

FOIA MARKER

**This is not a textual record. This is used as an
administrative marker by the William J. Clinton
Presidential Library Staff.**

Collection/Record Group: Clinton Presidential Records

Subgroup/Office of Origin: National AIDS Policy Office

Series/Staff Member: Kristine Gebbie

Subseries:

OA/ID Number: 8301

FolderID:

Folder Title:

[News Articles Relating to HIV/AIDS] [loose]

Stack:

S

Row:

66

Section:

5

Shelf:

2

Position:

2

PAGE 1

LEVEL 1 - 1 OF 3 STORIES

Copyright 1993 The Chronicle Publishing Co.
The San Francisco Chronicle

NOVEMBER 30, 1993, TUESDAY, FINAL EDITION

SECTION: NEWS; Pg. A4

LENGTH: 492 words

HEADLINE: Clinton, Ministers Discuss AIDS Tactics
They seek to renew public's concern

BYLINE: Aurelio Rojas, Chronicle Staff Writer

BODY:

President Clinton invited an interfaith group of religious leaders who minister to AIDS patients to breakfast yesterday in the White House, where he sought suggestions on how to refocus public attention on the epidemic and vowed to lend his support.

The president has been accused by some AIDS activists of putting the issue on the back burner after the administration became bogged down in its first few weeks in the battle over homosexuals in the military.

But he plans to use tomorrow's sixth annual World AIDS Day to restate his concern. John Gurrola, a spokesman for the administration's Office of National AIDS Policy, said Clinton is scheduled to visit a hospital or clinic where he will talk about the disease.

The White House lights will be dimmed, and people across the country will be asked to turn out their lights or dim them between 4:45 p.m. and 5 p.m. PST in "acknowledgement of the seriousness of the disease and the need to do something about it," said presidential press secretary Dee Dee Myers.

Vice President Al Gore also attended Clinton's 90-minute meeting with the group of 14 ministers who represented a cross section of denominations. The meeting was closed to reporters, but Myers said the president sought the ministers' ideas "for fighting both fears about AIDS and the disease itself."

During a telephone conference call with reporters, three ministers praised Clinton for demonstrating more interest in the battle against AIDS than the Reagan-Bush administrations.

The president did not speak about specific political initiatives. But Rabbi Joseph Edelheit, head of Temple Israel in Minneapolis, said Clinton asked the ministers to consider how to spur a "renewal" of public interest in fighting the epidemic. Edelheit, who has ministered to 23 people who died of AIDS, said the religious leaders suggested a coordinated effort involving the federal government and 6,000 church-based programs.

"We now have a comrade in arms who looks to us as much as we look to him," said the Rev. Ted Karph, executive director of the National Episcopal AIDS Coalition.

The San Francisco Chronicle, NOVEMBER 30, 1993

The Rev. Altagracia Perez of Chicago, a member of the General Convention Joint Commission on AIDS of the Episcopal Church, said there was a spirit of hope during the meeting that inspired "those of us who are in the trenches. We know we're not alone."

One of the ministers told the president that he has lost two sons to the disease.

Tomorrow's World AIDS Day also will include a Day Without Art, in which museums around the world will shroud artworks in black, and church bells will toll to commemorate those who have died of the disease.

The U.S. Postal Service will issue a commemorative red-ribbon stamp to promote AIDS awareness. In San Francisco, the Rev. Cecil Williams and his Glide Memorial United Methodist Church in the Tenderloin will help the Postal Service dedicate the AIDS stamp.

LANGUAGE: ENGLISH

LOAD-DATE-MDC: November 30, 1993

LEVEL 1 - 2 OF 3 STORIES

Copyright 1993 The Atlanta Constitution
The Atlanta Journal and Constitution

November 30, 1993

SECTION: NATIONAL NEWS; Section A; Page 6

LENGTH: 324 words

HEADLINE: Clinton finally ready to relax Roller-coaster first year was tiring even for him

BYLINE: FROM OUR NEWS SERVICES

BODY:

Washington - After a sometimes harried first 10 months, President Clinton is gearing down for a holiday season of relaxation and reflection.

"I think everybody's ready for a break," spokeswoman Dee Dee Myers sighed Monday.

Surviving early stumbles, including the messy search for an attorney general and the abrupt firing of his travel office staff, Clinton rebounded with a string of victories in Congress and unveiled the health care plan that will be a major issue in the next congressional session.

The pace occasionally took its toll. The president complained to aides that his schedule was sometimes too frantic. Two top aides, Deputy Chief of Staff Roy Neel and congressional liaison Howard Paster, announced their departures last week, citing fatigue.

Clinton had breakfast Monday with religious leaders active in the fight against AIDS and telephoned Ukrainian President Leonid Kravchuk and German Chancellor Helmut Kohl, but he steered clear of public appearances. Myers said Clinton would be less visible in December than in past months as he takes the opportunity to spend time with friends and family, while emphasizing "crime and national values" in pre-holiday speeches.

The president had "a lovely time" during a family Thanksgiving weekend at Camp David, Md., she said. Clinton, who has rarely visited the Catoctin Mountains presidential retreat, jogged, bowled, worked puzzles and played on the camp's one-hole golf course.

Over the next few weeks, aides say, Clinton will:

Review recommendations his staff will develop for his welfare reform plan, which may be revealed during his State of the Union address.

Talk more about health care reform. After unveiling his program in the fall, momentum was stalled by the divisive debate over the North American Free Trade Agreement.

Deliver more tough-on-crime talk. "Whether it's the crime bill or the Brady Bill . . . it's on the president's mind," Myers said.

1993 The Atlanta Journal and Constitution, November 30, 1993

PAGE 4

LANGUAGE: ENGLISH

LOAD-DATE-MDC: December 3, 1993

LEVEL 1 - 3 OF 3 STORIES

Copyright 1993 The Washington Post
The Washington Post

November 30, 1993, Tuesday, Final Edition

SECTION: FIRST SECTION; PAGE A8

LENGTH: 544 words

HEADLINE: Clinton Urged to Preach Compassion;
Religious Groups Tell President of Caring for People With AIDS

SERIES: Occasional

BYLINE: Gustav Niebuhr, Washington Post Staff Writer

BODY:

An interfaith group of 13 clergy and representatives of religious organizations yesterday asked President Clinton to speak out for compassion for persons with AIDS and to recognize the expertise of religious bodies that care for the afflicted.

The group, including several Protestants, a Catholic priest and a rabbi, conveyed its message during a private, 90-minute breakfast meeting in the White House's Old Family Dining Room. It was the third such breakfast gathering Clinton has held with religious leaders since becoming president.

In interviews afterward, five of those attending said the talk focused more on personal experience, rather than the politics of health care. They told Clinton of their own work with persons with AIDS, and spoke of how churches and synagogues try to help those with the disease.

The Rev. Altagracia Perez, who serves on the Episcopal Church's commission on AIDS, said that "many churches and many congregations are working on this issue."

The Rev. Ed Dobson, pastor of Calvary Church, an evangelical congregation in Grand Rapids, Mich., said he led a prayer, asking that "in the midst of programs and politics, they [Clinton and Vice President Gore] would see the face of human suffering. And that was the spirit of the whole meeting."

Some participants said they praised the administration for pushing for expanded treatment and research efforts, for establishing the National AIDS Policy Office and other initiatives. But they said they were mainly grateful simply to have their work recognized by the White House.

"In many cases, it's the religious community in a city that's carrying the brunt of the load for caring for people with HIV/AIDS," said the Rev. Russell Dillard, pastor of St. Augustine's Roman Catholic Church in Washington, who said he was speaking particularly about smaller cities.

"I came away feeling that we were heard," Dillard said, ". . . that here was the top government person in this country willing to spend private time with people who are serving the Lord, and he listened."

The Washington Post, November 30, 1993

Rabbi Joseph Edelheit of Temple Israel in Minneapolis said the gathering "crossed a threshold that had not been crossed before" in bringing an ethnically and religiously diverse group together with the president on this issue.

After the meeting, the White House put out a statement that it will observe World AIDS Day on Wednesday, dimming its lights for 15 minutes at 7:45 p.m. in memory of those who have died of the disease.

Although none of the participants at yesterday's meeting mentioned it, one Protestant denomination, the 1.6 million-member United Church of Christ, will announce today that it has created a special curriculum, for use in churches, to teach AIDS prevention to children and adults.

The curriculum, titled "Affirming Persons -- Saving Lives," is designed for Sunday school and adult study groups, and includes two videotapes and 1,000 pages of lesson plans, according to the Cleveland-based church. The curriculum emphasizes abstinence from sex and drug use as the only sure means of avoiding the disease. But the church said that because "not everyone will choose abstinence," the curriculum also provides for discussion by teenagers and adults of safe sexual practices.

LANGUAGE: ENGLISH

LOAD-DATE-MDC: November 30, 1993

LEVEL 3 - 5 OF 8 STORIES

Copyright 1993 The Houston Chronicle Publishing Company
The Houston Chronicle

December 1, 1993, Wednesday, 2 STAR Edition

SECTION: A; Pg. 21

LENGTH: 663 words

HEADLINE: Bishop's story about sons moves Clinton to tears

BYLINE: TOM WEBB; Knight-Ridder Newspapers

DATELINE: WASHINGTON

BODY:

WASHINGTON -- The United Methodist bishop of Kansas moved President Clinton to tears as he revealed a searing personal story of AIDS during a White House prayer breakfast.

Twice in the past three years, Bishop Fritz Mutti told the president, he and his wife, Etta Mae, have buried sons who've died of acquired immune deficiency syndrome. Their son, Tim, died at age 30. Their son, Fred, was 29.

At the prayer breakfast Monday with Clinton and Vice President Al Gore, Mutti talked about his two sons and about AIDS and about the power of family and faith. As Mutti spoke, tears began to well up in the president's eyes, some participants said.

The Rev. Ted Karpf of the National Episcopal AIDS Coalition recounted, "When a United Methodist bishop told the story of parents, and particularly told his own story of the death of his own sons to HIV, the president obviously was deeply moved."

For Mutti, who last year was named bishop of Kansas and its 180,000 United Methodists, the prayer breakfast was his most high-profile occasion yet to speak personally about Christian compassion, love and family in the context of AIDS.

"Etta Mae and I believe that there won't be a church in Kansas that won't be touched by this, and part of (our work) is to open up the church to this, to prepare the congregations," he said in a telephone interview after his return to Kansas.

"Our aim is to really share openly and to give people permission to talk to us. We've never talked about our experience anywhere where people haven't come up to us and said: 'Thank you.'"

There's nobody else I can talk to. . . . They have AIDS themselves, or someone in their family has AIDS, and they need to talk to somebody else about it."

For many years, though, the Muttis were silent, too. Even when one of their sons grew ill, Mrs. Mutti remembers, "we didn't

The Houston Chronicle, December 1, 1993

even tell people about it then. There was such a stigma about it then. That was in 1988, and there were so many people being thrown out of the communities or their homes, so we decided not to tell anyone what was going on. "

After their second son died in 1991, the Muttis began to speak publicly. They discovered not the wrath of the Christian community, but compassion and strength and love. Mutti mentioned that to Clinton.

"I was able to share with some people how tremendously supportive the churches have been, contrary to what you get sometimes," he said.

