

## RYAN WHITE CARE ACT -- (Senate - September 29, 2006)

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Mr. COBURN. Mr. President,

I wish to address a couple of issues that were raised by the Senator from New York as to the accuracies of the claims that have been made. I think it is real important.

I don't doubt for a minute that she genuinely cares for everybody who has HIV in this country. I think she does. I think her perspective on the challenges that face us as a nation in terms of finances is different from mine, and I will grant her that as well. But some of the claims made are not really accurate.

I ask unanimous consent to print in the RECORD an article from the New York Times stating specifically money was spent on walking dogs for HIV/AIDS patients, art classes, tickets to Broadway shows, free legal services, haircuts, things that other people can't do in any other place other than New York and California.

There being no objection, the material was ordered to be printed in the RECORD, as follows:

[The New York Times, November 12, 1997]

New Challenge to Idea That `AIDS Is Special' (By Sheryl Gay Stolberg)

Behind the swinging glass doors that welcome visitors to the Gay Men's Health Crisis is a world where H.I.V. is not just a deadly virus, but also a ticket to a host of unusual benefits.

At the center, the nation's oldest and largest AIDS social-service agency, almost everything is free: hot lunches, haircuts, art classes and even tickets to Broadway shows. Lawyers dispense advice free. Social workers guide patients through a Byzantine array of Government programs for people with H.I.V., and on Friday nights dinner is served by candlelight.

The philosophy underlying the niceties and necessities is ``AIDS exceptionalism." The idea, in the words of Mark Robinson, executive director of the organization, is that ``AIDS is special and it requires special status." That is a concept that has frequently been challenged by advocates for people with other diseases.

Now some advocates for people with AIDS are quietly questioning it themselves.

With death rates from the disease dropping for the first time in the history of the 16-year-old epidemic, the advocates suggest, it is time to re-examine the vast network of highly specialized support services for people with H.I.V. Some people are growing increasingly uncomfortable with the fact that the Government sets aside money for

doctors' visits, shelter and drugs for people with AIDS but that it does not have comparable programs for other diseases.

“Why do people with AIDS get funding for primary medical care?” Martin Delaney, founder of Project Inform, a group in San Francisco, asked in an interview. “There are certainly other life-threatening diseases out there. Some of them kill a lot more people than AIDS does. So in one sense it is almost an advantage to be H.I.V. positive. It makes no sense.”

Mr. Delaney, a prominent voice in AIDS affairs since the onset of the epidemic, is calling on advocates to band with people working on other diseases in demanding that programs for AIDS be replaced with a national health care system.

He complained that organizations like the Gay Men's Health Crisis had been “bought off” by the special status given to AIDS.

“We took our money and our jobs,” Mr. Delaney wrote in the Project Inform newsletter in the summer, “and we dropped out of the national debate.”

That criticism has not won many fans within “AIDS Inc.,” as some call the cottage industry of agencies that care for H.I.V. patients. But Mr. Delaney's article, “The Coming Sunset on AIDS Funding Programs,” has set off an intense debate.

“I think Delaney knows that he is putting out a provocative, stimulating kind of discussion,” said Jim Graham, executive director of the Whitman-Walker Clinic in Washington, a counterpart to Gay Men's Health Crisis. “This is the whole discussion about AIDS exceptionalism. I think AIDS is an exceptional situation. AIDS is caused by a virus. That infectious virus is loose in America. And when you have a virus, an infectious situation such as this, it takes an exceptional response.”

Yet many people involved with AIDS say some change is in order. Many programs created in response to the epidemic were intended as stopgaps, to help the dying in the health emergency. Some of the money that pays for free lunches at Gay Men's Health Crisis, for instance, is from the Federal Emergency Management Agency, which usually works on natural disasters like hurricanes and earthquakes.

But it is becoming clear that the AIDS crisis is long term. New treatments appear to be turning the disease from a certain death sentence to a chronic manageable illness. Accepting the projection that the epidemic will last for at least another generation, advocates say, the Government and private agencies need to take a hard look at spending in the coming years.

“We are not going to die, at least not all of us, and at least not all so soon,” said Bill Arnold, co-chairman of the ADAP Working Group, a coalition in Washington that is lobbying the Government to add money to its AIDS Drug Assistance Program. “A lot of us are saying that the AIDS network or AIDS Inc. or whatever you want to call it, this whole network that we have created in the last 15 years, needs to be reinvented. But reinvented as what?”

That question is provoking considerable anxiety among employees at the estimated 2,400 service agencies in the United States, several hundred of which are in New York City.

The agencies offer an array of services including sophisticated treatment advice and free dog walking. Although most are tiny, some have grown into huge institutions financed by Federal, state and local government dollars, as well as contributions.

Critics say the organizations cannot possibly re-examine themselves because they have become too dependent on the Government.

“They have all become co-opted by the very system that they were created to hold accountable,” Larry Kramer, the playwright, said.

Mr. Kramer founded Gay Men's Health Crisis in 1981, but has long been critical of the group. “It's staffed with a lot of people who have jobs at stake,” he said.

