA

**NATIONAL ASSOCIATION
OF PEOPLE WITH AIDS**

*10/27 pm
597 88 06
Gramercy Park
HOTEL
2134
CONFIRMATION

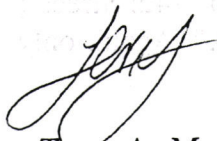
4/28-7/2*

As indicated on your Agenda, **breakout focus groups** are an essential part of the Workshop. These groups will discuss issues raised in plenaries and formulate ideas and recommendations, for example, guidelines for police training on HIV and violence, or for instituting domestic violence screening in HIV clinic settings. You will be assigned to one focus group which will meet twice on Thursday, comprised of persons from a mixture of backgrounds and expertise. You will be assigned to another focus group with persons of similar background and experience, which will meet once on Friday. You will receive your focus group assignments when you check in on Wednesday night or Thursday morning.

Anyone wishing to submit a **poster presentation** should return their registration slip as soon as possible to AVP. Poster presentations, which will be displayed during Thursday's reception and Friday's luncheon, should be designed to fit on a flat area measuring 3'x 4', maximum. Please mail the materials at least **one week ahead of time** to AVP, and we will mount the materials for you to ensure format standardization. If you have a pre-mounted display that you wish to bring, contact Leslie Herzik at (212)807-6761 to discuss logistics.

Again, thank you for your commitment to addressing violence against persons with real or perceived HIV infection. As this is an expert meeting with the goal of issuing a set of conclusions and recommendations, please be aware that all proceedings will be tape recorded. Finally, there will be peer counseling available for any person who may need it as a result of addressing these issues. We look forward to working with you on this important project.

Sincerely,



Terry A. Maroney
HIV-Related Violence Program Coordinator,
AVP



A. Cornelius Baker
Deputy Executive Director for Policy,
NAPWA

Travel Instructions

Air Travel. You may fly into Newark, Kennedy or La Guardia airports, but ground travel is easiest and cheapest from La Guardia. Each airport has a ground transportation desk, located near the baggage claim area, where you can ask any questions you may have.

From **La Guardia**, you may take a taxi or shuttle. If you take a taxi, a licensed dispatcher at the marked taxi stand will direct you to a yellow cab. Don't accept rides from others who may approach you. A yellow cab should cost roughly \$15.00-20.00, depending on traffic. Gray Line offers bus service directly to the Gramercy Park Hotel. The fare is \$13.00. Carey Transportation offers bus service to Grand Central Station. From there you can take a taxi or the downtown 6 train to "23rd Street." The fare is \$10.00. Finally, for experienced New York City travellers looking to save money, a City bus (Q33) is available to take you to the Roosevelt Avenue train station, where you can catch the E or F train to Manhattan. You will transfer to the downtown 6 train at "Lexington - 3rd Avenue" and get off at "23rd Street." The hotel is two blocks downtown. This is the slowest and riskiest option.

From **Kennedy Airport**, you can also take a taxi or shuttle, though prices will be significantly higher as it is farther away. Observe the above safety precautions as regards unsolicited offers for cab rides. Gray Line operates out of Kennedy at a rate of \$16.00. Carey buses are available at a rate of \$10.00. A shuttle bus goes from Kennedy to the "JFK Airport" station of the A and C subway line, which you can take to Manhattan. Transfer at "Broadway-Nassau" to the uptown 4 or 5 train to "14th Street"; at 14th Street, cross the platform and take the local 6 train to "23rd Street." Again, only take the subway if you are familiar with New York City.

From **Newark Airport** you can take a shuttle to the Port Authority bus station, and then take a taxi or the subway. From Port Authority, take the 7 train across town to Grand Central Station and change to the downtown 6 train to "23rd Street." You can also take the PATH train from New Jersey to 23rd Street and 6th Avenue, and take a taxi from there. Gray Line operates out of Newark at a rate of \$18.00.

Train Travel. If you take a train, you will arrive in either Penn Station or Grand Central Station. From Penn Station, it is easiest to take a yellow cab from the marked taxi stand. From Grand Central, you can take the downtown 6 train to "23rd Street."

Driving. Gramercy Park Hotel is easily accessible by car and is located at the corner of Lexington Avenue (which runs south) and 21st Street (which runs west). There is no hotel parking lot and leaving a car on the street can be risky. There is a parking lot nearby, however, which offers discounted rates for Gramercy Park guests. Unique Parking is located at 41 East 21st Street (Between Park Avenue South and Broadway). The discounted rate is \$34.00 for 48 hours.