Monday's breakfast was one of an occasional series of White House prayer breakfasts, this particular one with an AIDS ministry theme, timed to coincide with World AIDS Day today. Aside from Mutti, 13 other religious officials in AIDS ministries attended, including Roman Catholics, Jews, Baptists and evangelical Christians. Mutti said he came away from the meeting sensing Clinton's "genuine care and compassion. "

Of the Muttis' three children, one is still alive, the youngest son. Before their deaths, Tim Mutti lived in Atlanta, and Fred Mutti lived in New York City. Both were gay, although Mutti is reluctant to discuss this because it "tends to draw the possibility that (people think) this is the gay disease and this is God's punishment for people who are sinners and far removed from God. "

While the parents have found acceptance in the church, they also know their sons felt rejection.

Mrs. Mutti said her eldest son, Tim, "went to seminary for three years but did not feel like the church was accepting at all of him. . . . For the most part, I think both boys felt pretty excluded from the church. "

Mutti would like to change that, even while he and his wife continue to work through their own grief.

"We're not through that yet," he said. "People used to say you got through the grief process in a year. It's been more than two years for us, and we've kind of gotten to the point that it will never be over for us. That hole will always be there. "

GRAPHIC: Graph: AIDS' rise to No. 1 killer of young men (BAR GRAPH); Source: Centers for Disease Control

LANGUAGE: ENGLISH

LOAD-DATE-MDC: December 3, 1993

LEVEL 3 - 6 OF 8 STORIES

Copyright 1993 Star Tribune
Star Tribune

December 1, 1993, Saint Paul Edition

SECTION: News; Pg. 5B

LENGTH: 331 words

HEADLINE: Rabbi praises Clinton after White House AIDS meeting

BYLINE: Neal Gendler; Staff Writer

BODY:

President Clinton is listening and understands problems caused by AIDS, Rabbi Joseph Edelheit said Tuesday on his return from a breakfast meeting at the White House.

Edelheit, senior rabbi of Temple Israel in Minneapolis, was the only Minnesotan among a dozen clergy members invited to a private discussion Monday morning. He said he found the session, which ran 30 minutes longer than its scheduled hour, "exhilarating."

"This guy gets it," he said of the president. "He understands this as a spiritual person. We all praised him for bringing us together."

Edelheit said that at the meeting, he recited the Jewish prayer thanking God for enabling him to reach this day. "In some ways, I felt vindicated, validated," he said. "It isn't easy to be a rabbi who takes on these issues when some people don't want to discuss them."

Edelheit is rabbinic cochairman of the Committee on AIDS of Reform Judaism's Union of American Hebrew Congregations and Central Conference of American Rabbis. He has written and worked extensively on AIDS issues.

Clinton opened the meeting by discussing a story in the Nov. 28 New York Times Sunday Magazine, "Whatever happened to AIDS?" Edelheit said. Written by Times reporter Jeffrey Schmalz, who died of AIDS last month, it tracked the nation's response to the disease and criticized Clinton for failing to do enough to battle it.

Kristine Gebbie, Clinton's AIDS "czar;" Alexis Herman, a public liaison officer, and Vice President Al Gore also attended the meeting. Participants did not agree on everything. For example, they disagreed about emphasizing abstinence over condoms, "but there was complete agreement on the issue of hope, complete agreement that we have young lives to save," Edelheit said.

"This thing isn't going to go away. We all agreed that we needed the president to take the high moral ground, to help us, not to make it some chic idea but part of everyday living."

LANGUAGE: ENGLISH

LOAD-DATE-MDC: December 2, 1993

THE WHITE HOUSE
WASHINGTON

December 29, 1993

MEMORANDUM

TO: Sabine Beisler, Managing Editor
American Journal of Public Health
Sent via telefax: 789-5663

FROM: Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

Mr. Stum here for

SUBJECT: Final copy of AJPH article

Please find the final version of my article for publication in the AJPH. This version has been approved by Merv and he asked that I fax it to you directly. Please call me at (202) 632-1090 if you have any questions.

Attachment (7 pages)

Formulating Public Health Policy: The Case of AIDS
Submitted by
Kristine M. Gebbie, R.N. M.N.

As is true in many areas of American life, public health policy formulation is not a tidy process. All levels of government are involved: federal, state and local. At all these levels legislative bodies have been inconsistent in the breadth of power granted to executive agencies.

In some instances, statutory language is broad, and grants wide authority to define issues, prescribe public action or direct staff attention to a public health official. In other instances, laws go into great detail on specific conditions or circumstances to which a particular action applies, and the opportunity for public health judgement to vary individual application is very limited.

Federal policies may supersede state and local ones, and states may manage or strongly influence local actions, but the chain of command is not direct. Funding for most public health activities is shared among the levels of government, and money may be granted only in exchange for certain actions. Local actions are often constrained or directed by commitments made in order to gain access to funds available from the state or federal level. In few cases does a public health official simply "make policy."

Both law and good practice dictate some combination of consultation, oversight or concurrence from interested parties, advisory or decision-making health boards, elected officials, or legislators.

HIV infection and AIDS arrived on the public health policy scene early in the last decade, and presented multiple challenges to an

already strained public health system. Budget tightening due to a recession had restricted state and local appropriations. The "new Federalism" of the Reagan years included the merging of many

public health programs into block grants for greater local flexibility, but an associated cut of approximately 25% of funds made it nearly impossible to sustain activities. Efforts to increase the levels of school immunization, respond to the interest in safe drinking water, reduce toxic wastes, improve birth outcomes, and increase access to basic primary health care are examples of the many demands on public health officials.

Then came reports of a new syndrome, probably viral in origin, which was spreading rapidly and causing great public concern. The initial concentration of cases in a few geographic areas and population groups allowed many states to frame the issue as primarily of academic interest. Soon, however, the public outcry

for action became nationwide. "Business as usual" (epidemiological investigation of reported cases, consultation with the Centers for Disease Control and Prevention, distribution of updated information to key clinical and diagnostic centers) was swept away or confused by strong emotional responses. Advocates in the community most affected initially, gay men, argued strongly that the issue was ignored because of homophobia and that traditional record keeping or case identification methods would too easily support a variety of repressive, discriminatory or inappropriate control measures. Public fear of a devastating, community-wide disease explosion pushed others to call for more stringent measures, based on historical (and not scientifically supportable) public health measures such as isolation, quarantine and public notification.

The study by Robins and Backstrom in this issue was designed to identify the degree to which public health agencies were effective leaders in developing AIDS-related policies at the state level. The authors refer extensively to the Institute of Medicine study of public health published in 1988, which viewed "with great concern and some alarm. . . the current state of public health." This report indicated that lack of leadership, tightly constrained resources, and limited vision were preventing the public health infrastructure of the nation

from asserting a proper role in protecting the public from disease and promoting a healthier nation.

Robins and Backstrom, on the other hand, conclude that, at least in the case of AIDS, "public health departments are very influential [and] . . . promoted their ideas with a clear understanding of their political environments and the strategies appropriate in them." Their analysis of this different conclusion was at least in part that the Institute of Medicine used faulty criteria, focusing on failures to provide leadership and vision in areas which were beyond the scope of currently structured state health agencies. In using a case more in the mode of classic governmental public health responsibilities, namely, response to a communicable disease, appropriate leadership was found.

The study reported has some unusual features, at least in the context of understanding state policies regarding HIV infection and AIDS. Debate about this condition at all levels of government has included an extremely visible role for advocacy groups emerging out of those most affected by the epidemic. These include gay and lesbian rights and civil rights groups, and new associations focused exclusively on HIV issues, such as the AIDS Coalition to Unleash Power (ACT-UP), Gay Men's Health Crisis, and the National Minority AIDS Council. In two

states included in the reported study, New York and California, early legislative action regarding documentation and reporting of HIV-related information went in a direction contrary to traditional public health practice, and appeared not to stem from leadership activities by the state health officials.

The information on study methodology indicates that the sources of data were state health official themselves, chairs of health committees in state legislatures, and officials of hospital associations (apparently as a representative lobbying group). Given the interest of HIV advocacy groups, which emerged early in the epidemic, it would have been most appropriate to include at least some representative of that perspective in the study. One might expect that their views would be more critical of the role played by public health officials.

Further, in at least some states, the issues of legal restriction on HIV positive individuals were reviewed in committees other than the health committee, such as a committee on legal affairs. Yet only health committee chairs were surveyed. It would have been helpful to know whether the responding committee had actually had jurisdiction over and considered legislation relevant to quarantine or isolation during the relevant time period. If the health committee had not sponsored hearings on these matters, or had performed only a secondary role in bill

development, the health committee chair's understanding of the relative roles of interest groups and agencies might be limited.

An additional concern in data presentation is the question of which states responded. While it is possible that among the 42 state health departments, 39 hospital associations and 43 legislatures represented in the responses was at least one reply from every state, that is not made clear. In this particular policy area, the experiences of the states with high early infection rates had an enormous impact on the nation as a whole, and the relative roles of state health officials, legislatures and advocacy groups were shifted depending on whether early public or advocacy excitement rushed a legislature to action or whether there was time to develop a proposal more slowly.

It is very important, in the face of both the continuing HIV epidemic and the potential for major health system reform, that the nation's state health officials play an appropriate role in determining policies which can promote the health of the public and protect the nation from preventable conditions. The literature on the public policy role of health officials is sparse, and a great many senior health officials in this country have learned about policy development on the job. Critical reading of articles such as that by Robins and Backstrom can enlarge our understanding of the interplay of interest groups and

provide direction in how to communicate both concerns and successes to a wider audience. One would hope that others reading this piece will be stimulated to add to the body of literature, whether with a second generation of survey materials or well-developed case studies. Such a literature can assist us all in appreciating both what has been the experience in public policy in the case of HIV and AIDS, and what might be expanded within the broad role available to a state health official.

Office of the National AIDS Policy Coordinator



Executive Office of the President
750 17th Street, N.W. Suite 1060
Washington, D.C. 20500

Phone: (202)632-1090

Fax: (202)632-1096



Deliver To: Merv. Susser

Sent From:

Kristine Gebbie, RN, MN, National AIDS Policy Coordinator

✓ Steve Lee

Number of Pages: 11 - cover Fax Number: 914 478 4859 Date: 12/31

Message:

Please call me if any changes are unclear.
Steve

Doc 29: TP Kristine Gebbie:

Formulating Public Health Policy: The Case of
AIDS

Submitted by: Kristine M. Gebbie

Today I'm working at
home if you need me.

Ph: 914.478.0251

Fax:4859

As is true in many areas of American life, public
health policy formulation is not a tidy process.

All levels of government are involved: federal,
state and local. Legislative bodies at all ^{these} levels

have been inconsistent in the breadth of power
granted to executive agencies. // In some instances,

statutory language is very broad, ^{and} granting wide
authority to define issues, prescribe public

action or direct staff attention to a public
health official. In other ^{instances} cases, laws go into
great detail on specific conditions or

circumstances to which a particular action
applies, and the opportunity for variance of

individual application of public health judgement ^{to vary}
is very limited. // Federal policies may supersede

state and local ones, and states may manage or
strongly influence local actions, but the chain of

command is not direct. Funding for most public
health activities is shared among the levels of
government ^{and} local actions are often

constrained or directed by commitments made in
order to ^{gain} have access to funds available from the
state or federal level. // In few cases does a

and money may be
~~granted~~
~~made available~~
only in exchange
for certain
actions.

public health official simply "make policy" as both law and good practice dictate some combination of consultation, oversight or concurrence from interested parties, advisory or decision-making health boards, elected officials, or legislators.