With 280 employees and 7,000 volunteers, the program is the biggest and busiest agency of its kind. For many with human immunodeficiency virus, the organization and its lending library, arts-and-crafts center and comfortably decorated “living room” offer a home away from home, a place where, as one participant said, “your H.I.V. status is a nonevent.” For some, the hot lunches often provide the only nutritious meals the patients get all day. For others, they are simply a source of community.

Craig Gibson, 31, of the Bronx, is one of 10,000 people a year who seek services there. Several days each week, Mr. Gibson goes to the living room to play cards after lunch.

“You come here, you see your friends,” he said one afternoon. “Today they had a great chicken parmesan.”

A walk through the lobby shows the power and success of AIDS philanthropy. A huge plaque in the entryway lists dozens of donors who have contributed \$10,000 or more, including three who have given more than \$1 million. Even so, 19 percent of the \$30 million annual budget comes from Government sources, Mr. Robinson said.

“We still need this extraordinary short-term help,” he said.

But Mr. Robinson said he was aware that the financing might not last forever. Even as the organization expands, it is doing so with an eye toward eventually scaling back. It just spent \$12.5 million to renovate its new headquarters in a simple but expansive 12-story brick building on West 24th Street.

Mr. Robinson, a former accountant, said the building was designed so that any other business could easily move in. The lease is relatively short, 15 years.

The agency, he added, has realized that it cannot afford to be all things to all people. Until recently, Mr. Robinson said, “anybody with H.I.V. or AIDS could walk into our

advocacy department, and virtually anything that was wrong with their life was addressed."

"If they were having problems with their landlord," he said, "we would deal with it. If they needed an air-conditioner, we would deal with it. Now we are really trying to focus on what is specifically related to AIDS."

To understand why Mr. Robinson and others say they believe AIDS deserves special status, a person has to go back to the response to AIDS in the days when it was known as the "gay cancer." The Government and the rest of society all but ignored the illness, forcing the people who were affected--by and large homosexuals--to fend for themselves.

"The original reaction," Mr. Arnold said, "was in response to: 'This is not our problem. We don't like you. Go away and die.'"

"By the time you have got 200,000 to 300,000 people dead," he said, "they all have friends. They all have relatives. That's a lot of people impacted. So now you have some critical mass."

That mass has translated into a political force--and significant Federal money. In his budget proposal for 1998, President Clinton has asked Congress to allocate more than \$3.5 billion for AIDS programs, including \$1.5 billion for AIDS research at the National Institutes of Health and \$1.04 billion for the Ryan White Care Act, which provides medical care, counseling, prescription drugs and dental visits for people with H.I.V.

If Congress enacts the plan, AIDS spending would increase 4 percent over last year, and 70 percent over 1993, when Mr. Clinton took office.

In a paradox, some doctors say the array of services makes it harder to care for people whose behavior puts them at risk for AIDS, but who are not yet infected.

"We're trying to figure out how to provide services to H.I.V.-negative people to help them stay negative," said Dr. Michelle Roland, who treats indigent patients at San Francisco General Hospital. Many of Dr. Roland's patients are drug abusers, people at high risk.

"The truth is," she said, "we have a lot more access to resources for H.I.V.-positive people for drug treatment, education and housing."

While advocates for people with other diseases often lobby vociferously for more money for research, the notion of exceptionalism--that a particular illness deserves special Government status--is unique to AIDS, and it is generating a backlash.

For years, the American Heart Association has gone to Capitol Hill budget hearings with charts showing that more research money was spent per patient on AIDS than on heart disease. Advocates for people with Parkinson's disease have done the same. It will not be long, Mr. Delaney argues, before people with those and other diseases follow suit, demanding Ryan White-style programs for themselves.

Some authorities, including the president of the American Foundation for AIDS Research, Dr. Arthur Ammann, said Mr. Delaney was correct in pushing for universal health care. "We've got to form an alliance with these other diseases," Dr. Ammann said, "and say, None of us is going to get adequate health care the way the system is going."

But others call Mr. Delaney naive.

"It's interesting to muse about what he says," said Mr. Graham of the Whitman-Walker Clinic. "But it's both undesirable and impossible. So what's the point of talking about it?"

Naive or not, in challenging exceptionalism Mr. Delaney has clearly broken a taboo.

"We sort of question it among ourselves behind closed doors," said Mark Hannay, a member of the New York chapter of Act Up, the AIDS Coalition to Unleash Power. "Like, isn't this nice, but we're the only ones getting it."

Mr. COBURN. Mr. President, another key fact: New York State alone spends \$25 million a year just on administration of their Ryan White title I funds. That is more money on administration than 38 other States combined, 38 other States spend total on all of it.

The Senator from New York showed a chart on AIDS cases and spending. Well, she was right. It was about AIDS cases, but it wasn't about AIDS and HIV-infected individuals. When you look at it in terms of those infected with HIV rather than AIDS cases and when you look at AIDS cases, AIDS cases are based on those who have had AIDS in the past and those who have AIDS today but does not reflect the epidemic.