June 1, 1995

fn Bd mt

Dear Partner in the Fight to End HIV Disease:

We are writing to inform you of the official launch of the campaign by the National Association of People with AIDS (NAPWA) to encourage voluntary HIV-antibody testing and counseling. As a component of the campaign, NAPWA, in partnership with the National Alliance of State and Territorial AIDS Directors and the National Lesbian and Gay Health Association, have declared June 27 National HIV Testing Day. We are excited about this initiative and we hope to have your support in promoting the campaign. The following will give you more important information about the campaign:

RATIONALE

Over the past decade HIV antibody testing has been a controversial issue among those active in the HIV/AIDS arena and for those individuals who presumed themselves to be at risk. People were reluctant to be tested and few organizations encouraged testing for a number of reasons:

- 1) people interpreted a positive HIV test as a "death sentence" because of the limited treatment options;
- 2) partner notification and name reporting interfered with a person's privacy and confidentiality concerning their HIV status; and
- 3) acts of discrimination against people known to be or perceived to be HIV positive were widespread.

Medical and social advances of the past decade, however, lead us to the conclusion that everyone can now benefit from voluntary testing and comprehensive education and counseling.

As a result of new therapeutic medicines, especially treatments for opportunistic infections, and better nutritional regimens, HIV disease has become a more manageable condition. Equally important, we know that the earlier an infected person begins to monitor his or her health, the better the chances to stay healthy and live longer.

At the same time, disincentives to testing arising from civil rights concerns have been reduced. With the adoption of the Americans with Disabilities Act, people with HIV now have legal protection from those acts of discrimination which were the most problematic results of identification of an individual's HIV sero-status. However, acts of discrimination remain a chronic problem. We continue to urge people who do want to get tested to do so at an anonymous or confidential testing site and, if necessary, to protect their status from those with no need to know. Finally, the general public has grown more sympathetic and tolerant towards people struggling with HIV/AIDS, and this will continue to increase with education, awareness and visibility.

Therefore, while living with HIV remains difficult for a whole battery of medical, social and psychological reasons, NAPWA believes that HIV testing, when coupled with clear and comprehensive education, privacy and early intervention, has come to offer benefits that outweigh potential harm for the person being tested. Many community-based organizations, such as AIDS Project Los Angeles, Gay Men's Health Crisis (NY) and Whitman-Walker Clinic (Wash, DC), have begun promoting HIV testing and counseling on a local level; we intend to now take that message nationwide.

(over)

1413 K Street, NW
Washington, DC
20005-3405
tel (202) 898-0414
fax (202) 898-0435
NAPWA fax
(202) 789-2222

OUTLINE OF THE CAMPAIGN

This year, NAPWA will conduct a "soft launch" of the campaign. The principle purpose of this introduction of the campaign is to create awareness of the concept among AIDS service organizations and to generate public awareness of the campaign's message among key target populations. NAPWA will utilize a grassroots poster campaign, news media, public service announcements (television & radio) and print advertisements during this phase. We hope to create national media attention to this issue and to achieve local participation in the major state/urban areas with high prevalence rates.

States targeted for heavy radio PSA distribution (top 50 stations) :
(PSA will be distributed to top 10 stations in all remaining states and territories)

New York
Texas

California
Florida

Illinois

Cities targeted for print advertisements:

Boston
Chicago
Washington, DC

Miami
Houston
San Francisco

New York
San Juan
Los Angeles

HOW YOUR ORGANIZATION CAN HELP

- 1) Alert your various members and constituents about the campaign.
- 2) Use the campaign as an opportunity to promote your organization's mission and the impact HIV/AIDS is having on the United States and the world.
- 3) Endorse National HIV Testing Day.

It is by speaking in one voice -- one very loud voice -- that we make our best efforts towards ending HIV disease. Your participation makes a difference!

If you would like more information about our campaign, please contact Troy Petenbrink, NAPWA's Communications Coordinator, at 202/898-0414 ext. 12.

Until there's a cure,



William J. Freeman
Executive Director



1413 K Street, NW
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fax (202) 898-0435
NAPWA fax
(202) 789-2222

June 7, 1995

Gene Jones, Chair
Mike Shriver, Executive Director
Mobilization Against AIDS
1540 Market Street
Suite 160
San Francisco, CA 94102

Dear Gene and Mike,

NAPWA is fully aware of the longstanding advocacy work of Mobilization Against AIDS. To this end, I am enclosing a membership solicitation letter recently sent by Mark Barnes, Executive Director of AIDS Action Council. Therein, Mr. Barnes states that AIDS Action has "led", "have led", "single-handedly are leading", and "prevailed" regarding Ryan White reauthorization and HOPWA activities. Further, Mr. Barnes asserts that AIDS Action is "the largest and by far the most effective AIDS advocacy group in the nation."

I am enclosing this letter along with my response to Mr. Barnes. Despite repeated attempts, he has chosen not to speak with me. My letter has been copied to the executive committee of NORA and will become an agenda topic at an upcoming meeting. As you are aware, NAPWA is a NORA co-chair. While I made every attempt to discuss this matter privately with Mr. Barnes, I will not allow such self-serving grandstanding to misrepresent the collaborative work of a broad based national coalition of AIDS activists.

NAPWA respects and appreciates Mobilization's leadership and commitment to being a force of change in the face of an ever increasing epidemic.