HIV infection and AIDS arrived on the public health policy scene early in the last decade, and presented multiple challenges to an already strained public health system. Budget tightening due to a recession had restricted state and local appropriations. The "new Federalism" of the Reagan years included the merging of many public health programs into block grants for greater local flexibility, but an associated cut of approximately 25% of funds made it nearly impossible to sustain activities. Efforts to increase the levels of school immunization, respond to the interest in safe drinking water, reduce toxic wastes, improve birth outcomes, and increase access to basic primary health care are examples of the many demands on public health officials. Then came reports of a new syndrome, probably viral in origin, which was spreading rapidly and causing great public concern. The initial concentration of cases in a few geographic

areas and population groups, ^{allowed} meant that many states ^{to frame} could see the issue as one (of primarily) academic interest, ^{if so, however,} though the public outcry for action became nationwide. [Early,] "business as usual" responses (epidemiological investigation of reported cases, consultation with the Centers for Disease Control and Prevention, distribution of updated information to key clinical and diagnostic centers) ^{was} ~~were~~ swept away or confused by strong emotional responses. Advocates in the community most affected initially, gay men, argued strongly that the issue was ignored because of homophobia and that traditional record keeping or case identification methods would too easily support a variety of repressive, discriminatory or inappropriate control measures. Public fear of a devastating, community-wide disease explosion pushed others to call for more stringent measures, based on historical (and not scientifically supportable) public health measures such as isolation, quarantine and public notification.

The study by Robins and Backstrom in this issue was designed to identify the degree to which public health agencies were effective leaders in developing AIDS-related policies at the state level. The authors refer extensively to the

Institute of Medicine (IOM) study of public health published in 1988, which viewed "with great concern and some alarm. . . the current state of public health."¹ This report indicated that lack of leadership, tightly constrained resources, and limited vision were preventing the public health infrastructure of the nation from asserting a proper role in protecting the public from disease and promoting a healthier nation. ~~Robins and Backstrom~~ Robins and Backstrom, on the other hand, conclude that at least in the case of AIDS, "public health departments are very influential [and]. . . promoted their ideas with a clear understanding of their political environments and the strategies appropriate in them."² Their analysis of this different conclusion was at least in part that the IOM used faulty criteria, focusing on failures to provide leadership and vision in areas which were beyond the scope of currently structured state health agencies. ~~In this case, the focus is on the mode of~~ using a case more associated with classic governmental public health responsibilities, ~~namely,~~ response to a communicable disease, appropriate leadership was found.

¹Institute of Medicine. The Future of Public Health. Washington, D.C.: National Academy Press, 1989.

²Robins & Backstrom, mss p.11.

¶ The study reported has some unusual features, at least in the context of understanding state policies regarding HIV infection and AIDS. Debate about this condition at all levels of government has included an extremely visible role for advocacy groups emerging out of those most ^{affected} impacted by the epidemic. These include gay, gay and lesbian rights and civil rights groups, and new associations focused exclusively on HIV issues, such as the AIDS Coalition to Unleash Power (ACT-UP), Gay Men's Health Crisis, and the National Minority AIDS Council. In two of the states included in the reported study, New York and California, early legislative action regarding documentation and reporting of HIV-related information went in a direction contrary to traditional public health practice, and did not appear ^{ed not} to ^{stem from} be developed because of leadership activities by the state health officials.³ ¶ The information on study methodology indicates that the sources of data were state health official themselves, chairs of health committees in state legislatures, and officials of hospital associations (apparently as a representative

³It should be noted that many public health officials have agreed with advocacy groups on the principles to be reflected in public policy, such as public health science and protection of the confidentiality and rights of individuals, though there have been many disagreements on the specific responses to be employed.

lobbying group). Given the interest of HIV advocacy groups, which emerged early in the epidemic, it would have been most appropriate to include at least some representative of that perspective in the study. ^{One might} ~~I would~~ expect that ?  their views would be more critical of the role played by public health officials.

Further, in at least some states, the issues of legal restriction on HIV positive individuals were reviewed in committees other than the health committee, such as a committee on legal affairs. Yet only health committee chairs were surveyed. It would have been helpful to know whether the responding committee had actually had jurisdiction over and considered legislation relevant to quarantine or isolation during the relevant time period. If the health committee had not sponsored hearings on these matters, or had performed only a secondary role in bill development, the health committee chair's understanding of the relative roles of interest groups and agencies might be limited.

An additional concern in data presentation is the question of which states responded. While it is possible that among the 42 state health

departments, 39 hospital associations and 43 legislatures represented in the responses was at least one reply from every state, that is not made clear. In this particular policy area, the experiences of the states with high early infection rates had an enormous impact on the nation as a whole, and the relative roles of state health officials, legislatures and advocacy groups were shifted depending on whether early public or advocacy excitement rushed a legislature to action or whether there was time to develop a proposal more slowly.

It is very important, in the face of both the continuing HIV epidemic and the potential for major health system reform, that the nation's state health officials play an appropriate role in determining policies which can promote the health of the public and protect the nation from preventable conditions. The literature on the public policy role of health officials is sparse, and a great many senior health officials in this country have learned about policy development on the job. Critical reading of articles such as that by Robins and Backstrom can enlarge our understanding of the interplay of interest groups and provide direction in how to communicate both

concerns and successes to a wider audience. ^{One} I would hope that others reading this piece will be stimulated to add to the body of literature, whether with a second generation of survey materials ^{or} well-developed case studies ^{Such a literature ?} ~~which~~ can assist us all in appreciating both what has been the experience in public policy in the case of HIV and AIDS, and what might be expanded within the broad role available to a state health official.

Formulating Public Health Policy: The Case of AIDS
Submitted by: Kristine M. Gebbie

As is true in many areas of American life, public health policy formulation is not a tidy process. All levels of government are involved: federal, state and local. At all these levels legislative bodies have been inconsistent in the breadth of power granted to executive agencies.

In some instances, statutory language is broad, and grants wide authority to define issues, prescribe public action or direct staff attention to a public health official. In other instances, laws go into great detail on specific conditions or circumstances to which a particular action applies, and the opportunity for public health judgement to vary individual application is very limited.

Federal policies may supersede state and local ones, and states may manage or strongly influence local actions, but the chain of command is not direct. Funding for most public health activities is shared among the levels of government, and money may be granted only in exchange for certain actions. Local actions are often constrained or directed by commitments made in order to gain access to funds available from the state or federal level. In few cases does a public health official simply "make policy." Both law and good practice dictate some combination of consultation, oversight or concurrence from interested parties, advisory or decision-making health boards, elected officials, or legislators.

HIV infection and AIDS arrived on the public health policy scene early in the last decade, and presented multiple challenges to an

already strained public health system. Budget tightening due to a recession had restricted state and local appropriations. The "new Federalism" of the Reagan years included the merging of many

public health programs into block grants for greater local flexibility, but an associated cut of approximately 25% of funds made it nearly impossible to sustain activities. Efforts to increase the levels of school immunization, respond to the interest in safe drinking water, reduce toxic wastes, improve birth outcomes, and increase access to basic primary health care are examples of the many demands on public health officials.

Then came reports of a new syndrome, probably viral in origin, which was spreading rapidly and causing great public concern. The initial concentration of cases in a few geographic areas and population groups allowed many states to frame the issue as primarily of academic interest. Soon, however, the public outcry for action became nationwide. "Business as usual" (epidemiological investigation of reported cases, consultation with the Centers for Disease Control and Prevention, distribution

of updated information to key clinical and diagnostic centers) was swept away or confused by strong emotional responses. Advocates in the community most affected initially, gay men, argued strongly that the issue was ignored because of homophobia and that traditional record keeping or case identification methods would too easily support a variety of repressive, discriminatory or inappropriate control measures. Public fear of a devastating, community-wide disease explosion pushed others to call for more stringent measures, based on historical (and not scientifically supportable) public health measures such as isolation, quarantine and public notification.

The study by Robins and Backstrom in this issue was designed to identify the degree to which public health agencies were effective leaders in developing AIDS-related policies at the state level. The authors refer extensively to the Institute of Medicine (IOM) study of public health published in 1988, which viewed "with great concern and some alarm. . . the current state of public health." This report indicated that lack of leadership, tightly constrained resources, and limited vision were preventing the public health infrastructure of the nation from asserting a proper role in protecting the public from disease and promoting a healthier nation.

Robins and Backstrom, on the other hand, conclude that, at least in the case of AIDS, "public health departments are very influential [and]. . . promoted their ideas with a clear understanding of their political environments and the strategies appropriate in them." Their analysis of this different conclusion was at least in part that the IOM used faulty criteria, focusing on failures to provide leadership and vision in areas which were beyond the scope of currently structured state health agencies. In using a case more in the mode of classic governmental public health responsibilities, namely, response to a communicable disease, appropriate leadership was found.

The study reported has some unusual features, at least in the context of understanding state policies regarding HIV infection and AIDS. Debate about this condition at all levels of government has included an extremely visible role for advocacy groups emerging out of those most affected by the epidemic. These include gay and lesbian rights and civil rights groups, and new associations focused exclusively on HIV issues, such as the AIDS Coalition to Unleash Power (ACT-UP), Gay Men's Health Crisis, and the National Minority AIDS Council. In two states included in the reported study, New York and California, early legislative action regarding documentation and reporting of HIV-related information went in a direction contrary to traditional public health practice, and appeared not to stem from leadership activities by the state health officials.

The information on study methodology indicates that the sources of data were state health official themselves, chairs of health

committees in state legislatures, and officials of hospital associations (apparently as a representative lobbying group). Given the interest of HIV advocacy groups, which emerged early in the epidemic, it would have been most appropriate to include at least some representative of that perspective in the study. One might expect that their views would be more critical of the role played by public health officials.

Further, in at least some states, the issues of legal restriction on HIV positive individuals were reviewed in committees other than the health committee, such as a committee on legal affairs. Yet only health committee chairs were surveyed. It would have been helpful to know whether the responding committee had actually had jurisdiction over and considered legislation relevant to quarantine or isolation during the relevant time period. If the health committee had not sponsored hearings on these matters, or had performed only a secondary role in bill development, the health committee chair's understanding of the relative roles of interest groups and agencies might be limited.

An additional concern in data presentation is the question of which states responded. While it is possible that among the 42 state health departments, 39 hospital associations and 43 legislatures represented in the responses was at least one reply from every state, that is not made clear. In this particular policy area, the experiences of the states with high early infection rates had an enormous impact on the nation as a whole, and the relative roles of state health officials, legislatures and advocacy groups were shifted depending on whether early public or advocacy excitement rushed a legislature to action or whether there was time to develop a proposal more slowly.

It is very important, in the face of both the continuing HIV epidemic and the potential for major health system reform, that the nation's state health officials play an appropriate role in determining policies which can promote the health of the public and protect the nation from preventable conditions. The literature on the public policy role of health officials is sparse, and a great many senior health officials in this country have learned about policy development on the job. Critical reading of articles such as that by Robins and Backstrom can enlarge our understanding of the interplay of interest groups and

provide direction in how to communicate both concerns and successes to a wider audience. One would hope that others reading this piece will be stimulated to add to the body of literature, whether with a second generation of survey materials or well-developed case studies. Such a literature can assist us all in appreciating both what has been the experience in public policy in the case of HIV and AIDS, and what might be expanded within the broad role available to a state health official.

