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Issues - Partner Notification

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U.S. House of Representatives
Committee on Commerce
Room 2125, Rayburn House Office Building
Washington, DC 20515–6115

June 25, 1998

ISSUES- Partner Notification

The Honorable Donna E. Shalala
Secretary
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Shalala:

Congressman Coburn wrote to you on March 6, June 2, and June 16, 1998, concerning the compliance of States with respect to the notification requirements for spouses of HIV-infected individuals as provided by the Ryan White CARE Act Amendments of 1996. In his letters, Congressman Coburn expressed concern that States which have been certified to receive Ryan White CARE grants may not have enacted a spousal notification program in accordance with statutory requirements and Congressional intent. In each of his three letters, Congressman Coburn asked 1) if a State had not yet enacted a spousal notification program, how was that State certified to receive Ryan White CARE grants?, and 2) how do we know that other states which have been certified as complying were actually fulfilling this and other federal conditions necessary to be eligible for such grants? However, to date, no response has been received to *any* of Congressman Coburn's requests. Therefore, we are writing to you to follow-up on Congressman Coburn's previous letters and to request certain information and documents.

Specifically, Congressman Coburn's concerns stemmed from a January 25, 1998 article in the *New York Times* which stated that New York State's "existing policy prohibits caseworkers from notifying any sex partner, including spouses, without the voluntary consent of the HIV-positive person." Furthermore, the article stated that, "a Health Department spokesman, Fred Winters, said the spouse policy was 'under review.'" In addition, an article from the May 29, 1998 *New York Times* stated that "New Jersey's system of notifying partners is voluntary. Spouses or other partners of infected peoples are not notified without the consent of the infected person." Finally, Congressman Coburn recently came across a copy of "A Brief Guide to California's HIV/AIDS Laws 1997," which states that California law "permits (but does not require)" spousal notification.

We are very troubled by the Department's lack of attention and *any* reply to Congressman Coburn's requests, and are concerned that the Department believes that it is acceptable not to

06/29/98 025

respond to Congressional inquiries. As you will recall, we wrote to you on December 19, 1997 after the Department had failed to reply -- after eight months -- to another of Congressman Coburn's numerous requests. Furthermore, the Committee is becoming increasingly concerned that States are falling considerably short of complying with the Ryan White law, which states "the Secretary of Health and Human Services shall not make a grant under Part B of Title XXVI of the Public Health Service Act (42 U.S.C. 300ff-21 et seq.) to any State unless such State takes administrative or legislative action to require that a good faith effort be made to notify a spouse of a known HIV-infected patient that such spouse may have been exposed to the human immunodeficiency virus and should seek testing." We are very concerned that the approaches of the States mentioned above, and perhaps others, fail to meet the qualifications of a "good faith effort." Accordingly, pursuant to Rules X and XI of the U.S. House of Representatives, please provide the Committee the following information and documents by July 15, 1998:

1. Please explain why the Department has failed to respond *at all* to any of Congressman Coburn's requests.

2. Please provide all records related to the consideration, review and development of a response to Congressman Coburn's requests.

3. With respect to the concerns mentioned above related to New York's, New Jersey's, and California's programs, please explain how it is that these states, which apparently failed to enact a spousal notification program consistent with statutory requirements, were certified to receive Ryan White CARE grants?

4. Please provide the Department's justification for certification for each State and all documents related to the basis for such justification.

   a) Please explain in detail how certification was determined.

   b) Please provide a list of who made the certification determination for each State.

5. Please provide a complete list of the number of individuals that have been notified in each State.

   a) Please explain if there has been any follow-up to determine if States are actually conducting notification. If not, please explain why not?