Warm personal regards,

William J. Freeman
Executive Director

Mark Barnes
May 31, 1995
Page 2

Unfortunately, this type of posturing has long been common to the AIDS Action Council. Many of us had hoped that with a change in executive leadership at AIDS Action, there would be an opportunity for a true Washington-based AIDS advocacy coalition. This letter combined with recent actions of the Council, unfortunately, bodes poorly for any true change.

On behalf of people living with HIV/AIDS who are depending on the success of our collective work in Washington, I would request that you honestly work as a partner in a collaboration that is much wider than AIDS Action.

Sincerely yours,

A handwritten signature in cursive script, appearing to read "W. Freeman".

William J. Freeman

cc: National Organizations Responding to AIDS (NORA)
Executive Committee



May 31, 1995

1413 K Street, NW
Washington, DC
20005-3405
tel (202) 898-0414
fax (202) 898-0435
NAPWA fax
(202) 789-2222

Mark Barnes
Executive Director
AIDS Action Council
1875 Connecticut Avenue, N.W.
Suite 700
Washington, D.C. 20009

Dear Mark,

Last week, it came to my attention that you had sent out a membership solicitation letter claiming sole responsibility for recent successes in the House and Senate. I am attaching a copy of this letter that was forwarded to NAPWA by one of our constituents who was deeply concerned about the suggestion made in this membership appeal as it relates to NAPWA's work and that of other AIDS organizations. On Friday and again yesterday, I attempted to discuss this matter with you. Since you have chosen to ignore my request for a conversation, I am putting to paper my concerns and copying this letter to NORA's executive committee.

We who represent those living with HIV/AIDS find the overreaching nature of your comments insulting and disrespectful of the true coalition that has been and continues to be responsible for the "successes" that the HIV community has achieved with Congress over the past few months. For you to claim that AIDS Action "led", "have led", "single-handedly are leading", and "prevailed" in work related to either Ryan White reauthorization or HOPWA is insulting and continues to set up a dynamic that is harmful to coalition building. And to add insult to injury, to claim that AIDS Action is "the largest and by far the most effective AIDS advocacy group in the nation" is simply wrong.



Dear

I am delighted to inform you of two recent successes accomplished by AIDS Action Council which demonstrate some of the ways we benefit organizations such as yours.

As Congress debates issues like the Ryan White CARE Act, Housing Opportunities for People with AIDS (HOPWA) program, and Medicaid, we represent your interests in the Senate and House.

RYAN WHITE - The CARE Act will expire in September, and as you probably know, it has been widely mentioned as a candidate for severe cutbacks or even extinction. Any funding you receive via Ryan White is therefore entirely at risk. Instead of waiting until the last minute and facing an uphill fight in Congress, we led a well thought-out acceleration of the re-authorization process. For example, in March and April, we worked intensely to develop a comprehensive bill with Nancy Kassebaum (R-KS) and Ted Kennedy (D-MA) that provides for a five-year re-authorization and not only preserves the Act's fundamental integrity and distinct funding, but also reflects the changes in the epidemic over the last five years. Moreover, we are pleased to report that in the Senate, we have led the effort to persuade 57 senators to co-sponsor this bill, which should be coming to the floor soon.

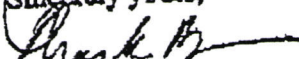
HOPWA - Despite enormous pressure from very outspoken senators and House members to rescind all of the \$186 million fiscal year 1995 HOPWA funds, we single-handedly are leading the advocacy effort to preserve the funding. While the House voted to cut 100% of HOPWA money, due to our efforts the Senate preserved all of the funding. Overcoming fierce opposition by House members, we prevailed in the Senate-House conference committee agreement with just a 16% reduction. And, we continue to press for full funding.

1975
Connecticut Ave NW
Suite 701
Washington DC
20009
Fax 202 966 1345
Tel 202 966 1300

We are the largest and by far the most effective AIDS advocacy group in the nation, and we work for your interests full-time. Our principal mission is to help your organization receive federal funding. In turn, we need your financial support. Therefore, I would greatly appreciate it if you would become a 1995 member of AIDS Action today by returning the enclosed membership form.

If I can be of service, please call me at (202) 966-1300 ext. 11. I look forward to you supporting AIDS Action.

Sincerely yours,


Mack Barnes
Executive Director



1413 K Street, NW
Washington, DC
20005-3405
tel (202) 898-0414
fax (202) 898-0435
NAPWA fax
(202) 789-2222

June 12, 1995

Mike Shriver
Mobilization Against AIDS
584-B Castro St.
San Francisco, CA 94114

Dear Mike:

NAPWA would once again like to thank you for your contribution to our manual on HIV Prevention Community Planning, *The Positive Input*. The Community Education and Technical Assistance program is in the process of producing the second edition of *The Positive Input*, and would greatly appreciate your taking the time to review, and if necessary, update your article.

We have enclosed the original copy of your article, and would appreciate receiving any changes you feel are necessary by **June 26, 1995**. NAPWA is continuing our series of regional workshops on community planning, and the second edition of the manual must be completed prior to the first workshop in early August. You will receive a copy of the second edition of *The Positive Input* as soon as it is completed.