***** -JOURNAL- ***** DATE DEC-29-1993 ***** TIME 12:12 *****

DATE/TIME = DEC-29 12:07

JOURNAL NO. = 02

COMM.RESULT = OK

PAGES = 12

DURATION = 00:05'26

MODE = XMT

STATION NAME =

TELEPHONE NO. = T 919144784859

RECEIVED ID = 9144784859

RESOLUTION = STANDARD

-NAP0 202-472-7054

***** -

- *****

RECEIVED

NOV 19 1993

AMERICAN SOCIETY OF
LAW, MEDICINE & ETHICS

262 4990

11/19/93

Dear JLME 21:3-4 Author:

Enclosed is a proof of your article for the special issue of *The Journal of Law, Medicine & Ethics* entitled *The Dual Epidemics of Tuberculosis and AIDS*.

We ask that you examine it carefully and fax any requests for changes to us by Wednesday, November 24. If this quick turnaround is not feasible, please contact Janie Rangel or me as soon as possible.

We also ask that you limit any requests for changes to items that are absolutely necessary and that, if possible, changes be limited to revisions that do not change the line count of the article. Please fax your suggested corrections to us at 617-437-7596.

Thank you very much for your participation in this important project. The issue, due to be mailed by the end of the year, will make a valuable contribution in what is, unfortunately, a field of increasingly critical importance.

Sincerely,

Merrill Kaitz
Director of Publications

Speeches/Papers

Post-It™ brand fax transmittal memo 7671		# of pages 5
To	KEISTINE GEARIE	
Co.	ASLME	
Dept.	Phone #	
Fax #	Fax #	

Comment

Rebuilding a Public Health Infrastructure

Kristine M. Gebbie

A major focus of current interest in rebuilding public health infrastructure has been New York City, and to a lesser extent the other large cities which are already experiencing outbreaks of multiple-drug resistant tuberculosis (MDR-TB). Concerns of how to secure an appropriate public health infrastructure permeate the public health circles of this country, and the emergence of MDR-TB has only increased the level of worry.

Infrastructure

In discussions of state and local government, "infrastructure" usually refers to the capital improvements which make life in modern society possible—roads and bridges, water and sewer systems, waste water treatment systems. These systems are often built and even managed by the public sector for the good of all.

Any component, like a bridge, is only as strong as its weakest part; structures must be built with planned uses in mind. If the middle span is weak, strong railings won't compensate. While it is not unusual for railroads to have separate bridges from auto or truck traffic, or for a pedestrian bridge to be apart from a bridge for wheeled conveyances, we do not see individual bridges for each type of movement: commercial activity, commuting, recreation.

With good planning a limited number of spans are organized and structured to convey all traffic (pedestrian or wheeled, private or commercial) from one bank to the other. In fact, we find it an eyesore if there is an unnecessary proliferation of structures, and a safety hazard when a bridge is used for traffic for which it was not designed. As we learned during our response to the HIV epidemic when it emerged a decade ago, our capacity to respond was severely limited by the weak links of underfunded surveillance networks, minimal STD or substance abuse treatment capacity, and underdeveloped community outreach in the most affected communities.

Public health infrastructure

Public health infrastructure can be developed just like bridges: one structure for each disease or risk or activity; or a coordinated system which serves all effectively. And since diseases know no political boundaries, it is appropriate to think of the infrastructure needs across the country, not just in any one city, county or state. Over 70 percent of the local health departments in this country have less than 100 staff, and over half have less than 10 full time equivalent employees (based on data collected by the National Association of County Health Officials). Local health depart-

ments are often overwhelmed by demands for personal medical care by those without access to the existing care system.¹

In the years since the Institute of Medicine (IOM) Report on the Future of Public Health² was published, the discussion of what to do to repair the infrastructure has been subsumed into the national debate on health care reform.

If we are to have a personal care system which works well for all residents, at a cost which is affordable, personal care must be part of a larger system which includes adequately funded and efficient state and local health departments. The recently enacted Washington State Health reform plan makes it clear that both personal care and population-based health services must be supported in a reformed system which strives for a higher level of health for all.³ This same model is under discussion nationally. If it were enacted, we would have a well supported public health system available to respond to outbreaks of communicable diseases, or spills of toxic chemicals, continuously monitoring health status through vital records and reportable conditions and through collaboration with care providers and others to assure reduction and health promotion activities in a variety of settings. Such a model would assure quality in the overall system.

It is important to understand and separate personal care activities from public health actions. Tuberculosis presents a challenge because it overlaps with both systems. Both in large cities with large numbers of patients, and in smaller communities with only an occasional case, the lack of a universal personal care system means that the health department may be the only source of care available to the infected individual. This means not only providing anti-tuberculosis drugs, but all other primary care as well as needed hospitalization. If there were a functioning care system, the health department could limit itself to the identification of new cases, intensive casework with difficult-to-treat individuals, development and enforcement of infection control guidelines, and consideration of additional primary prevention strategies, such as participation in a neighborhood housing improvement project. In the current situation, there is little or no capacity to expand tuberculosis screening into all recommended settings, let alone to do a truly thorough job of follow-up on all of those screened. A similar story could be told of capacity to respond to HIV infection, teen pregnancy, lead poisoning or threatened drinking water sources.

Core public health functions

The Institute of Medicine report cited earlier developed a rubric of terms which have become fairly common in describing the basic infrastructure role of an official health

agency. These "core functions" are identified as assessment, policy development and assurance. A brief description of each will provide a framework for discussing what needs to be rebuilt across this nation.

Assessment is the process of determining what is happening in the community: gathering facts and interpreting them to provide useful information. Such data includes information on health status, as identified through traditional vital statistics or disease reporting systems. Assessment also encompasses information on threats to health such as data collected through environmental monitoring programs. Finally, a good assessment process will include attention to the community capacity to respond to threats to health, or to maintain and promote health. This includes information on all health related resources and community development resources. In most areas, assessment is a function shared by state and local health agencies; information may be collected or analyzed at either level and is shared between them as it is applied to provide either a local or statewide perspective. This local network is the foundation of the Centers for Disease Control & Prevention (CDC) national surveillance system, as well.

Policy development may be the least expensive, though occasionally the most visible, of the core functions. This is the development of proposals for action, based on the information made available from assessment. Policy development may be internal to the health community, as when public health agencies and pediatric groups work to refine the schedule of childhood immunizations. It may also be national in scope, as in our ongoing efforts to develop appropriate responses to tobacco-related diseases. At all levels, good policy development means effective communication with community leaders, political decision-makers and those directly affected by the proposed actions. A major reflection of public health policy in any jurisdiction will be the health agency's budget allocation, though policy is also expressed in statutes, ordinances, executive orders, organizational charts, or public education messages.

The concept of assurance as the third core function has been more difficult for many to understand and communicate. As I have considered it, it encompasses the entire range of actions needed to see that policy decisions are carried out, and carried out well.

It does not mean, however, that the official health agency has sole, or even any, responsibility for the direct actions required. For example, it is public policy in all jurisdictions in this country that public water supplies be safe; I do not know of any health departments which directly manage drinking water systems. The health agency is responsible for technical assistance to and education of water systems operators, for monitoring the water actually pumped to households, and for taking action should there be a failure.

The provision of personal care services, either as the community's provider of last resort, or for special populations which do not readily fit into the mainstream of service, is an assurance function assumed by many health departments. In others, there is a very strong bias against such activities, and the official agency's role is seen as that of organizer, stimulator, or even payer, of others who provide direct service. In either case, there is a risk that attention to individual ill persons will be an endless distraction from responding to the community as a whole.

These three functions do not stand in a sequence which, once completed, ends the process. Rather, they form a continuous circle, or spiral, in which assessment leads to policy development which leads to assurance which leads to a new assessment and so on. In the present state of affairs, there are so many demands for activity on the part of health agencies, and so many unmet needs, that there is little time for thoughtful assessment of more than the obvious indicators, and policy development is often a hurried response to public outcry. According to the IOM report, and the thinking of leaders in the field, a major need is to keep the three functions in balance and complementing one another over time.

Rebuilding

It is not clear whether the term should be "rebuilding" or just plain "building," but the capacity fully to perform the core public health functions is not in place in this country. In Washington State, a recent careful look at funding for public health agencies yielded the reliable estimates that less than 3 percent of total health-related expenditures were directed to public health, and that this was less than half of what was needed. Further, a sizeable portion of what is now spent by the public health agencies was services. There is no reason to think that the circumstances are markedly different in any of the other 49 states.

The infrastructure of official health agencies should be built with the goal of a system which can be responsive over an extended period of time to a variety of threats to health, in a variety of changing circumstances. It would be wasteful to invest in a system which can only respond to tuberculosis in 1993 and which would need complete replacement were TB to be brought under control and some other condition emerge in its place. The system, in fact, needs to be built with the assumption of such change, based on the findings of assessment and on the decisions which emerge in the policy development process.

The assessment capacity must be an active one, based on planned surveillance of issues of concern. That means staff must be available to talk regularly to hospitals, physicians and other care providers. It means a system of local reporting which is pooled at the state and national

levels, and which includes capacity to follow up on unusual events or suspicious circumstances. It also means active thinking about the results of surveillance—continually asking the question "what am I *not* seeing?"⁴ For example, given the emergence of MDR-TB, every health agency should be critiquing current tuberculosis surveillance techniques to see if they are adequate to identify a drug-resistant infection, if it were present. Those responsible for assessment in adjoining jurisdictions should have an efficiently functioning system of comparing notes and sharing information.

Policy development should be responsive, both to emerging health information and to the needs and concerns of the community served. We are only beginning to understand fully the cultural diversity of this country, and what it might take to make all of our public programs truly relevant to all. Because so many illness problems, and so many threats to health, are disproportionately felt by those in communities of color, and those using languages other than English as their first languages, it is essential that we learn ways of building those communities into the infrastructure of public health, as advisors, as staff, and most particularly as comfortable participants in shaping direction. The public health system must be constantly alert to inclusion of those threatened, for whatever reason, with disenfranchisement, as has happened in the case of stigmatized conditions such as substance abuse.

A further challenge to policy development is that of continuous improvement. No policy is either perfect or permanent. Many of our public health laws are outdated; written decades ago, they do not reflect current scientific understanding of diseases, or current expectations about assurance of individual civil rights while acting to protect the community. As many learned in early AIDS-related policy debates, discussions of core public health law can be difficult and painful. In some jurisdictions, public health agencies were forbidden to take actions which they felt were appropriate, and in others they were given unwanted authority to limit the actions of individuals. A responsive policy development function will include ongoing communications with all components of the community so that difficult policy decisions will not be debated among strangers, and the goals of the health agency will be transparent to all concerned. Laws would be updated as the social system evolves, before crises occur.

As with the more abstract discussion of assurance above, describing a rebuilt assurance function is difficult. This is because assurance will be, in each community, a locally unique blend of care and prevention, of public and private activities. The policy debates should spell out what is expected, and who is expected to do it, so that the health agency can concentrate its efforts appropriately, either as an organizer, a provider, or a monitor of programs. In all

cases, each program included in the agency should be "rich" enough that an unusual demand in one area does not necessitate shutting down all other activity. For example, while it might be reasonable to curtail most other services during a once-a-year, back-to-school immunization day, it should be possible to investigate a food-borne outbreak, immunize children, conduct tuberculosis case-finding, and instruct water system operators at the same time. To use the analogy of a fire department: it is only the rare and very large fire which demands all available equipment; in ordinary circumstances, even while a fire is being extinguished in one part of town, other engines are on standby elsewhere, and the school fire prevention class continues.

Beyond the direct outreach and service activities of each agency, there must be a capacity to work with and adapt quality assurance guidelines to local circumstances. That generally means staff time to attend regional or statewide meetings to learn about the applicable standards, and then local meetings with affected parties to consider applications and variations. Too often, people think the job is done when the standard is published in the MMWR or the Federal Register. Blind adherence to such standards can be a "force fit," wasting resources and leaving important matters untended.