6. Congressman Coburn also wrote to the Department on April 7, 1998, about his concern that States are receiving federal funding without following 42 U.S.C.300ff-47, which provides that no State will receive federal funding for HIV support services unless the State has implemented criminal laws sufficient to prosecute any HIV-infected individual who intentionally exposes another to HIV.

a) Please explain why the Department has failed to respond to this request.

b) Please provide all records related to the consideration, review and development of a response to this request.

c) Has this requirement been implemented? If not, please explain in detail why not?

d) With respect to compliance with 42 U.S.C. 300ff-47, please provide the following:

i) a copy of each State's completed certification form and "summary" provided to CDC and HRSA and the date it was originally submitted;

ii) whether each State's summary was determined to be in compliance with the statute as submitted and the date the Department made that determination; and

iii) if a State's proposal was found to be not in compliance as submitted, please explain in detail the deficiencies. If a State took subsequent steps to gain approval, please explain in detail the steps taken.

For purposes of responding to this request, the term "records," "relating," and "relate" should be interpreted in accordance with the Attachment to this letter.

If you have any questions, please contact Mr. Matthew Saylor, Committee counsel for oversight and investigations, at (202) 226-2424. We appreciate your cooperation in this matter.

Sincerely,

Tom Bliley
Chairman

Tom A. Coburn
Member of Congress

cc: The Honorable John D. Dingell, Ranking Member
The Honorable Joe Barton, Chairman
Subcommittee on Oversight and Investigations
The Honorable Ron Klink, Ranking Member
Subcommittee on Oversight and Investigations

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HEALTH AND ENVIRONMENT
ENERGY AND POWER

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Congress of the United States
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Washington, DC 20515–3602

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(918) 542-6887 (Fax)

April 7, 1998

Honorable Donna E. Shalala
Secretary
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

Dear Secretary Shalala,

Recently I wrote to you about my concern that some states may not be complying with the HIV spousal notification provisions of the Ryan White Care Act. It has come to my attention that there is another provision regarding the intentional transmission of HIV that many states may have also ignored.

42 U.S.C. Section 300ff- 47 provides that no state will receive federal funding for HIV support services unless the state has implemented criminal laws sufficient to prosecute any HIV-infected individual who intentionally exposes another to HIV. It is my understanding that at present only 28 states have HIV specific laws that impose criminal laws for exposing and/or transmitting HIV. New York state, for example, has no such law, which has made it difficult for prosecutors to adequately charge Nushawn Williams who knowingly infected at least 13 women in Chautauqua County since testing positive for HIV in September 1996.

I would like to know if this requirement has been implemented. If it has not, I would appreciate a detailed explanation as to why not. If it has, please provide the following information:

(a) a copy of each state's completed certification form and "summary" provided to CDC and HRSA and the date it was originally submitted;
(b) whether each state's summary was determined to be in compliance with the statute as submitted and the date the Department made the determination; and
(c) if a state's proposal was found to be not in compliance as submitted, please explain in detail the deficiencies. If a state took subsequent steps to gain approval, please explain in detail the steps taken.

Thank you for your attention to this matter. I look forward to a timely response.

Sincerely yours,

Tom A. Coburn, MD
Member of Congress

cc: The Honorable Thomas J. Bliley, Jr., Chairman
Committee on Commerce

429 Cannon House Office Building,
Washington, DC 20515
(202) 225-2701 Fax: (202) 225-3038

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JESSE HELMS
NORTH CAROLINA

United States Senate

WASHINGTON, DC 20510-3301

June 19, 1998

98 JUN 22 AM 11:29

The Honorable Donna Shalala
U.S. Secretary of Health and Human Services
200 Independence Avenue, SW
Washington, D.C. 20201

Dear Madam Secretary:

I trust you are as deeply concerned as I am that the Department of Labor HHS is certifying States as eligible to receive grants under Part B of Title XXVI of the Public Health Service Act despite the unwillingness of such states to comply with statutory requirements attendant to receiving these grants. Such certification by Labor clearly violates Public Law 104-146 requiring states to notify spouses of HIV-infected persons of their exposure to the human immunodeficiency virus.

The purpose of this legislation is, of course, to protect spouses who have unknowingly been exposed to HIV and to encourage them to seek immediate and appropriate medical care.