Thank you for taking the time to review your article. Your contribution is very important to the success of the manual. If you have any questions or comments, please do not hesitate to call myself or Lisa Ragain at 202.898.0414.

Sincerely,

Beri Hull
Community Education and
Technical Assistance Coordinator

A Brief History of Federal HIV Prevention Funding

By Mike Shriver

The history of HIV prevention funding from the U.S. government is a political and puzzling one. This funding covers all fifty states, the District of Columbia, U.S. territories, and the six major cities treated like states by the Centers for Disease Control and Prevention (CDC). One of the easiest ways to understand the magnitude of the HIV Prevention Community Planning process being put in place is to take a quick look at how we got to where we are.

It is important to remember that the CDC is the federal health agency principally responsible for funding HIV prevention efforts across the United States and the territories. While some HIV prevention efforts are funded through the National Institutes of Health (NIH) and the Substance Abuse and Mental Health Services Administration (SAMHSA), the CDC has been the key player in the federal HIV prevention funding arena.

HIV prevention efforts have been hampered from the earliest days of the epidemic. In 1984-85, the CDC began their first funding for "AIDS Innovative Risk Reduction Strategies" using both their competitive grant program and the "cooperative agreement" program (a block grant) as funding mechanisms. As early as 1986, however, the first guidelines issued by the CDC concerning the type of information that could be included in a community educational piece (as well as what kind of program that could be

developed) mandated that these materials and programs should not be "offensive" to "most educated adults."

1987 saw the passage of the infamous "Helms Amendment." This was passed as part of a bill that appropriated money for the CDC. The amendment stated that CDC-funded materials could not "promote or encourage, directly, homosexual activities" or "drug abuse." The amendment threatened to cut off all federal funding for programs addressing the two most significant risks for HIV infection (unsafe sex or unsafe needle use). In effect, we could not have honest talk about these activities in any educational materials developed with CDC money.

Around this time, several cities began receiving direct funding from the CDC for their HIV prevention activities (as well as HIV/AIDS surveillance). These cities, now known as the "Cooperative Agreement Cities," were the epicenters of the HIV/AIDS epidemic at the time. This recognition of epicenters of the epidemic is still with us today. In 1994, there are six Cooperative Agreement cities: New York, Los Angeles, San Francisco, Houston, Chicago and Philadelphia (Philadelphia was not one of the original cities in this category and did not become a Cooperative Agreement City until 1990).

In October of 1988, the Gay Men's Health Crisis (GMHC) filed a lawsuit

against the CDC because of the Helms Amendment. They believed that the CDC was unconstitutionally using the Helms Amendment when making grants. It wasn't until May 11, 1992 that the court finally decided in favor of the GMHC position. (Between October, 1988 and May, 1992, there was one interim court decision which ruled against GMHC but gave them enough room to appeal this decision. The appeal was ultimately successful.)

The first modification of the extremely outrageous Helms Amendment came in 1988 when Congress passed their appropriations bill for 1989 (which included money for the CDC). This modification was an amendment by Senators Ted Kennedy of Massachusetts and Alan Cranston of California. The "Kennedy-Cranston Amendment" modified the strong Helms Amendment and stated that CDC-funded programs should not be "designed to promote or encourage, directly, intravenous drug abuse or sexual activity, homosexual or heterosexual." By inserting the phrase, "designed to promote," this amendment gave HIV prevention programs more leeway in addressing current activities that placed people at-risk, without having to be concerned about "promoting" behaviors. It appears, in retrospect, to be a minor change, but given the tenor of Congress, this small change in language is actually significant. By the way, the Kennedy-Cranston Amendment stayed in effect from 1989 to 1991.

In 1990, Congress passed the Ryan White CARE Act, the first piece of federal legislation with specific authorized funding levels for HIV/AIDS care. The CARE Act was in part a reaction to the fact that the Reagan and Bush administrations had neglected HIV/AIDS care. While the funding of the CARE Act has no relationship to funding for HIV prevention in its legislation, there is an historical complication between HIV prevention funds and CARE. In 1991, Congress cut the CDC budget, overall, by \$15 million. This money was moved by Congress from the CDC to the Health Resources Services Administration (HRSA) for their 1992 budget. HRSA was Congressionally directed to spend this money in the CARE Act, but the CDC was not directed by Congress as to where it was to take this \$15 million cut.

What the CDC did was to cut HIV prevention funding for 1992, and specifically reduced funding that went directly into national minority and regional minority programs, as well as direct funding for organizations that serve communities of color. This outraged many of these organizations and led to the birth of the "Campaign for Fairness," a coalition of gay and bisexual men of color prevention advocates who advocated before Congress to correct this problem.