If we fail to connect the assurance function with a continuing assessment, there is a further gap. For example, despite many years of consensus that all HIV infected individuals should be screened for TB, as well as the reverse, we are far from full implementation. The gap is due to the shortage of staff in both TB and HIV related programs, and to lack of planning and training time in which to develop ways to integrate these two concerns. A fully developed assurance function would have anticipated the need for staff development, for revised clinic protocols

and for provider education. A more active assessment function might have revealed the gap between policy and reality more fully before the enormous jump in TB cases.

The emergence of a new TB epidemic, in part resistant to many of our otherwise effective therapies, and the interrelationship of that epidemic with the continuing expansion of HIV infection provide a stimulus to invest in public health agencies. Policy makers are frightened by the thoughts of an old disease once again attacking the public, and they continue fearful in the face of the personal and economic cost of these communicable conditions. It would be possible to create disease-specific responses, and in part we must do so—the response to any disease or threat to health must be uniquely grounded in the biology, behavior, and impact of the causative organism. But what is really needed is a basic public health system vigorous enough to respond in the short term not only to these widespread conditions, but over time to all of the many conditions which keep us from collectively living up to our potential. This infrastructure may never be as visible and glamorous as many of our high-technology curative palaces, but it is probably even more essential if we are to keep our communities viable.

References

1. Kevin A. Cahill, *Imminent Peril: Public Health in a Declining Economy* (20th Century Fund Press: New York City, 1991).
2. Institute of Medicine, *The Future of Public Health* (Washington, DC: National Academy Press, 1988).
3. Washington Health Care Commission. *Final Report to Governor Booth Gardner and the Washington State Legislature*, November 30, 1992.
4. Institute of Medicine, *Emerging Infections* (Washington, DC: National Academy Press, 1992).



JOURNAL OF PUBLIC HEALTH POLICY

208 Meadowood Drive, South Burlington, Vermont 05403

Tel. (802) 658-0136 Fax (802) 862-4011

REVIEWER'S COMMENTS

(Although this journal follows the usual practice of maintaining strict anonymity of reviewers, it is sometimes both useful and encouraging to authors to know the stature of those who comment on their work, particularly when the comments are favorable and specific suggestions are made to improve the paper. If you are willing to be identified, please indicate this below.)

This paper is a straightforward account of a federally-sponsored effort to delineate the agenda for the next generation of studies regarding HIV-related care services. While it might be of more interest to an HIV-specific audience, it is of value to anyone interested in public health policy for at least 3 reasons:

1. HIV services are consuming a growing proportion of service dollars, & we must be sure we are spending those funds wisely
2. The process of planning service delivery via local councils is a model not fully developed or understood
3. The agenda-setting process could be used in other situations.

Two points could be made more clearly:

- 1) what information was available to process participants in advance, to be sure they knew what had been done
- 2) what evidence is there that communities are aware of & using evaluative information

The piece is certainly appropriate for JPHP publication.

Name

K. Hulse



You may use my name.

12-29-93



JOURNAL OF PUBLIC HEALTH POLICY

NOV 29 1993

208 Meadowood Drive, South Burlington, Vermont 05403

Tel. (802) 658-0136 Fax (802) 862-4011

November 24, 1993

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator
750 17th Street, NW
Suite 1060
Washington, DC 20503

Dear Kristine:

I should greatly appreciate your reviewing the enclosed paper which has been submitted to the Journal. Please use the attached form for your comments.

If you cannot review this paper within the next three weeks, please return it *at once*. This request is made in order that contributors may not have to wait inordinately long periods of time before hearing from us.

Thank you very much for your help.

Sincerely,

Milton Terris, M.D., M.P.H.
Editor

NATIONAL AIDS POLICY OFFICE
OFFICE OF THE COORDINATOR

ROUTING SLIP

DATE:

papers
Speeches/

TO:

Steve

FROM: KRISTINE M. GEBBIE

For your information

For your action

Review and comment by (date)

Prepare reply for Coordinator's signature

Reply directly and blind copy Coordinator

Circulate/forward to:

File

COMMENTS:

*I need at least an
hour to develop
this - could be an
early morning -*

NOV - 2 1993

November 1, 1993



American Public Health Association

1015 Fifteenth Street, NW
Washington, DC 20005
202/789-5660

Mervyn Susser, MB, BCh,
FRCP(E), DPH
Editor, American Journal
of Public Health

Kristine Gebbie, RN, MN, FAAN
National AIDS Policy Coordinator
Office of National AIDS Policy
Executive Office of the President
750 Seventeenth Street, NW
Suite 1060
Washington, DC 20503

Dear Ms. Gebbie:

I understand from George Silver that you will be writing an Editorial or Commentary for an upcoming issue of the American Journal of Public Health. **Editorials can be up to 1500 words. Commentaries can be up to 2500 words and are usually accompanied by an unstructured abstract of 100 to 140 words.**

Enclosed is an article central to your topic:

92/777--Backstrom, G.

"The Role of State Health Departments in
Formulating Policy: The Case of Acquired
Immunodeficiency Syndrome (AIDS)"

Please submit your manuscript **double spaced**, including references, with a **2 1/2 inch margin on the right side**. This format gives Dr. Susser sufficient room to add comments or make suggestions for changes.

As Dr. Silver may have mentioned in his conversation with you, we need to receive your manuscript **by December 15**. This will enable us to complete the peer review and editing process (to which all Journal articles are submitted) in time for our tight publication deadline.

It would help us greatly if you could send one copy to the Washington, DC, office and another by **FEDERAL EXPRESS** to Dr. Susser's New York address: Columbia University, Sergievsky Center, 622 West 168th Street, 19th Fl., Room 112, New York, NY 10032. In addition to the typed copy, we would welcome it if you could also send your text on a disk to the Washington office (MAC or IBM are both acceptable. Please indicate the software used).

Sabine
Beiser
212
3059081



American Public Health Association

1015 Fifteenth Street, NW
Washington, DC 20005
202/789-5660

Mervyn Susser, MB, BCh,
FRCP(E), DPH
*Editor, American Journal
of Public Health*

Page 2
Ms. Gebbie

I am enclosing a copyright release form for you to sign and include when you send us your paper. We also require a short written statement indicating that the editorial you are submitting or its essential substance has not been previously published and is not under publication consideration elsewhere.

Please don't hesitate to contact me if you have any questions (tel: 212-305-9081, fax: 212-305-9080). We greatly appreciate your willingness to undertake this task and look forward to seeing your manuscript.

Sincerely,

Joan Abrams
Editorial Coordinator
JA:jw

Enclosures

cc: Mervyn Susser
Sabine Beisler
George Silver

AMERICAN JOURNAL OF PUBLIC HEALTH

OFFICIAL JOURNAL OF THE
American Public Health Association
1015 Fifteenth Street, N.W.
Washington, D.C. 20005
(202) 789-5600

RE: MS# _____

Date: _____

Dear _____

Please ask each author to read and sign one (1) of the two statements below on copyright transfer or federal employment. If necessary, photocopy this document to distribute to co-authors for their signatures. Please return all copies promptly to the above address.

COPYRIGHT AGREEMENT

In compliance with the Copyright Revision Act of 1976, effective January 1, 1978, the American Public Health Association (APHA) in consideration of taking further action in reviewing and editing your submission, requests that each author sign a copy of this form before manuscript review can proceed. Such signatures shall evidence the mutual understanding between the APHA and the undersigned author(s) thereby transferring, assigning, or otherwise conveying all copyright ownership to the APHA.

In consideration of the action of the APHA in reviewing and editing this submission, the authors undersigned hereby transfer, assign, or otherwise convey all copyright ownership to the APHA in the event that such work is published by the APHA.

Author(s)	Signature(s)	Date Signed
-----------	--------------	-------------

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

US FEDERAL EMPLOYEES: If you prepared this manuscript as an employee of the ~~US~~ federal government, please so indicate by signing the following statement: I was an employee of the US federal government when this work was investigated and prepared for publication; therefore it is not protected by the Copyright Act and there is no copyright of which the ownership can be transferred.

Author(s)	Signature(s)	Date Signed
-----------	--------------	-------------

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

THE ROLE OF STATE HEALTH DEPARTMENTS IN FORMULATING POLICY:
THE CASE OF ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS)

by Leonard Robins, PhD
Professor of Public Administration
Roosevelt University, Chicago, Illinois

and Charles Backstrom, PhD
Professor of Political Science
University of Minnesota/Twin Cities

Acknowledgements

We wish to thank Theodor J. Litman, Ph.D., and three anonymous referees for helpful comments on drafts of this work.

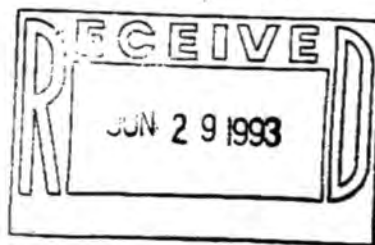
An earlier version of this article was presented before the American Political Science Association, Chicago, September 5, 1992.

Address for correspondence:

Charles Backstrom
Professor of Political Science
1414 Social Science Building
University of Minnesota
Minneapolis, MN 55414

Request for reprints should be sent to:

Charles Backstrom
1414 Social Science Building
University of Minnesota
Minneapolis, MN 55414



Number of words in text: 2904

Number of tables: 4

Key words:

Acquired Immunodeficiency Syndrome
health politics
public health administration

92/777R MWS

THE ROLE OF STATE HEALTH DEPARTMENTS IN FORMULATING POLICY:
THE CASE OF ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS)



ABSTRACT

Objectives. Public health departments have been criticized by the Institute of Medicine generally for not being at the cutting edge of health policy formation in the United States, and in particular for being ineffective in dealing with Acquired Immunodeficiency Syndrome (AIDS). This study examines the attitudes and influence of public health officials on this major new problem.

Methods. The study is based on a survey of state health department officials, supplemented by surveys of state legislature health committee chairs and hospital association directors, as well as interviews with key AIDS policymakers and observers in six states.

Results. Both in their own eyes, and in those of legislative leaders and hospital association officials, public health officials were found to be the principal initiators and designers of public policy on AIDS.

Conclusions. Contrary to the Institute of Medicine, this study found state health departments to be leaders in the fight against AIDS at the state level. Moreover, we argue that public health departments should be judged on how effectively they ^{perform} ~~perform~~ functions for which they have primary legal responsibilities, not for other roles for which they have been given neither responsibility nor resources.

Introduction

In 1986 the Institute of Medicine (IOM) established a Committee on the Future of Public Health. It was created to address a growing perception that the nation has "allowed the system of public health activities to fall into disarray."¹ After two years of study the committee concluded that "Unfortunately, the findings of this committee confirm the concerns that led to the study."¹

The IOM report chose Acquired Immunodeficiency Syndrome (AIDS) as an example of how poorly the public health system works. The report emphasized the danger of public health officials having overly broad statutory power for imposing quarantine. It implied that health agencies overemphasize surveillance at the expense of education. Finally, it asserted that health agencies have not supplied leadership in dealing with this new disease.¹

The IOM report gave several reasons for the general inadequacy of public health departments. Among the most important was its belief that public health officials were both naive about and contemptuous of the political process and hence lacking in political power.¹

The purpose of this article is to examine these conclusions. But instead of focusing on the influence of public health professionals on the overall health care system of the United States, we ask a different question: How well are they performing the classic public health functions that are still within their jurisdiction. We propose to do this by emphasizing their role in

the fight against AIDS -- the greatest communicable disease challenge of our time and an issue that obviously offers an important role for public health agencies to play.