I also ask unanimous consent to have printed in the RECORD an article on the housing and rooming in New York for people who are no longer alive but for which they paid for a number of months, a large number of people, where money was wasted.

There being no objection, the material was ordered to be printed in the RECORD, as follows:

#### HIV/AIDS Shelter Costs Challenged (By Ellen Yan)

JULY 5, 2005.--The [New York] city agency that secures temporary shelter for indigent people with HIV/AIDS shelled out \$2.2 million in questionable payments over 2 1/2 years, partly to rent rooms listed to people who had died, the city comptroller charged in an audit released yesterday.

The Human Resources Administration paid \$182,391 for rooms listed to 26 people up to two years after their deaths, with one housing provider getting 76 percent of the money, \$137,920, said the report from Comptroller William Thompson Jr.

Auditors said many of the problems stemmed from the agency's failure to review its own data and client files before making payments to housing providers. In the audit,

Thompson's office looked at five housing facilities as well as payments and records made from July 2002 to December 2004.

Among the findings, auditors said, \$1 million went to housing providers for residents who did not sign registration logs; \$456,292 was paid for overnight stays on or after clients' last days of occupancy; \$417,463 in payments for people not in the agency's new database; \$118,185 in double billing; and a \$20,030 check to one vendor who submitted a \$2,030 bill, an overpayment the agency said it will correct.

HRA spokesman Bob McHugh said yesterday that agency heads had not seen the comptroller's final report.

“For whatever reason, they chose to release it on the Fourth of July, so we're not going to comment ..... until we get a chance to review it,” McHugh said.

In letters sent to the comptroller's office, HRA disagreed with many findings. In a June 15 letter, the agency said it's still waiting for Thompson's office to provide all the details so it can double-check the findings.

For example, officials replied in letters to the comptroller's office that at least three people were erroneously listed as dead in Social Security records.

In addition, the agency wrote, weekly registration logs are not final proof of whether housing was provided, because people with AIDS may have been too sick to sign.

The agency also accused Thompson's office of giving an “unbalanced” picture of housing conditions by concluding the 91 units checked were “generally in satisfactory condition” but then rating 25 of them as “unsafe and unsanitary.”

The housing agency agreed with most of the audit's recommendations, including checking vendors' bills against client and Social Security records.

Mr. COBURN. Mr. President, it is disingenuous to use AIDS cases alone to make comparisons. The reason for that is because this is an epidemic. And thanks to the wonderful presence of modern-day medicines, medicines are preventing people who have HIV from ever contracting the fullblown AIDS syndrome.

The whole idea behind the bill that Senators ENZI and KENNEDY have offered and that has passed the House with over 300 votes is to have the money follow the epidemic. That is what this bill does. There are small declines in the amount of money per person in New York so that marked increases in funds are available for those in the nonmetropolitan areas throughout the South.

We know the face of the epidemic is changing. That epidemic says that we ought to be caring for them. The Senator's answer is just spend more money. But last year, when I offered an amendment to add \$60 million to the ADAP by cutting pork projects, she voted against it. So you can come to the floor and claim you are for spending more money, but if you don't want to cut out a Japanese garden which is for a Federal

Government building which was \$60 million so you can put \$60 million into lifesaving drugs, some would claim that is not real support for more money.

The final point I wish to make is that last year, New York received over \$1.4 billion in earmarks, earmarks that aren't a priority, earmarks that aren't necessarily needed in a time of war. There was no offer to cut back on the earmarks for the State of New York to pay for greater care for AIDS patients. Some want to have it both ways: earmarks in the bill that are going to come back to us this November for New York, \$600,000 for exhibits, \$500,000 for New York City. We have to get a hold of priorities. Is HIV/AIDS a priority? Yes. And can we put more money into it? Yes. But we ought to be making the tough choices.

So I would say to my colleague that I have great respect for her desire to make sure everybody is cared for, but I also have a desire to make sure our children are cared for. And we need to pass this bill. It is a fair bill in the long term. We will work hard to make sure the moneys are there. We will work hard.

A final point. This new bill directs that 75 percent of the money ought to go to treatment. Less than 50 percent of the money in New York goes for treatment. Fifty percent goes for other things. So we have people living in South Carolina, North Carolina, Oklahoma, and in other States who are now on a drug waiting list who can't get treatment, and we are quibbling about \$300 in other programs--not treatment--other programs these people won't ever have any access to, but yet they can't get drugs. Is it a geographical disagreement? Yes. Everybody who is talking on this is for taking care of this problem. This is a great way. This bill is a good start.

Here is the other problem. If we don't pass this bill before October 1, lots of people in New York and in other States will be hurt because of the legislation in the previous Ryan White Act in terms of forcing the redistribution of this. It is my hope we can work this out.

I appreciate the Senator's sentiments in terms of her caring for those with HIV, but I know, in fact, what has been offered and worked and gotten through the House is a good approach that takes a little bit from New York, takes a little bit from San Francisco, and gives lifesaving drugs. It doesn't take any lifesaving drugs away from New York or San Francisco or California but gives lifesaving drugs to the people who don't have them today. We ought to be about doing that.

I yield the floor.