1991 also saw the revelation that Magic Johnson had tested positive for HIV. This event compelled the CDC to release a one-time funding allowance to deal with the

increased public demand for HIV antibody testing brought on by Magic's announcement. It is important to remember that by this time, Congress had also directed the CDC to mandate that at least 65 percent of their cooperative agreement funding to the states, territories and cities had to be spent on counseling, testing, referral and partner notification (CTRPN). Congress, which had reduced funding for the CDC, was now mandating how the CDC was to direct the states, territories and cities to spend their limited HIV prevention dollars.

In 1992, the year GMHC finally won their court case against the CDC, two separate initiatives began to address comprehensive HIV prevention reform and advocacy. On the east coast, the development of *Blueprint for HIV Prevention* was begun under the direction of AIDS Action Foundation (and the AIDS Action Council), while on the west coast, the Greater Bay Area HIV Prevention Reform Working Group began working with Congressperson Nancy Pelosi of San Francisco on the *Comprehensive HIV Prevention Reform Act*.

Both efforts recognized that HIV prevention was being hampered by a variety of forces, including lack of resources, too many federal funding restrictions, and

Congress, which had reduced funding for the CDC, was now mandating how the CDC was to direct the states, territories and cities to spend their limited HIV prevention dollars.

too little input from the affected and infected communities. March of 1993 saw the introduction of the *Comprehensive HIV Prevention Act of 1993*. The bill was introduced by

Representative Nancy Pelosi and it, along with AIDS Action Foundation's *Blueprint* work, became the two principle documents that fueled all of the HIV prevention reform activities in place right now. They also established the first aggressive HIV prevention advocacy at the national level in years, apart from the work of NORA (the National Organizations Responding to AIDS) and CAPE (Coalition for AIDS Prevention and Education), which was chaired by the now-deceased Bill Bailey of the American Psychological Association.

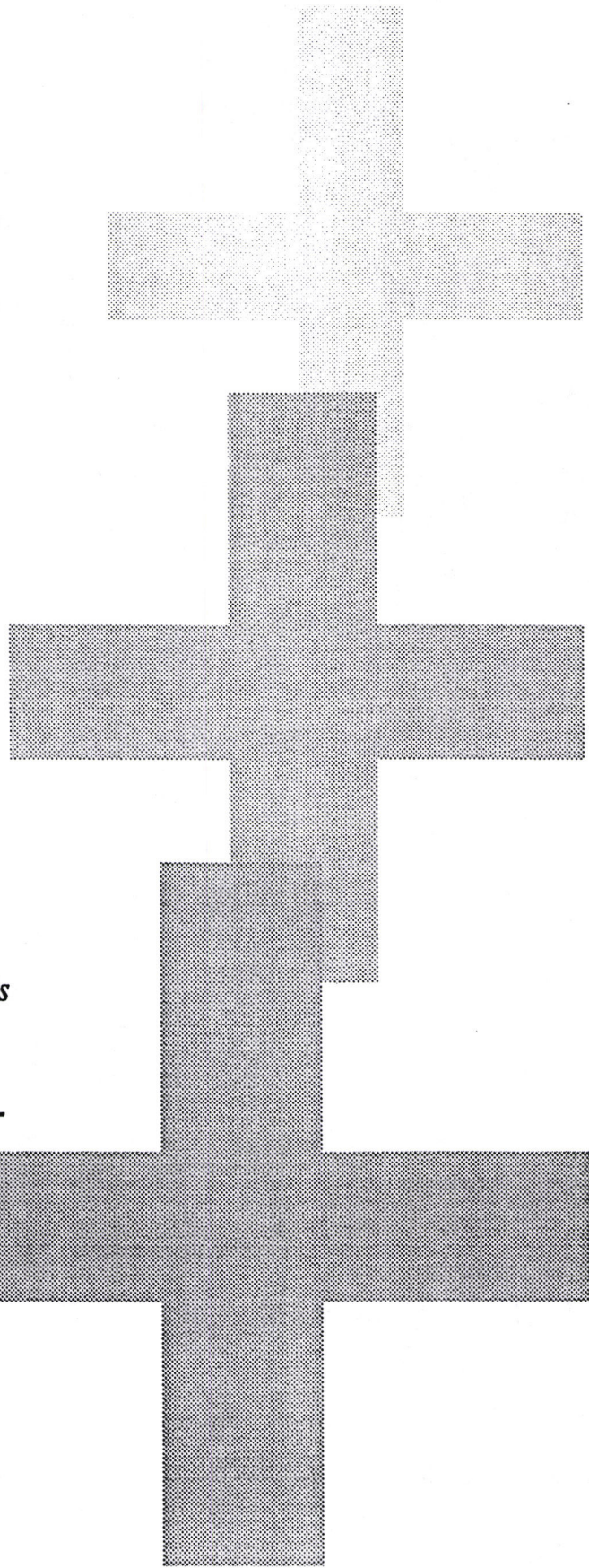
In 1993, Congress appropriated an additional 45 million new dollars for HIV prevention for 1994. This was the first real increase in HIV prevention funding in four years. In fact, HIV prevention funding was increased by only 10 percent between 1990 and 1994. This additional \$45 million increase represented, by itself, a 9 percent increase in funding. Congress mandated the CDC to begin the process of HIV Prevention Community Planning and finally lifted the 65 percent cap on CTRPN in the appropria-

tions bill for fiscal year 1994 money.