Methods

As part of an ongoing study of AIDS politics,² in the spring and fall of 1989, questionnaires concerning their state's policies on AIDS were sent to the nation's 50 state health departments, the 75 area-wide hospital associations in the United States, and to the chairs of all state House and Senate health committees. Those not responding within three weeks were sent a followup letter with another questionnaire. Ultimately, usable responses were received from 42 (82%) of the state health departments; 51 of the 76 (67%) state and regional hospital associations representing 39 (76%) of the states; and 68 legislative committees (68%) in 43 (84%) of the states. A number of the questions were common to all sets of respondents, while others were geared to the special concerns of each category of respondents. Although the response rate was gratifyingly high, the total number of responses is necessarily relatively small. Because the universe of states was surveyed, no tests of statistical significance are used.

In addition to the surveys, in fall and winter of 1989-90, field interviews were conducted with AIDS policymakers in six states -- Arizona, California, Georgia, Illinois, New York, and Minnesota.

This paper mainly reports the results from the state health departments survey, supplemented by selected findings from the

other surveys and occasional insights from the interviews.

Results

The Statutory Authority of Public Health Agencies. The IOM report asserted that "the statutory base of public health is poorly suited to dealing with AIDS." In particular, the committee was concerned with overly restrictive powers that had earlier been given to health departments including full isolation and quarantine.¹

The relevant issue is whether state health departments endorse a policy of quarantining persons with AIDS or who test HIV-positive, or instead support a less restrictive policy. One alternative would be reliance on civil commitment procedures, to be used if an HIV-positive person persists in behavior that endangers others even after being warned to cease. This would operate similarly to dealing with someone who is mentally ill and thought to need control. Unlike quarantine, civil commitment is hedged with due process protections. Another option is using existing criminal statutes, where a charge of assault could be brought against someone who is HIV-positive and wantonly or carelessly infects others.

Respondents to our survey were asked whether their present state policy included quarantine especially for AIDS, civil commitment authority, and/or making risky behavior criminally liable. They were also asked whether the health department favored such policies. In only one instance was quarantine for AIDS the theoretically official policy of the state, and in only that instance was quarantine favored. Thus it is clear that

quarantine is overwhelmingly opposed by state health officials, and that whether taking the lead or in alliance with others they have been successful in preventing it from becoming policy.

As for civil commitment, of all respondents about two in five (43%) said their states had such policy. Just over half (52%) of all respondents said they favored it, while just over one-quarter (26%) opposed. On the issue of criminal liability, nearly two-fifths (38%) of the states had this as their policy. Not only was that policy favored by only one-third (33%) of the health departments, but it was opposed by the same proportion, with the rest uncertain or not responding.

In Minnesota³, interviews with health and legal officials dealing with AIDS revealed that state health officers were fully aware of the danger of untrammelled governmental powers. Although general quarantine statutes from the earliest days of statehood gave unrestricted power to the chief state health officer to isolate anyone with a serious communicable disease who appeared to be a threat to the public health, the state health department actually feared that use of this statute -- which contained no due process provisions such as notice and hearing -- against AIDS would open them to justifiable complaint. As a result they sought and obtained from the legislature a modification to make their powers conform to modern practice in civil commitment of the mentally ill. They did not want the quarantine statute repealed, however, because it provided a cover for opposing more restrictive laws about AIDS that might well have been passed. In fact, they pointed to two, but only two (an infected female and male prostitute), instances when they have used the authority to

restrain persons who did not respond to orders to desist as evidence that the health department was actively protecting the larger public.

It would appear that the state health officers are heeding the IOM report's warning that public health statutes give state health departments overly broad and restrictive powers. Not only did they not want additional draconian powers, but in fact oppose use of "solutions" such as quarantine. Contrary to the common assumption that any bureaucracy always desires more power, they exhibited a sophisticated understanding of what constitute appropriate legal powers against AIDS.

Data gathering and analysis. The IOM report noted that "Some health agencies are accused of overemphasizing surveillance at the expense of preventive efforts such as education."¹ Given the use of the word "some" this is undoubtedly true. Surveillance is the traditional core of classic public health, and AIDS education's inevitable interface with sex and drug use insures that it will be controversial. Nonetheless, as Table 1

[TABLE 1 ABOUT HERE]

shows, in terms of efforts to deal with the disease they are far from being totally preoccupied by surveillance issues.

Although in no state did public health officials assign knowing the extent of AIDS in their state a low priority, five other AIDS efforts were considered by state health departments to have highest priority. Surveillance, however, was ranked as highest priority by more health officials than two other listed efforts. Thus while all state health departments consider surveillance important, many are equally or more strongly

committed to more activist aspects of AIDS control.

Influence on Policy. According to the IOM report:

Among the many groups and individuals, public and private, engaged in fighting AIDS, health agencies have not taken a clear initiative in supplying leadership, and the public is unclear about what level of government it should look to for guidance or what it can appropriately and realistically expect any particular health agency to do.¹

It is indeed undoubtedly true that the public is unsure of which level of government is responsible for various activities. Alas, that is true of almost all public policy problems, save perhaps for national defense at one extreme and fire protection at the other. The only concern of the public is whether anyone is doing the job. In this case the issue is whether state health departments have a leading role in AIDS policy development.

As evidence that health departments are often not critical players in the formulation of AIDS policies, the IOM report quoted a legislative staffer who said:

The legislature has been the leader.... Such leadership should have come from the Department of Health Services. The state health director knows less than I do about what's happening in the state!¹

Our study finds otherwise.

Table 2 presents the relative assessment of the influence of
[TABLE 2 ABOUT HERE]
various actors on state AIDS policy by state health department

heads, legislative health committee chairs, and hospital association directors. Potential actors are grouped into the following categories: health department heads, elected officials health providers, affected groups, and ideological groups.

Perhaps not surprisingly, health departments rated themselves as being the most influential actors on AIDS policymaking in their states. Three in five (60%) felt that they were very influential, nearly another two in five (38%) thought they were somewhat influential in setting AIDS policy, with only one respondent indicating they had little influence and not a single one asserting they had no influence.

Strong confirmation of the influential role health departments play in AIDS policymaking is provided by the other groups surveyed. Legislative health committee chairs and hospital association professionals ranked the health departments clearly higher in influence than any other actor.

The next most influential AIDS policymakers were seen to be legislative leaders. Well over half (57%) of the health departments perceived legislative leaders as very influential and more than one-third (36%) said somewhat influential. This assessment was seconded by the legislative chairs and the hospital association professionals.

Although somewhat less important, the governor was the only other actor believed to have substantial influence on AIDS policymaking. Just over two-fifths (43%) of health departments rated their governor as very influential, and about the same proportion (41%) said somewhat influential. Hospital associations

ranked the governor similarly. Legislative respondents, on the other hand, ranked the governor substantially lower.

At a distinctly lower level of influence stand health provider associations. About a quarter (24%) of the health departments rated the state medical association to be highly influential, but over three in five (62%) classified them as having some influence. Legislative chairs pegged the medical associations somewhat higher, but hospital association directors ranked them far lower in influence. As for hospital associations, one-seventh (14%) of the health departments believed that hospital associations were very influential in AIDS policymaking, but more than three in five said they had some influence. Legislative chairs ranked them higher, but with only one-quarter (25%) classifying them as very influential, while slightly fewer (23%) of hospital associations ranked themselves very influential.

Weakest among provider groups is the insurance industry, whom fewer than one in ten (7%) of the health departments rated as very influential. Legislative chairs and hospital associations ranked them somewhat higher, but still below the other providers.

Affected groups such as persons living with AIDS and organized gays were seen by fewer than one in ten health departments as being very influential. At an even lower level of influence were ideological organizations and church leaders. Only conservative organizations were seen as highly influential by any rating group, with one in seven (14%) of health departments classifying them so.

Political scientists have long debated the utility of

reputation as a surrogate measure for actual public policy influence, since there may well be a low correlation between who is thought to have influence and who does in reality. This doubt is especially persuasive when those whose opinions are asked are not experts on the subject and are not themselves involved in decisionmaking on the matter at hand. In this case, however, those responding were themselves specialized elites working in the same subject matter area -- here AIDS.

Understanding the Political Process. The IOM report was also very critical of public health officials for their lack of political skill and understanding. In its words:

Too frequently during its investigations, the committee heard legislators and members of the general public castigate public health professionals as paper-shufflers, out of touch with reality, and caught up in red tape.... Yet many public health professionals who talked with us seemed to regard politics as a contaminant of ideally rational decisionmaking processes rather than as an essential element of democratic governance. We saw much evidence of isolation and little evidence of constituency-building, citizen participation, or continuing (as opposed to crisis-driven) communication with elected officials or with the community at large.¹

Although it is undoubtedly true that some public health officials lack political sophistication, our study results contradict the view that public health officials are generally politically inept and ignorant, at least as regards to AIDS. Two

questions from our survey had political content most pertinent to this subject.

First, to test the view that state health departments were preoccupied with their internal procedures, respondents were asked how important they regarded each of various aspects of their job as it concerned AIDS (Table 3). Developing innovations

[TABLE 3 ABOUT HERE]

in the agency's AIDS program -- an inward-focused activity -- was found to be the least important function in the eyes of the respondents. Although all respondents believed that internal innovations were important, fewer than one-third (29%) considered it the highest priority, the lowest among the six categories suggested.

It should be acknowledged that higher importance given by state health departments to external rather than internal functions does not automatically mean that they are doing a good job of constituency building or fostering citizen participation. It does strongly suggest, however, that they are not preoccupied with paperwork and that communication with elected officials is more than episodic. Evidence earlier presented ranking their influence on AIDS policy reinforces this view.

To investigate the charge that public health professionals are ignorant of and have contempt for the political process, a second set of questions presented a wide array of various "liberal" and "conservative" strategies for influencing AIDS policy. Respondents were asked to rate the effectiveness of these strategies as good or poor. We then computed the "edge" by which respondents label a strategy as good over the proportion who

think it is poor (Table 4).

[TABLE 4 ABOUT HERE]

Least support (36% and the only negative edge) was given to stressing civil liberties as an effective liberal strategy. Conversely, an overwhelming majority (70% with a 63% edge) considered emphasizing the suffering of real people as a good strategy from the liberal perspective. A massive majority (87% with a 71% edge) endorsed emphasizing the need to protect innocent victims as a good conservative strategy. On balance, a small group (21% with a -5% edge) thought arguing that AIDS is a valid election issue would be a poor strategy.

To us as political scientists these judgments show political sagacity. While the analysis of these responses as indicators of political sophistication must inevitably be subjective, interviews with non-health policy actors and observers of the legislative process in the six states visited generally show agreement with these assessments by health departments.

Discussion

Our study of AIDS policymaking found that in dealing with AIDS, public health departments are very influential.

Moreover, both our surveys and interviews convinced us that public health professionals promoted their ideas with a clear understanding of their political environments and the strategies appropriate in them.

These findings dramatically differ from the indictment of public health professionals by the Institute of Medicine, which characterized public health as being in disarray and politically

amateurish.

How do we account for these different perspectives? One explanation may be that the negative view expressed in the IOM report is generally correct, and that our findings refute these assertions only when applied to AIDS.

