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10B

U.S. HOUSE OF REPRESENTATIVES

COMMITTEE ON ENERGY AND COMMERCE

SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT

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PUBLIC HEARING

DATE AND TIME: Tuesday, February 27, 1990 at 9:45 am

PLACE: 2123 Rayburn House Office Building

SUBJECT: The AIDS Epidemic and Medicaid
H.R. 4080

Witnesses:

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To Dr. Koop, Mary Lee (202-939-4993; FAX 202-939-4838)
From Tim Westmoreland (202-225-4952; FAX 202-225-7090)
Re: February 27th hearing on AIDS
February 13, 1990

Henry has asked me to contact you regarding the hearing two weeks from today. Please feel free to contact me if you have any questions or need any assistance.

The Hearing

This hearing is intended to be the opening of attempts to improve AIDS health care services. Although bills will be introduced by that time, the hearing will not be limited to specific legislative provisions, although some may be discussed; instead we hope to remind Members and the press that the epidemic is not over and that problems in health care are going to get a lot worse.

The tentative plan for witnesses is:

1) Koop
2) Representatives of Grady Memorial Hospital, Newark Children's Hospital, and Jackson Memorial Hospital
3) Representatives of Medicaid authorities from Michigan, and Washington (state)
4) A health economist on financing trends

Your Presentation

We would hope that you would address the ongoing seriousness of the epidemic. Henry is especially interested in pressing for Federal legislation to get prophylactic and early intervention drugs to people in an attempt to forestall the development of disease and the need for hospital and institutional care; he would welcome any comments you might have on this point.

The Legislation

Waxman will have two major bills for this legislative year [illegible] referred to as the AIDS Prevention Act and one that is made up [illegible] Medicaid improvements. I have attached more detailed de[illegible]pt but this is a brief summary.

AIDS Prevention Legislation

This bill would provide Federal funds to States and primary care clinics (e.g., TB, STD, Family Planning, Drug, Homeless, etc.). Grantees would agree to provide pre-test counseling, testing, post-test counseling, diagnostic services for those infected (e.g., T-cell [illegible]s), and early intervention drugs as indicated (e.g., aerosol pentamidine).

In addition, the bill would make low-income people who are HIV-positive and severely immuno-compromised eligible for ambulatory care coverage under Medicaid (i.e., prescription drugs and related outpatient services, such as physician, lab, and clinic services).

The goal of such legislation is to prevent infections among the uninfected and to prevent disease in the infected. It is to do so by giving people access to counseling, testing, and early intervention drugs. Patients in a variety of settings would be encouraged to be counseled and tested. Those testing positive would be encouraged to have diagnostics. Those who have severe immune deficiencies would be able to get early intervention drugs paid for by Medicaid (if they are poor) or on a sliding scale by the grantees (if they are not poor enough to qualify for Medicaid).

AIDS Health Care Financing

This legislation provides for improvement of acute and long-term care services for people with AIDS. It would do so in three ways:

1) It would require to require States to pay a higher rate to hospitals that care for a large number of Medicaid AIDS patients. (Such an adjustment already exists in the law for hospitals that care for a large number of Medicaid or no-payment patients; this AIDS adjustment would be in addition to this existing Disproportionate Share Adjustment.) Such a rate increase can be justified by the resource requirements of treating AIDS patients (e.g., the above-average use of personnel and lab services, as well as the above-average length of stay) as well as the shortfalls of current reimbursements under Medicaid.

2) It would allow States to use Federal Medicaid matching funds to pay for continuation of group insurance coverage for HIV-infected persons who have left their jobs because of disability. This continuation coverage is already available by law, but is quite expensive since the patient must pay <u>both</u> the employer and employee share of the premium. This provision would help slow the process of private insurers shifting the cost of AIDS care onto public programs.

3) It would allow States to use Federal Medicaid matching funds to provide home- and community-based care to children (i.e., under 18) with AIDS. This would allow States to create alternatives to hospital care and thus allow these kids to be treated at home, in foster care, or in other community settings. States may now provide such services if they apply to HCFA for a waiver to do so, but HCFA may only approve a waiver that is "budget neutral," i.e. that spends no more on home- and community-based care than would be spent on institutional care. Because OMB has construed such budget neutrality to be a very strict test, waivers have been very difficult to get. This legislation would eliminate the "budget neutrality" requirement for these services to

children with AIDS.

TESTIMONY

SUBCOMMITTEE ON HEALTH

HENRY WAXMAN, Chair.

C. EVERETT KOOP, M.D

FEBRUARY 27, 1990

Mr. Chairman, I appreciate this opportunity to address the committee on certain aspects of the Aids epidemic. I am also grateful that you maintain a forum for continuing discussion of the AIDS epidemic

First may I remind the committee that there are still several aspects of aids that color everything we say and do about the disease and raise barriers to dealing with the epidemic comfortably. — AIDS is still somewhat of a mystery, it is fatal, and people get Aids by doing things the majority of people dont do and dont approve. it

These factors still keep many from addressing the issues that might contain the epidemic and provide necessary care for those afflicted. Instead our attention is frequently turned toward more volatile issues of Law - Ethics - Economics - Morality - and Social Cohesion.

The close of 1989 saw 117000 diagnoses of AIDs, with 35000 new cases in 1989 and 40000 new cases predicted for this year.