The Ryan White CARE Act prohibits Labor-HHS from distributing funds to a State unless that State requires that a good faith effort be made to notify a spouse of an AIDS-infected patient that they are at risk for AIDS. According to your office, all 50 states have complied with this condition, but I am resentful that the Department is obviously certifying states that are engaging in legal fiction in order to pass the "good faith test," thereby endangering unsuspecting spouses.

Madam Secretary, I am committed to enforcing this provision, and I intend to offer legislation to specify criteria for state compliance unless the department establishes a credible good faith test consistent with Congress' intent under the original law.

I am certain you agree that enforcement of the spousal notification requirement should not be taken lightly, and I look forward to working with you to rectify this problem.

Sincerely,

Jesse Helms

06/24/1998-0700

ISSUES - Partner Notification

UNITED STATES SENATE
REPUBLICAN
POLICY COMMITTEE

Larry E. Craig, Chairman
Jade West, Staff Director
347 Russell Senate Office Building
Washington, DC 20510
(202) 224-2946
http://www.senate.gov/~rpc/

July 9, 1998

New York Leads the Way on Partner Notification Law, Why Won't Kennedy Follow?

Kennedy Managed Care Bill Ought to Incorporate an AIDS Disclosure Provision in a "New York Minute"

The New York State Legislature recently passed by large majorities in both chambers a bill designed to assure the notification of the contacts of AIDS-infected individuals (sexual partners and needle sharers). For those at-risk persons, this notification (and the providing of information about where to get assistance and counseling) could literally mean the difference between life and death. However, as critical as the disclosure of such information is, it is *not* included in Senator Kennedy's so-called patients' rights bill, S.1890, which the Minority Leader this week offered as an amendment to the VA-HUD appropriations bill.

This glaring omission in the Kennedy-Daschle healthcare legislation is compounded by the sponsors' own rhetoric: they purport (inaccurately) to be advancing legislation that embodies the recommendations made by the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry — the so-called Quality Commission. Said Senator Kennedy on the Senate floor last month: "The President last year called forth a commission, which made unanimous recommendations — Republican and Democrat alike. The Patients' Bill of Rights legislation (S.1890) . . . basically reflects the judgment put forward by that bipartisan group. . ." Yet, the Kennedy-Daschle bill contains *neither* the concept of consumer responsibility (as does the Quality Commission) *nor* any procedure for informing AIDS-infected individuals' contacts.

The Quality Commission in its report to the President last year devoted an entire chapter to consumer responsibilities. The Commission stated:

> "In a health care system that protects consumers' rights, it is reasonable to expect and encourage consumers to assume reasonable responsibilities. Greater individual involvement by consumers in their care increases the likelihood of achieving the best outcomes and helps support a quality improvement, cost-conscious environment. Such responsibilities include . . .

- "Work collaboratively with health care providers in developing and carrying out agreed-upon treatment plans.
- "Disclose relevant information and clearly communicate wants and needs.
- "Avoid knowingly spreading disease.
- "Be aware of a health care provider's obligation to be reasonably efficient and equitable in providing care to other patients and the community.
- "Show respect for other patients and health workers."

[The information quoted is all taken verbatim from the Nov. 1997 report, but some bullet-points have been omitted.]

All of these points made by the Quality Commission speak to the principle of informing sexual partners and other contacts of infected individuals that they have been exposed to the deadly virus. Yet neither the principle of consumer responsibility in general nor the specific one of informing exposed persons is included in the Kennedy bill.

As already pointed out in a previous RPC paper ["The Kennedy-Daschle Bill: Healthcare Reform in Reverse," 7/8/98], S. 1890 is a case of false advertising: it does not embody the Quality Commission's recommendations as it claims, but rather it turns recommendations into mandates, adds provisions not even addressed by the Commission (such as increased litigation, including the right to sue employers), and extends Commission recommendations beyond their original scope.