But the context in which public health operates has also changed with the challenge of AIDS. A massive communicable disease threat at a time when antibiotics had seemingly downgraded the necessity for classic public health presented the opportunity for public health agencies once again to move to center stage, instead of being relegated to unglamorous activities like restaurant inspection.

More fundamentally, however, we suggest that our conclusions arise from different evaluation criteria. The IOM spent a good deal of time noting that many important health issues are not under the jurisdiction of public health departments. This, however, is a strange criterion. It is perfectly appropriate to recommend the consolidation of health functions under a superagency, but wrong to use the failure of this to occur as evidence of the inadequacies of public health professionals. Why should we be surprised that environmentalists or mental health specialists want their own agencies or that they have been able to succeed in getting them in a separate department, since public health professionals themselves do not like to be a division of a superagency.

Likewise, the criticism that public health agencies have not acted to institute major reform of the health delivery system is

unfair. Unfortunately the United States government has not yet enacted national health insurance, but this requires a political decision at a more fundamental level than bureaucrats can provide.

Thus we show that these maligned public health agencies reacted with professional competence and political skill (two not unrelated aspects) to deal with the threat of AIDS. Perhaps public health professionals are rarely thought about in routine times, but are nonetheless quite competent when a public health emergency arises in which they are needed. Their apparent decline is at most true only in a relative sense.

REFERENCES

1. Institute of Medicine. The Future of Public Health.
Washington,DC: National Academy Press, 1988.
2. Robins L and Backstrom C. The Politics of AIDS. In Litman T
and Robins L. Health Politics and Policy. Albany,NY:
Delmar Pub, 2d ed., 1991:370-386.
3. Backstrom C and Robins L. The Minnesota Response to AIDS.
Minneapolis,MN: Center for Urban and Regional Affairs, Univ of
MN,1992.

TABLE 1

PRIORITIES GIVEN VARIOUS AIDS EFFORTS BY STATE HEALTH DEPARTMENTS (n=40)

	<u>PRIORITY</u>			<u>SHOULD</u>
	<u>HIGHEST</u>	<u>HIGH</u>	<u>LOW</u>	<u>NOT DO</u>
<u>EFFORT TO DEAL WITH AIDS</u>	Percent	Percent	Percent	Percent*
GETTING HIGH RISK PERSONS TO CHANGE SEXUAL BEHAVIOR	70.0	27.5	2.5	0.0
REACHING MINORITIES ON AIDS PREVENTION	52.5	42.5	5.0	0.0
GETTING HIGH RISK PERSONS TO TEST FOR HIV	43.9	51.2	4.9	0.0
INFORMING PUBLIC ABOUT HOW AIDS IS SPREAD	34.1	56.1	9.8	0.0
KNOWING EXTENT OF AIDS PROBLEM	26.8	73.2	0.0	0.0
PROVIDING SUFFICIENT DRUG REHABILITATION	32.5	47.5	20.0	0.0
RESTRICTING PERSONS WITH HIV FROM SPREADING IT	24.3	51.4	13.5	10.8
GETTING HETEROSEXUALS TO USE SAFE SEX	14.6	65.9	17.1	2.4

 *In this and subsequent tables row percentages may not total 100% because of rounding.

TABLE 2

RELATIVE ASSESSMENT OF INFLUENCE OF VARIOUS ACTORS ON STATE AIDS POLICYMAKING
BY HEALTH DEPARTMENTS (n=42), LEGISLATIVE CHAIRS (n=68), AND HOSPITAL ASSOCIATION DIRECTORS (n=47)

Policy Actor	VERY INFLUENTIAL			SOME INFLUENCE			LITTLE INFLUENCE			NO INFLUENCE			
	Rater	Health Dept.	Leg. Chair	Hosp. Assn.	Health Dept.	Leg. Chair	Hosp. Assn.	Health Dept.	Leg. Chair	Hosp. Assn.	Health Dept.	Leg. Chair	Hosp. Assn.
	Percent	Percent	Percent	Percent	Percent	Percent	Percent	Percent	Percent	Percent	Percent	Percent	Percent
<u>State Administrators</u>													
STATE DEPARTMENT OF HEALTH	59.5	67.6	72.3	38.1	30.9	25.5	2.4	1.5	2.1	0.0	0.0	0.0	
<u>Elected officials</u>													
LEGISLATIVE LEADERS	57.1	48.5	46.8	35.7	45.6	44.7	7.1	5.9	6.4	0.0	0.0	2.1	
GOVERNOR	42.9	20.6	42.6	40.5	52.9	29.8	9.5	22.1	25.5	7.1	4.4	2.1	
<u>Health providers</u>													
STATE MEDICAL ASSOCIATION	23.8	29.9	19.1	61.9	62.7	40.4	14.3	7.5	2.1	0.0	0.0	38.3	
STATE HOSPITAL ASSOCIATION	14.3	25.0	23.4	64.3	61.8	46.8	16.7	11.8	25.5	2.4	1.5	4.3	
INSURANCE INDUSTRY	7.1	11.8	17.0	52.4	57.4	55.3	31.0	27.9	23.4	7.1	2.9	4.3	
<u>Affected groups</u>													
PERSONS LIVING WITH AIDS	9.5	15.2	6.4	40.5	43.9	34.0	42.9	39.4	51.1	7.1	1.5	8.5	
ORGANIZED GAY GROUPS	9.5	10.3	6.4	54.8	29.4	34.0	26.2	44.1	42.6	7.1	16.2	17.0	
<u>Ideological organizations</u>													
CONSERVATIVE IDEOLOGICAL GROUPS	14.3	2.9	4.3	28.6	26.5	38.3	38.1	50.0	48.9	16.7	20.6	8.5	
LIBERAL IDEOLOGICAL GROUPS	2.4	4.4	2.1	38.1	27.9	31.9	42.9	54.4	53.2	14.3	13.2	12.8	
MAINLINE CHURCH LEADERS	4.8	1.5	4.3	47.6	35.3	34.8	42.9	50.0	50.0	4.8	13.2	10.9	
FUNDAMENTALIST CHURCH LEADERS	2.4	0.0	6.5	35.7	20.6	23.9	42.9	50.0	45.7	19.0	29.4	23.9	

*Percentages of a single rating group may not total 100.0 across because volunteered "Don't know" is not tabulated.

TABLE 3

PERCEIVED IMPORTANCE OF VARIOUS FUNCTIONS OF STATE HEALTH DEPARTMENT REGARDING AIDS POLICY (n=42)

<u>FUNCTIONS</u>	<u>PERCEIVED DEGREE OF IMPORTANCE</u>			
	<u>HIGHEST</u>	<u>HIGH</u>	<u>NOT</u>	
	<u>IMPORTANCE</u>	<u>IMPORTANCE</u>	<u>IMPORTANT</u>	<u>IMPORTANT</u>
	Percent	Percent	Percent	Percent
DEVisING APPROPRIATE STATEWIDE POLICIES	54.8	42.9	2.4	0.0
MAKING THE PUBLIC MORE AWARE OF AIDS	45.2	38.1	16.7	0.0
LEADERSHIP OF HEALTH PROFESSIONALS	40.5	45.2	11.9	2.4
PROFESSIONAL ADVISER TO THE LEGISLATURE	31.0	50.0	14.3	4.8
PROFESSIONAL ADVISER TO THE GOVERNOR	29.3	48.8	14.6	7.3
DEVELOPING INNOVATIONS IN AGENCIES PROGRAMS	28.6	42.9	28.6	0.0

TABLE 4

EFFECTIVENESS OF POSSIBLE "LIBERAL" AND "CONSERVATIVE" STRATEGIES FOR ADOPTING AIDS POLICIES (n=39)

<u>POSSIBLE STRATEGY</u>	<u>EFFECTIVENESS OF STRATEGY</u>			
	GOOD	UN-	POOR	EDGE:
	<u>STRATEGY</u>	<u>CERTAIN</u>	<u>STRATEGY</u>	<u>GOOD-POOR</u>
	Percent	Percent	Percent	Percent
<u>"Liberal" strategies:</u>				
EMPHASIZE HUMAN INTEREST; PEOPLE SUFFER	70.0	22.5	7.5	62.5
ARGUE THE EFFECTIVENESS OF LIBERAL MEASURES	64.1	28.2	7.7	56.4
STRESS COMMUNITY VALUES; HELPING OTHERS	43.6	41.0	15.4	28.2
URGE KEEPING AIDS OUT OF ELECTORAL POLITICS	38.5	48.7	12.8	25.7
ENCOURAGE THREATENED GROUPS TO WORK TOGETHER	30.8	43.6	25.6	5.2
MAKE STAND ON PROTECTION OF CIVIL LIBERTIES	33.3	30.8	35.9	-2.6
<u>"Conservative" strategies:</u>				
POINT OUT THE NEED TO PROTECT INNOCENT PEOPLE	87.2	10.3	2.6	70.7
MAKE STAND ON THE DUTY TO PROTECT PUBLIC	64.1	30.8	5.1	59.0
DRAMATIZE THE THREAT TO THE GENERAL PUBLIC	61.5	33.3	5.1	56.4
EMPHASIZE HOW THOSE AT RISK DIFFER FROM MAJORITY	43.6	33.3	23.1	20.5
ENCOURAGE GREATER COHESION AMONG CONSERVATIVES	33.2	56.4	10.3	22.9
ARGUE THAT AIDS IS A VALID ELECTION ISSUE	17.9	59.0	23.1	-5.2

THE WHITE HOUSE
WASHINGTON

December 14, 1993

Dr. Mervyn Susser, Editor
American Journal of Public Health
Columbia University
Sergievsky Center
622 West 168th, 19th Floor, Room 112
New York, NY 10032

Dear Dr. Susser:

On behalf of Kristine M. Gebbie, please accept her editorial, "Formulating Public Health Policy: The Case of AIDS." In addition to the typed copy, I am enclosing a IBM-formatted WordPerfect disk (sent to the Washington office) and a biographical sketch.

This week, Kristine is travelling out of the country. Please call me at (202) 632-1090 if you any questions or need additional information.

Sincerely,

W. Steve Lee, Executive Assistant and
Scheduler to
National AIDS Policy Coordinator

Enclosures

cc: Sabine Beisler
American Public Health Association
1015 15th Street, N.W.
Washington, D.C. 20005

Formulating Public Health Policy: The Case of AIDS

Submitted by: Kristine M. Gebbie

As is true in many areas of American life, public health policy formulation is not a tidy process. All levels of government are involved: federal, state and local. Legislative bodies at all levels have been inconsistent in the breadth of power granted to executive agencies. In some instances, statutory language is very broad, granting wide authority to define issues, prescribe public action or direct staff attention to a public health official. In other cases, laws go into great detail on specific conditions or circumstances to which a particular action applies, and the opportunity for variance of individual application of public health judgement is very limited. Federal policies may supersede state and local ones, and states may manage or strongly influence local actions, but the chain of command is not direct. Funding for most public health activities is shared among the levels of government, and local actions are often constrained or directed by commitments made in order to have access to funds available from the state or federal level. In few cases does a public health official simply "make policy," as both law and good practice dictate some combination of consultation, oversight or concurrence from interested parties, advisory or decision-making health boards, elected officials, or legislators.