Finally, in October of 1993, the CDC published their revisions to the program and content restrictions (the Helms Amendment) in the federal register, describing their proposed new process. No formal announcement has been made to date about the new guidelines, but they promise to be fair and totally unlike those established by Senator Helms.

In short, all of the HIV prevention reforms in place right now, especially the HIV Prevention Community Planning processes, are nothing short of miraculous when you look at the historically crooked path regarding HIV prevention efforts at the CDC and Congress. One can only hope that all those reforms so desperately needed, and now finally being put in place, will be effective in helping to break the back of the HIV pandemic.

Mike Shriver is Executive Director of Mobilization Against AIDS, California's oldest nonprofit HIV/AIDS organization and the coordinator of the world's largest annual AIDS event, the International AIDS Candlelight Memorial and Mobilization; he is an openly gay man living with HIV who is a Health Commissioner for the City and County of San Francisco.



TAKE ACTION TO PROTECT AND IMPROVE MEDICAID!

The Issues

As the 1996 budget process moves forward in Congress, plans are being enacted to cut \$180 billion from Medicaid over the next 7 years and radically change the nature of the program by funding Medicaid through block grants. To protect people living with HIV who depend on Medicaid, we must take action to ensure that Medicaid remains able to guarantee access to health care for all who qualify.

Medicaid is the single largest health care program for people with AIDS, other people with disabilities, and low income women and children. Medicaid provides basic health care services to 90% of all children with HIV disease and at least 40% of all adults with AIDS.

Block grant proposals are being developed to give states more flexibility and responsibility for their Medicaid programs. Block grants would give states less money for Medicaid and the federal government would not fulfill its current role of ensuring that states provide coverage to the needy. Block grants do not come with any solutions for providing better health care or for providing it more cheaply. Block grants take away the security that people with AIDS will be able to depend on Medicaid when they need it.

Senators Chafee, Bradley, Conrad, and Graham--Republicans and Democrats--have come together to propose a plan to improve the Medicaid program. They have designed a plan that will protect the guarantee that those who need care will get it. The Medicaid Managed Care Act of 1995 (S. 839) is a reform that guarantees health care for low income people with AIDS and it protects us from the harm of block grants.

The Actions

- **Make appointments to visit your Members of Congress when they are at home for the Fourth of July Holiday (July 5-7).**
- **Call or Write your Senators and Representatives in Washington.**
- **Thank Senators Chafee, Bradley, Conrad, and Graham for sponsoring S. 839.**

The Message

Tell your story and explain why Medicaid is important to you. Ask your Senators and Representative to:

- **Responsibly reform Medicaid!**
- **Protect the guarantee that eligible persons will get care they need!**
- **Oppose block grants!**
- **Support people with AIDS!**
- **Sponsor the Medicaid Managed Care Act of 1995 (S. 839)!**

Sample letter:

Your Address

The Honorable _____
United States House of Representatives
_____ Office Building
Washington, DC 20510

Dear Representative _____:

I am writing to you about an issue of vital importance to my health and the health of our nation. Presently, the Congress is considering changes to the Medicaid program that would be devastating to the millions of Americans who depend on the program for essential health care services. Huge cuts are being proposed that could lead to millions of people losing access to health care and that would exacerbate pressure on our private health care system.

I am a person living with AIDS and Medicaid is my lifeline. Before I became sick enough to qualify for Medicaid, I had no access to health care. Now, I have a little more security since I can visit a physician regularly and if I become sick, I know that my hospital will not turn me away.

I understand that Medicaid needs to be improved. The only reforms you should consider, however, are those that maintain the guarantee that all persons who meet the program requirements will get the care they need. This must be your bottom line. I support Senator Chafee's approach to reforming Medicaid, and I urge you to co-sponsor the Medicaid Managed Care Act of 1995 (S. 839). This bill, which has bi-partisan support, moves the Medicaid system into managed care, but it takes steps to protect the consumer in the process. Most importantly, this approach to Medicaid reform does not involve block granting Medicaid. I believe that Medicaid block grants would be terribly destructive to the health of persons who depend on Medicaid and they are not a solution to current problems with the Medicaid program.

I urge you to demonstrate leadership and show your support for people living with HIV disease and other people with disabilities by supporting S. 839 and responsible Medicaid reform.

Sincerely,

Your name

Sample phone message:

Hello, my name is _____. I'm calling as a constituent of Senator (or Representative) _____ to ask him/her to protect the Medicaid program. For many people with AIDS and other disabilities, Medicaid is their only source of health care. I believe that Medicaid should be reformed and improved, but large cuts in funding would be devastating to the millions of people who depend on the program. I urge Senator (or Representative) _____ to demonstrate leadership by supporting reasonable reform for the Medicaid program and sign on as a co-sponsor of the Medicaid Managed Care Act of 1995 (S. 839).