Yet, if Senators Kennedy and Daschle want to legislate the Quality Commission's recommendations, why don't they incorporate that overlooked chapter of the Quality Commission's recommendations on patient responsibilities? Why don't they include this critical life-or-death disclosure provision — AIDS contact tracing — an area where patient information is so critical that government action clearly is required?

The Kennedy-Daschle bill:

- Ignores the principle of consumer responsibility and the specific issue of informing contacts of AIDS-infected individuals.
- Ignores America's primary health care issue — access — and instead will decrease it through costly mandates, litigation, and bureaucracy;
- Ignores the fact that the Quality Commission did not recommend the mandating of its recommendations;
- Adds proposals that the Quality Commission never envisioned; and
- Expands proposals beyond the scope of the Quality Commission's recommendations.

Staff Contact: Dr. J.T. Young, 224-2946

UNITED STATES SENATE
REPUBLICAN
POLICY COMMITTEE

Larry E. Craig, Chairman
Jude West, Staff Director
347 Russell Senate Office Building
Washington, DC 20510
(202) 224-2946
http://www.senate.gov/~rpc/

July 8, 1998

To: Republican LDs and Health LAs
From: JT Young, RPC

Re: **Attached Op-Ed, "Deadly Privacy," from today's *Washington Post***

Nat Hentoff's op-ed from today's *Washington Post* highlights an issue that legislators considering patient information should consider — the life and death circumstances of unwitting exposure to AIDs.

Hentoff writes that the bill recently passed by both houses in the New York State Legislature "would require that doctors report the names of HIV-positive people to the State Health Department." He further describes the process that New York will soon undertake (he reports that Gov. Pataki will sign the bill), which includes attempting to notify (in person where possible) known contacts of HIV- or AIDS-infected persons, and provide them with sources for information and counseling. The identity of the infected person would not be revealed. [RPC was provided a copy of the bill language by the Senate Library.]

Despite its common-sense nature, its life-saving intent, and its mild form, opposition to the bill "was fierce," Hentoff observed. He describes one unwitting victim, Barbara Williams, who found herself HIV positive. Here's what, according to Hentoff, she wrote about the danger:

> *"'AIDS is the leading cause of death in New York State . . . of mothers of children under 18 — like myself. That makes AIDS the leading creator of orphans. . . . According to the New York City Health Department, for 18,000 HIV tests last year, it completed only 350 partner notifications."*

If Congress chooses to impose healthcare information requirements — as Senators Kennedy and Daschle are demanding it do — policymakers should consider the importance of disclosure of such critical information as that provided by this New York legislation.

WEDNESDAY, JULY 8, 1998 A17

Nat Hentoff

Deadly Privacy

From the beginning, the AIDS epidemic has been relentlessly politicized—notably by various gay organizations and the ACLU. Their emphasis has been less on public health than on safeguarding the privacy of those infected in order to protect them from discrimination.

That is a logical goal, but there's been little concern for their sexual partners who may be exposed to HIV or AIDS because they have not been told by their infected lovers that they too can now be in danger.

This sometimes lethal lack of communication became vivid for me when a number of infected Puerto Rican women in East Harlem were furious on finding out that their husbands or companions had been going to an AIDS clinic, but had never told them. Another victim of a frightening surprise was Barbara Williams.

SWEET LAND OF LIBERTY

who later became a counselor—at Health Force: Women and Men Against AIDS—in the Bronx. She is HIV positive, and points out that "neither my boyfriend [now dead] or any of his doctors told me why he was sick."

Recently, Barbara Williams went to Albany, where the New York state legislature was debating a bill by Assemblywoman Nettie Mayersohn that would require that doctors report the names of HIV-positive people to the State Health Department. The names would become part of a central registry. Local health agencies would then interview those in the registry and ask them to name their sexual partners—who would be notified by government health workers that they are at risk. The identity of the infected source of the information would not be revealed. There would be no penalty, however, for HIV-infected people who refused to disclose the names of their sexual partners. Furthermore, some sites for anonymous testing would be preserved.