The media has done a creditable job,

of informing the public of a most complicated disease and of keeping the epidemic before them. I have been surprised that the public's attention could be held so long.

Mr. Chairman, since leaving public office I have continued to travel about the country and indeed may, in some circumstances, have better access to parts of the health care system than I did previously. I have become convinced that the figures I quoted for you are under reported. I also am disappointed to sense

a kind of complacency about the AIDS epidemic ~~for~~ FOR at least three reasons:

First, There are those who interpret the slightly reduced ~~figures~~ projection for new cases this year as evidence that the epidemic is over, ~~and~~ Secondly, there are others who view the disease as "NOT THEIR PROBLEM" - after all aren't new cases turning up in predominantly in black and hispanic IV drug abusers? They say. ⟶

~~My final concerns, Mr. Chairman, have to do with health care for persons with AIDS. When I release the~~ 2

Third, there are many, misled by ~~popular~~ inaccurate assessments in books and magazines that are convinced AIDS is not spread heterosexually. The truth is that it is passed heterosexually male to female and female to male – and don't forget: their progeny.

My final concerns, Mr. Chairman, have to do with with health care for persons with AIDS. When I released the →

Surgeon General's report on AIDS in October 1986, ~~I~~ a report, incidentally, which is still accurate — I said that the epidemic of AIDS would impact on ~~each~~ everyone. It already has in many subtle ways but let me speak about the care of patients.

In New York City it is estimated that a quarter of the hospital beds are occupied by AIDS patients. and the ~~plight~~ problem of babies with AIDS is growing by the day. There is ~~growing~~ ample anecdotal evidence of the anger and frustration . . .

families who cannot get a hospital bed for a loved one because it is occupied by an AIDS patient. I think it was before this committee, Mr Chairman that I predicted this situation and urged that it be prevented.

Babies born HIV positive, who eventually develop AIDS, are frequently addicted to the drug their mothers were addicted to at the time of delivery. In a city I visited just recently, an addicted mother, her baby less than a day old, walked out of the hospital with 6

an intravenous still attached to her arm — either forgetting or not caring that she left her child behind to the abandoned state so many of these youngsters inherit.

Mr. Chairman, public health and government's goals in the epidemic remain the same — even as the situation worsens and will continue to do so. We need to keep the infected from infecting others, and where possible we must postpone the onset of opportunistic disease and

~~[illegible] [illegible]~~ treat [illegible]

other than acute care hospitals.

Persons with AIDS need help, physically, financially.

Hospitals that have a disproportionate case load of AIDS patients need help.

An alternate to hospital care for AIDS babies — especially those abandoned — must be found.

Much of what I have said this morning Mr. Chairman I have said over and over again for the last five years. My concerns expressed this morning have yet to be addressed at a National level. Unless there is Congressional intervention the situation can only get worse. Indeed

it is a critical [illegible]

LIVE A FICTION

Repeatability & C.T —
They are separate
What have you to offer —
Ask one question —

Terminal Care
can be changed

II. Although AIDS has receded from newspaper headlines for the moment the epidemic is far from over.

A. There have been about 120,000 cases of AIDS in total over the last eight years. There are about 50,000 Americans living with AIDS now. We can expect that many people to be diagnosed <u>this year alone.</u>

B. There are an estimated one million people in the U.S. infected with HIV. 51% of these people have T-cells below 500 and are thus on the verge of being sick. 20% of these people have T-cells below 200 and are at very high risk of pneumonia and other serious AIDS-related illnesses.

C. As far as health care spending goes, the epidemic is just building up force. People who are recently infected are relatively inexpensive to care for because their illnesses are mild. But the 20% of the infected who have low T-cell counts have been getting progressively more sick and progressively more expensive to care for.

III. The best response is, of course, prevention.

A. We should take all necessary courses to prevent infection among the uninfected.

1. Education
    a. Of high risk groups
    b. Of young people
2. Risk reduction
    a. Abstinence and safer sex
    b. Treatment of drug abusers
    c. Abstinence and safer drug use
3. Counseling and testing of people at high risk

B. We should also expand the prevention agenda to include prevention of AIDS among the infected.

1. A lot has changed over the past year in this area of prevention

    a. Development of aerosol pentamidine and other preventive drugs means that pneumonia--the leading cause of hospitalization and of death among people with AIDS--is not inevitable any more.

    b. Trials of early intervention use of AZT mean that immune system collapse can be postponed.

    c. Trials of lower dosages of AZT mean that more people can take this drug with fewer side effects.

    d. Other drugs to prevent illness are being developed and still more research should be undertaken.

2. But this research must be gotten to people who need it.

    a. If we are to prevent AIDS effectively and limit the need for expensive hospital care, we must get such early intervention to the people who need it.

    b. Everyone--NIH, CDC, FDA--all agree that such treatment is State-of-the-Art Medicine

    c. It is wrong to structure our whole health care system on treating acute AIDS when we could prevent much of the illness. Prevention is cheaper and better for everyone.

    d. It is wrong to bring people in for testing and then deprive them of the treatments they need.

    e. It is especially wrong to make the poor get sick while providing prevention only to those who can afford it.

IV. Conclusion

A. We've come a long way since the early days of AIDS.

1. In understanding AIDS
2. In learning to deal with it without fear
3. In learning how to prevent it
4. In learning how to care for those who have it.

B. We should not rest, however, until we take what we've learned and gotten it to the Nation.