FACTS ABOUT MEDICAID

What is Medicaid?

- Medicaid is the nation's primary federal/state program for providing health and long-term care coverage to vulnerable elderly, disabled and low-income Americans.
- The Medicaid program is the single largest form of federal assistance to the states, accounting for 40% of federal funding to the states.

People with HIV and Other Disabilities

- Medicaid is the single most important health care program for people with HIV. At least 40% of people with AIDS and 90% of children with HIV receive Medicaid benefits at some stage of their illness.
- 8.7 million blind, elderly, and disabled Americans receive their health care coverage from Medicaid.
- Discrimination, pre-existing condition exclusions, lifetime coverage limits, experience rating and other practices have all served as barriers to people with HIV disease receiving health care coverage. Medicaid has become the only form of health care coverage available to many people living with HIV/AIDS.

Medicaid and the Ryan White CARE Act

- The Ryan White CARE Act could not absorb the huge cuts proposed for Medicaid. Medicaid is a program that costs roughly \$125 billion per year (including federal and state contributions). In contrast, the CARE Act is funded at a level of less than \$650 million.
- Ryan White has never been adequately funded and cannot begin to replace Medicaid as the fundamental health care safety net for low-income Americans. Many AIDS service providers offer comprehensive services to people with HIV disease in their area through funding from both the Medicaid and CARE Act programs.
- Medicaid and the Ryan White CARE Act are distinct and complementary programs. Medicaid provides health care coverage to low-income people and the services available under Medicaid vary state by state. The CARE Act augments those services by providing primary health care, including dental care, home health care and drug reimbursement services, as well as enabling services like child care and transportation to people living with HIV disease.

Changes to Medicaid

- The House and Senate have proposed a concurrent resolution that would cut \$180 billion from Medicaid over the next 7 years.
- Congress has proposed eliminating the current guarantee that all individuals who meet state and federal eligibility guidelines will receive coverage for their health care. This is a sweeping change that would profoundly diminish the ability of people with HIV to access health care.
- Block granting Medicaid would shift the full burden of providing health care to the states while reducing the level of funds available to run the program. States already face difficulties in funding their portion of the Medicaid program at existing levels. It is unlikely that states would be able to make up for reduced federal support. Funding shortfalls are likely to translate into fewer people qualifying for Medicaid and beneficiaries receiving fewer benefits.
- People with AIDS who lose Medicaid health coverage would be forced to seek care in hospital emergency rooms. Hospitals and state taxpayers would ultimately bear the burden of this high-cost care.
- Cuts in Medicaid would worsen the health of people with HIV and AIDS by taking away their guarantee to essential services, such as prenatal care and prescription medications that treat and prevent a whole variety of secondary infections such as PCP and TB.

As health care costs increase, individuals are less able to cover the costs of their care. Now is the time for Congress to rededicate itself to protecting the most vulnerable in our society, such as men, women, and children living with HIV. Congress must not take steps that result in less health care coverage for those needing it most.

SUPPORT THE CHAFEE PROPOSAL— THE MEDICAID MANAGED CARE ACT OF 1995

Background

On May 22, 1995, Senator John Chafee (R-Rhode Island) introduced in the Senate the Medicaid Managed Care Act of 1995 (S. 839). Three other members of the Senate Finance Committee (that has responsibility for the Medicaid program) have signed on as co-sponsors: Senator Bradley (D-New Jersey), Senator Conrad (D-North Dakota), and Senator Graham (D-Florida).

NAPWA's Board of Directors has endorsed S. 839 as a reasonable alternative to block granting Medicaid. We continue to look for additional consumer protections in the bill, as well as other responsible Medicaid reforms, but we believe that this proposal will make Medicaid a more viable program, over the long term, for guaranteeing health care access for disabled and low-income persons. NAPWA urges you to support the Medicaid Managed Care Act of 1995.

What will S. 839 do?

Senator Chafee's Medicaid proposal, S. 839, will move all Medicaid clients into managed care plans. Most individuals with private (employer provided) health insurance and many women and children receiving Medicaid obtain their care through managed care plans. Many people look to managed care as a method for controlling Medicaid costs because the private insurance market has slowed the rate of increase in health care costs under managed care plans and because managed care focuses on comprehensive care. We do know, however, that people with HIV have complex health care needs, and any changes in Medicaid must provide protections to the consumer.

The following are things we like about S. 839:

- Medicaid enrollees must be given a choice of more than one managed care plan
- Enrollees can disenroll from a plan at any time for cause (for example, if you can show that the plan provided you with substandard care).
- An open season is created that allows individuals to switch from one managed care plan to another during a certain time period every year.
- The Secretary of HHS and the states can impose penalties on plans that do not comply with their contracts.
- Special needs children, the homeless, and migrant workers are exempted from mandatory enrollment in managed care plans.

How can S. 839 be improved?