Opposition to the Mayersohn bill was fierce. The opponents were largely the same as those who, for three years, had blocked the passage of an earlier bill of hers that would no longer keep secret the tests of newborns that revealed HIV infections of the infants and their mothers. Parents had never been told that an infant was infected, and so some of the children with weakened immune systems died early.

Mayersohn's contact-tracing bill this year was attacked, as before, by the AIDS establishment and the ACLU. There was strong support, on the other hand, from the New York State Medical Society and the New York State Association of County Health Officials.

One reason for the intensity of the opposition was the likelihood—as noted in the New York Times—that "as the state with the highest rate of AIDS cases, New York could be influential in promoting other states to adopt such reporting." And that might "change the nation's system of monitoring the epidemic."

One of those critical of the partner-notification bill was Lawrence O. Gostin, a prominent figure in the AIDS establishment. He is a member of the advisory committee of the Federal Centers for Disease Control and Prevention. "Partner notification," Gostin told the New York Times, "is the one thing that the AIDS community deeply fears—that intimate sexual partners will be called to and their names will be given to the government, and that they will lose control of whatever small amount of intimacy and privacy they had."

I have heard that argument from nearly the beginning of the AIDS epidemic. The fears of loss of privacy were certainly realistic, but what of the uninformed partners who may discover the privacy of the grave? Moreover, these partners, unaware of the danger they're in, can pass on the HIV virus to others.

In the face of the voluble opposition, Nettie Mayersohn won the battle. Her contact-tracing bill passed the Assembly 111 to 35 and also had no difficulty in the Senate, where it sailed through 55 to 6. New York Gov. George Pataki will sign the bill into law.

Barbara Williams's contribution to the debate in Albany was compelling, as was her preliminary article in the New York Post:

"AIDS," she wrote, "is the leading cause of death in New York State not only of white gay men and blacks 25 to 44 years old, but of mothers of children under 18—like myself. That makes AIDS the leading cause of orphans. . . . According to the New York City Health Department, for 18,000 HIV tests last year, it completed only 350 partner notifications."

That was before Nettie Mayersohn, who never gives up, got her partner notification bill into law.

LEVEL 1 - 1 OF 1 STORY

The Washington Post

July 08, 1998, Wednesday, Final Edition

SECTION: OP-ED; Pg. A17

LENGTH: 742 words

HEADLINE: Deadly Privacy

BYLINE: Nat Hentoff

BODY:

From the beginning, the AIDS epidemic has been relentlessly politicized -- notably by various gay organizations and the ACLU. Their emphasis has been less on public health than on safeguarding the privacy of those infected in order to protect them from discrimination.

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One reason for the intensity of the opposition was the likelihood -- as noted in the New York Times -- that "as the state with the highest rate of AIDS cases, New York could be influential in promoting other states to adopt such reporting." And that might "change the nation's system of monitoring the epidemic."

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LANGUAGE: ENGLISH

LOAD-DATE: July 08, 1998

Partner Notification for H.I.V.

A bill before the New York State Senate would notify spouses, sex partners and needle-sharing partners of H.I.V.-infected people of their exposure to the virus. Notification is particularly important as AIDS and H.I.V. become more prevalent among women, minorities and the young. There are too many cases where women and their babies have become infected because husbands and boyfriends hid the truth. The bill, sponsored by Assemblywoman Nettie Mayersohn and Senator Guy Velella, and supported by the New York State Association of County Health Officials and the New York State Medical Society, would give spouses and others access to crucial information so that they can take steps to avoid infection.

Current state law already allows doctors to notify partners or ask local health authorities to do so. But doctors have neither the time nor training to perform the task. Under the bill, they would report cases to the state Health Department, and a public-health worker would contact the patient for names of individuals who may have been exposed. There would be no penalty for refusing to cooperate.

The health worker is not allowed to reveal the identity of the infected person. The partners would be told only that they have been exposed to the virus and be given data about the disease. Such reporting and notification would not apply in current anonymous testing programs. This approach balances public-health imperatives and patients' privacy.