HIV infection and AIDS arrived on the public health policy scene early in the last decade, and presented multiple challenges to an

already strained public health system. Budget tightening due to a recession had restricted state and local appropriations. The "new Federalism" of the Reagan years included the merging of many public health programs into block grants for greater local flexibility, but an associated cut of approximately 25% of funds made it nearly impossible to sustain activities. Efforts to increase the levels of school immunization, respond to the interest in safe drinking water, reduce toxic wastes, improve birth outcomes, and increase access to basic primary health care are examples of the many demands on public health officials. Then came reports of a new syndrome, probably viral in origin, which was spreading rapidly and causing great public concern. The initial concentration of cases in a few geographic areas and population groups meant that many states could see the issue as one of primarily academic interest, though the public outcry for action became nationwide. Early, "business as usual" responses (epidemiological investigation of reported cases, consultation with the Centers for Disease Control and Prevention, distribution of updated information to key clinical and diagnostic centers) were swept away or confused by strong emotional responses. Advocates in the community most affected initially, gay men, argued strongly that the issue was ignored because of homophobia and that traditional record keeping or case identification methods would too easily support a variety of repressive, discriminatory or inappropriate control measures. Public fear of a devastating, community-wide disease explosion pushed others to call for more stringent measures, based on historical (and not

scientifically supportable) public health measures such as isolation, quarantine and public notification.

The study by Robins and Backstrom in this issue was designed to identify the degree to which public health agencies were effective leaders in developing AIDS-related policies at the state level. The authors refer extensively to the Institute of Medicine (IOM) study of public health published in 1988, which viewed "with great concern and some alarm. . . the current state of public health."¹ This report indicated that lack of leadership, tightly constrained resources, and limited vision were preventing the public health infrastructure of the nation from asserting a proper role in protecting the public from disease and promoting a healthier nation. Robins and Backstrom, on the other hand, conclude that at least in the case of AIDS, "public health departments are very influential [and]. . . promoted their ideas with a clear understanding of their political environments and the strategies appropriate in them."² Their analysis of this different conclusion was at least in part that the IOM used faulty criteria, focusing on failures to provide leadership and vision in areas which were beyond the scope of currently structured state health agencies. Using a case more associated with classic governmental public health responsibilities, response to a communicable disease, appropriate

¹Institute of Medicine. The Future of Public Health. Washington, D.C.: National Academy Press, 1989.

²Robins & Backstrom, mss p.11.

leadership was found.

The study reported has some unusual features, at least in the context of understanding state policies regarding HIV infection and AIDS. Debate about this condition at all levels of government has included an extremely visible role for advocacy groups emerging out of those most impacted by the epidemic. These include gay, gay and lesbian rights and civil rights groups, and new associations focused exclusively on HIV issues, such as the AIDS Coalition to Unleash Power (ACT-UP), Gay Men's Health Crisis, and the National Minority AIDS Council. In two of the states included in the reported study, New York and California, early legislative action regarding documentation and reporting of HIV-related information went in a direction contrary to traditional public health practice, and did not appear to be developed because of leadership activities by the state health officials.³ The information on study methodology indicates that the sources of data were state health official themselves, chairs of health committees in state legislatures, and officials of hospital associations (apparently as a representative lobbying group). Given the interest of HIV advocacy groups, which emerged early in the epidemic, it would have been most appropriate to include at least some representative of that perspective in the study. I would expect that their views would be more critical of

³It should be noted that many public health officials have agreed with advocacy groups on the principles to be reflected in public policy, such as public health science and protection of the confidentiality and rights of individuals, though there have been many disagreements on the specific responses to be employed.

the role played by public health officials.

Further, in at least some states, the issues of legal restriction on HIV positive individuals were reviewed in committees other than the health committee, such as a committee on legal affairs. Yet only health committee chairs were surveyed. It would have been helpful to know whether the responding committee had actually had jurisdiction over and considered legislation relevant to quarantine or isolation during the relevant time period. If the health committee had not sponsored hearings on these matters, or had performed only a secondary role in bill development, the health committee chair's understanding of the relative roles of interest groups and agencies might be limited.

An additional concern in data presentation is the question of which states responded. While it is possible that among the 42 state health departments, 39 hospital associations and 43 legislatures represented in the responses was at least one reply from every state, that is not made clear. In this particular policy area, the experiences of the states with high early infection rates had an enormous impact on the nation as a whole, and the relative roles of state health officials, legislatures and advocacy groups were shifted depending on whether early public or advocacy excitement rushed a legislature to action or whether there was time to develop a proposal more slowly.

It is very important, in the face of both the continuing HIV

epidemic and the potential for major health system reform, that the nation's state health officials play an appropriate role in determining policies which can promote the health of the public and protect the nation from preventable conditions. The literature on the public policy role of health officials is sparse, and a great many senior health officials in this country have learned about policy development on the job. Critical reading of articles such as that by Robins and Backstrom can enlarge our understanding of the interplay of interest groups and provide direction in how to communicate both concerns and successes to a wider audience. I would hope that others reading this piece will be stimulated to add to the body of literature, whether with a second generation of survey materials, or well-developed case studies, which can assist us all in appreciating both what has been the experience in public policy in the case of HIV and AIDS, and what might be expanded within the broad role available to a state health official.

Formulating Public Health Policy: the Case of AIDS

formulation
As is true in many areas of American life, public health policy ~~formation~~ is not a tidy process. All levels of government are involved; federal, state and local. Legislative bodies at all levels have been inconsistent in the breadth of power granted to executive agencies. In some instances, statutory language is very broad, granting wide authority to define issues, prescribe public action or direct staff attention to a public health official. In other cases, laws go into great detail on specific conditions or circumstances to which a particular action applies, and the opportunity for *variance or* individual application of public health judgement is very limited. Federal policies may supersede state and local ones, and states may manage or strongly influence local actions, but the chain of command is not direct. Funding for most public health activities is shared among the levels of government, and local actions are often constrained or directed by commitments made in order to have access to funds available from the state or federal level. In few cases does a public health official simply "make policy" *no* as both law and good practice dictate some combination of consultation, oversight or concurrence from interested parties, advisory or decision-making health boards, elected officials, or legislators.

HIV infection and AIDS arrived on the public health policy scene early in the last decade, and presented multiple challenges to an already strained public health system. Budget tightening due to

a recession had restricted state and local appropriations. The "new Federalism" of the Reagan years included the merging of many public health programs into block grants for greater local flexibility, but an associated cut of approximately 25% of funds made it nearly impossible to sustain activities. Efforts to increase the levels of school immunization, respond to the interest in safe drinking water, reduce toxic wastes, improve birth outcomes, and increase access to basic primary health care are ~~but~~ examples of the many demands on public health officials.

Then came reports of a new syndrome, probably viral in origin, which was ~~increasing~~ ^{spreading} rapidly and causing great public concern.

The initial concentration of cases in a few geographic areas

meant that many states could see the issue as of primarily academic interest, though the public outcry for action was

nationwide. Early, "business as usual" responses

(epidemiological investigation of reported cases, consultation with the Centers for Disease Control, ^{for research} distribution of updated information to key clinical and diagnostic centers) were swept

away or confused by strong emotional responses. Advocates in the

most affected ^{initially} community, gay men, argued strongly that the issue was ignored because of homophobia and that traditional record

keeping or case identification methods would too easily support a variety of repressive, ^{discriminatory or} and inappropriate control measures. Public fear of a devastating, community-wide disease explosion pushed

others to call for more stringent measures, based on historical (and scientifically ^{insupportable}) public health measures such as isolation, quarantine and public notification.

The study by Robins and Backstrom in this issue was designed to identify the degree to which public health agencies were effective leaders in developing AIDS-related policies at the state level. The authors refer extensively to the Institute of Medicine study of public health published in 1988, which viewed "with great concern and some alarm. . . the current state of public health."¹ This report indicated that lack of leadership, tightly constrained resources, and limited vision were preventing the public health infrastructure of the nation from asserting a proper role in protecting the public from disease and promoting a healthier nation. Robins and Backstrom, on the other hand, conclude that at least in the case of AIDS, "public health departments are very influential [and]. . . promoted their ideas with a clear understanding of their political environments and the strategies appropriate in them."² Their analysis of this different conclusion was at least in part that the IOM used faulty criteria, focusing on failures to provide leadership and vision in areas which were beyond the scope of currently structured state health agencies. Using a case more associated with classic governmental public health responsibilities, response to a communicable disease, appropriate leadership was found.

The study reported has some unusual features, at least in the

¹Institute of Medicine. The Future of Public Health. Washington, D.C.: National Academy Press, 1989.

²Robins & Backstrom, mss p.11.

context of understanding state policies regarding HIV infection and AIDS. Debate about this condition at all levels of government has included an extremely visible role for advocacy groups emerging out of those most impacted by the epidemic. These include ~~pre-existing~~ ^{and lesbian} gay, gay rights and civil rights groups, and new associations focused exclusively on HIV issues, such as the AIDS Coalition to Unleash Power (ACT-UP). In two of the states included in the reported study, New York and California, early legislative action regarding documentation and reporting of HIV-related information went in a direction contrary to traditional public health practice, and did not appear to be developed because of leadership activities by the state health officials.³ The information on study methodology indicates that the sources of data were state health official themselves, chairs of health committees in state legislatures, and officials of hospital associations (apparently as a representative lobbying group). Given the interest of HIV advocacy groups, which emerged early in the epidemic, it would have been most appropriate to include at least some representative of that perspective in the study. I would expect that ~~inclusion of~~ their views would ~~be less supportive of~~ be more critical of the role played by ~~state~~ public health officials. Further, in at least some states, the issues of legal restriction on HIV positive individuals were reviewed in committees other than the health committee, such as a committee on legal affairs.

~~Yet it was the health committee chairs were surveyed.~~

³It should be noted that many public health officials have agreed with advocacy groups on the principles to be reflected in public policy, such as public health science and protection of the confidentiality and rights of individuals, though there have been many disagreements on the specific responses to be employed.

~~the AIDS Coalition~~
Men's Health Crisis
Gay and the National Minority AIDS Council.

It would have been helpful to know whether the responding committee had actually had jurisdiction over and considered ^{legislation} ~~bills~~ relevant to quarantine or isolation during the relevant time period. If the health committee had not sponsored hearings on these matters, or had performed only a secondary role in bill development, ^{the health committee chair's} ~~the~~ ^{the} understanding of relative roles of interest groups and agencies might be limited.

} what does this mean?

An additional concern in ~~the~~ data presentation is the question of which states responded. While it is possible that among the 42 state health departments, 39 hospital associations and 43 legislatures represented in the responses ^{was} ~~were~~ at least one reply from every state, that is not made clear. In this particular policy area, the experiences of the states with high early infection rates had an enormous impact on the nation as a whole, and the relative roles of state health officials, legislatures and advocacy groups were shifted depending on whether early public or advocacy excitement rushed a legislature to action or whether there was time to develop a proposal more slowly.

It is very important, in the face of both the continuing HIV epidemic and the potential for major health system reform, that the nation's state health officials play an appropriate role in determining policies which can promote the health of the public and protect the nation from preventable conditions. The literature on the public policy role of health officials is sparse, and a great many senior health officials in this country

have learned about policy development on the job. Critical reading of articles such as that by Robins and Backstrom can enlarge our understanding of the interplay of interest groups and provide direction in how to communicate both concerns and successes to a wider audience. I would hope that others reading this piece will be stimulated to add to the body of literature, whether with a second generation of survey materials, or well-developed case studies, which can assist us all in appreciating both what has been the experience in public policy in the case of HIV and AIDS, and what might be expanded within the broad role available to an state health official.

QUEST for QUALITY '93

PH Policy - Case of AIDS

- who formulates or directs -
~~what~~

- Article by - suggests states of

- Gaps in article -
data sources

- Gaps in policy -