When a bill is introduced in the House or Senate for consideration, this is the beginning of a review process that includes analysis by subcommittees, committees, as well as the full House and Senate. At all of these stages, bills can be (and usually are) modified. While NAPWA supports the general approach taken in the Medicaid Managed Care Act of 1995 and while we believe that it is an essential alternative to block grants that would be highly destructive to Medicaid, we still believe that the proposal can be improved. We will continue to work with Senator Chafee and the other co-sponsors, as well as other Senators to seek modifications to S. 839. Improvements to S. 839 for which you should advocate include:

- Creating an exemption from mandatory enrollment in managed care plans that includes special needs adults.
- Inserting language into the legislation that specifies prescription drug coverage as a covered benefit. S. 839 specifies coverage for all medically necessary medical assistance. This is an improvement over the current law, but given the importance of prescription drug coverage to people living with HIV and considering that prescription drugs are currently an optional benefit, we believe the legislation must clearly state that prescription drugs are covered.
- Strengthening language in the legislation regarding standards of care and mandating grievance procedures that make it easier for consumers to lodge complaints about problems with their health care or if they have received substandard care.

Do you have questions?

Medicaid is a huge federal/state program of enormous importance to people living with HIV disease. The Medicaid Managed Care Act of 1995 is full of details that will directly affect access to health care for people living with HIV. Are you confused? If you have questions about Medicaid or S. 839, please feel free to contact the public policy and education department at NAPWA. Jeff Crowley, Senior Policy Associate has primary oversight for all issues related to Medicaid. Lisa Ragain-Lovett, Program Assistant coordinates all of NAPWA's grassroots activities. Please feel free to contact either Jeff or Lisa at NAPWA at 202.898.0414 for more information.



July 20, 1995

Michael Shriver
Mobilization Against AIDS
584-B Castro St
San Francisco, CA 94114-1465

Dear Michael:

On behalf of the National Association of People with AIDS, I am pleased that you have agreed to participate as a consultant for the NAPWA Eastern Regional Prevention Planning Workshop. The workshop will be held in New Haven, Connecticut, August 5-6 at the Holiday Inn at Yale, 30 Whalley Avenue. NAPWA will provide you with lodging. Your transportation and per diem check will come in a separate mailing.

Your lodging has already been confirmed with the hotel for arrival on Friday, August 4 and departure on August 6. Please contact me directly if there is any change to your travel plans affecting your hotel reservation. Pillsbury and Co. Travel Services will be assisting you with your transportation. Please contact the agency at 202.232.2737 or at 800.544.4316. Call the hotel in advance at 203.777.6221 to make shuttle pick up arrangements.

Enclosed is a draft of what will be covered during the meeting. At the meeting you will be provided with the final agenda, list of participants, and a copy of our manual "Positive Input: Your guide to HIV Prevention Community Planning".

If you have any additional questions, please do not hesitate to call me or Lisa Ragain at 202.898.0414. I look forward to your participation in this important gathering.

Sincerely,

A handwritten signature in cursive script that reads "Beri Hull".

Beri Hull
Community Education and
Technical Assistance Coordinator

1413 K Street, NW
Washington, DC
20005-3405
tel (202) 898-0414
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Draft Agenda for Eastern Regional Meeting

August 5, 1995

8:00 - 5:00

Registration

9:00 - 10:30

Opening Session

Welcome Address and Announcements

Beri Hull, Community Education and Technical Assistance Coordinator, National Association of People With AIDS

HIV Community Planning from the Federal Perspective

Mike Shriver, Mobilization Against AIDS

The Role of People With HIV in Prevention Planning

Jesus Gomez, Co-chair, State of Connecticut

10:30 - 10:45

Break

10:45 - 12:15

Workshop 1

Understanding the Rules

Carol Robinson, Centers for Disease Control and Prevention, Atlanta, GA

Group Planning and Diversity

Elena Perez, New Jersey AIDS Education and Training Center

12:15 - 1:45

Lunch

1:45 - 3:15

Workshop 2

Harm Reduction as a Prevention Strategy

To be announced

Using Epidemiological Data in Community Planning

Cibele Barbosa, Centers for Disease Control

3:15 - 3:30

Break

3:30 - 5:00

Workshop 3

Harm Reduction as a Prevention Strategy (repeated)

Using Epidemiological Data in Community Planning (repeated)

August 6, 1995

9:00 - 10:30

Workshop 4

Understanding the Rules (repeated)

Recruitment and Inclusion of PLWA's -
J. Miles Jr., Gay Mens Health Crisis

10:30 - 10:45

Break

10:45 - 12:15

Workshop 5

Need Assessments and Priority Setting
Mike Shriver, Mobilization Against AIDS

Group Planning and Diversity -(repeated)

12:15 - 1:45

Lunch

1:45 - 3:15

Workshop 6

Needs Assessments and Priority Setting (repeated)

Recruitment and Inclusion of PLWA's -(repeated)

3:15 - 3:30

Break

3:30 - 5:00

Closing Session

Open Mike Feedback Session