Many patient advocates oppose the use of names for privacy reasons, but using code numbers can be unreliable. Twenty-eight states use name reporting, with no evidence that reporting has caused a significant decline in testing rates. New Jersey has had H.I.V. reporting for six years with no breaches of confidentiality. New York State has required reporting by name of full-fledged AIDS cases for 15 years, with no loss of confidentiality.

The changing nature of the AIDS epidemic and effective new treatments make it necessary to rethink the public-health response to the disease. Partner notification is standard with other communicable diseases such as syphilis. The people most at risk for AIDS have a right to information that could prolong their lives and prevent them from unknowingly spreading H.I.V. to others.

TUESDAY, OCTOBER 6, 1998

Regional news
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Mass Millions: 11,12,19,30,38,41 *Bonus*:46 (Oct.5)
Megabucks: 7, 15, 18, 27, 32, 38 (Oct. 3)

Bill would allow state to notify sexual partners of AIDS/HIV victims

By Wendy Ruderman, Associated Press, 10/05/98 20:23

TRENTON, N.J. (AP) - New Jersey residents who go to a private doctor to get an AIDS test are told that if they test positive, their name must be given to the state.

But one state lawmaker wants to take that process a step further.

Assemblywoman Charlotte Vandervalk, R-Bergen, is sponsoring a bill requiring the names of people who are diagnosed with AIDS or HIV to not only go into a statewide database but to be given to a state worker as well.

Under the bill, that state worker would be required to contact those infected people to ask them who they've had unprotected sex with and whether they want the state to let those partners know they're at risk of getting HIV or AIDS.

Vandervalk's controversial bill passed out of the Assembly Health Committee unanimously and without debate on Monday.

Riki E. Jacobs, executive director of the Hyacinth AIDS Foundation in New Brunswick, said the bill caught her off guard.

Jacobs and other AIDS activists didn't realize Vandervalk's bill would mandate that a state worker contact people with AIDS or HIV without giving them a chance to say they don't want to hear back from the state, she said.

Jacobs said she fears the bill would erode confidentiality and discourage people from getting an AIDS test.

``It would be a definite invasion of a person's privacy,'' Jacobs said.

Vandervalk said she believes it's more important to save lives than worry about chipping away at confidentiality.

Jacobs said people may not be aware that someone from the state is going to call and ask if they want to participate in the state's ``partner notification program.'' Jacobs questioned what would happen if a spouse or partner took the phone call.

Vandervalk said field workers get training on how to avoid tipping off a partner without the infected person's permission.

``They are very sensitized to what could go wrong and the repercussions,'' Vandervalk said. ``They don't arouse suspicions. They're professionals.''

Vandervalk added that if people are worried about their privacy they can go to one of 16 state-run clinics where they can choose to give a fake name and remain anonymous.

Jacobs also questioned how the state would pay for the additional field workers needed to contact everyone with AIDS or HIV statewide.

Vandervalk said the bill does not address funding.

Under the bill, A-654, those who do not want to tell the state who they've had unprotected sex with or who they've shared drug-injection needles with are not required to do so. There would be no penalties for those who refuse to participate in the state's ``partner notification program.''

Currently, employees at more than 200 public counseling and testing sites, including family planning and drug treatment clinics, must let AIDS and HIV victims know about the state's ``partner notification program,'' said Department of Human Services spokeswoman Marilyn Riley. It's a state policy and not a law.

Just like with the bill, people don't have to participate. Unlike the bill, people are given the chance to say whether they want to participate. If they don't, the state does not contact them.

But if they do, one of the state's eight field workers contacts the person to ask for the names of their sexual or needle-sharing partners. From there, the field worker lets those partners know they're at risk.

Under current policy, those field workers cannot disclose who gave the state their name, and the bill has the same provision of confidentiality.

Since the notification program was started in 1988, field workers have conducted about 10,000 ``investigations,'' in which they contacted the infected person and asked for a list of partners, Riley said.

The bill can now be put before Assembly members for a

vote.

INTERACTIVE

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