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July 20, 1995

MEMORANDUM TO PATSY AND JEFF

From: Rachael Smith

Re: News 7/20

"Fear of Contagion Prompts Recall of Blood Products in Canada"
(Washington Post 7/20/95)

The Canadian Red Cross is in the midst of its largest recall of blood products ever. The reason for the recall is that two donors have been diagnosed with Creutzfeldt-Jakob disease (CJD), a rare, fatal disease of the brain. While there is no evidence that CJD is transmittable by blood, there is no evidence to suggest otherwise. The Red Cross is taking drastic precautions as a result of their delayed reaction in dealing with HIV tainted blood in the mid 1980s. In the U.S. and FDA advisory committee recommended that blood products containing CJD be removed from the market to maintain confidence in the blood supply.

"Medicare As We Know It" (Washington Post 7/20/95)

This editorial explores the idea of giving Medicare recipients vouchers to buy what would presumably amount to private insurance. The author of this editorial believes Medicare as we know it, is too costly to be sustained and therefore, must be restructured.

Fear of Contagion Prompts Recall of Blood Products in Canada

By Anne Swardson

Washington Post Foreign Service

TORONTO, July 19—Spurred by fears of another AIDS-type crisis in the blood supply, the Canadian Red Cross is in the midst of the largest recall of blood products in its history.

The Red Cross, which handles all blood donations and all distribution of blood and blood products in Cana-

da, is withdrawing all blood or derivatives that might include blood from two donors who were later diagnosed with a rare, fatal disease of the brain.

There is no evidence that the illness, known as Creutzfeldt-Jakob disease (CJD), can be transmitted through transfusions. But science also has not proven that it cannot, and the disease is known to be transmittable from person to person through

injections of human growth hormones and through corneal and brain-membrane transplants. Creutzfeldt-Jakob disease, whose most famous victim was ballet choreographer George Balanchine, is untreatable.

Critics here charged that the Canadian Red Cross was acting so hastily—one donor was identified last week and the other on Tuesday, and the recalls were initiated immediate-

ly—because the agency was so slow in dealing with HIV-tainted blood in the mid-1980s. Then, the Canadian Red Cross began requiring that blood be heat-treated about nine months after the United States instituted the practice. Heat-treating blood products kills the HIV virus, which leads to AIDS. More than 1,000 Canadians, many of them hemophiliacs, were infected with the HIV virus around that time.

"It's somewhat of a hollow gesture," Durhane Wong-Rieger, president of the Canadian Hemophilia Society, said of the current recall. "If they genuinely meant it, they should be going out and looking for other donors and for people who have received these products. It's no good just doing this by itself." Hemophiliacs, whose blood does not clot normally, are particularly vulnerable to

while the FDA decides what policy to follow.

The Canadian recalls, in which the products will be destroyed, grew out of testimony before an official commission looking into the Red Cross's failure to act promptly on HIV-tainted blood 10 years ago. Testifying before that commission, one medical expert warned that CJD threatened to become the next tainted-blood scandal.

Press reports of that testimony were seen in a Vancouver newspaper by a woman who called the Red Cross and said that her father, who had donated blood 21 times since 1989, recently had been diagnosed with CJD. The Canadian Red Cross announced Friday night that all

blood products containing blood from that donor would be withdrawn. Then on Tuesday, Red Cross officials learned that a Toronto donor who gave blood in August 1991 subsequently had been diagnosed with the disease, and it recalled blood products that could be linked with that donor.

Red Cross officials said that even taken together, both recalls would not cause a serious shortage of most blood products in Canada, and said they were shipping in extra products from the United States to meet demand.

"I believe the [Canadian] Red Cross has shown it can rapidly and effectively respond" to situations requiring quick action, secretary general Douglas Lindores said.

tainted blood because many of them receive regular transfusions of blood products pooled from multiple donors to improve clotting.

The United States also is struggling to design a policy on CJD and the blood supply. Last month, a Food and Drug Administration advisory committee recommended that blood products containing blood from donors with CJD be removed from the market to maintain confidence in the blood-donor system. Agency spokesman Lawrence Bachorik said a decision on the recommendation is expected within several months.

In the last seven years, seven cases of CJD have been confirmed in blood donors in the United States, three of them since October 1994. In each case, the affected blood products were withdrawn. The American Red Cross has overseen two major withdrawals, one last November and one in March 1995, that together involved more than 100 lots of blood. Depending on dosage, each lot has the potential to transfuse 1,000 to 10,000 patients. The products have been quarantined

Medicare as We Know It

ABOUT A FOURTH of the money that congressional Republicans need to balance the budget over the next seven years would come from Medicare. By the seventh year, they propose that Medicare spending be 23 percent less than projected under current law. To achieve or even approximate such savings without seriously undermining the health care of the elderly and disabled, they'll have to restructure the system. It isn't clear they can do it even then; nor is it clear even to the most ardent among them what form the restructuring might take. But one idea they're considering to get them partway to the goal is a shift toward vouchers.

Instead of paying the medical bills of the elderly and disabled itself as the bills roll in, the government would give recipients vouchers to buy what would amount to private insurance. The voucher would presumably be enough to buy all or most of a standard health insurance policy, somehow defined; one notion is that it should be enough to allow the recipient to buy basic coverage through a health maintenance organization (HMO). Recipients who wanted to buy more expensive coverage could do so, but would have to use their own funds.

The voucher would be a device for limiting the government's liability; that's the goal. Medicare would cease to be a system of defined benefits and become instead a defined contribution toward the cost of health care, on which recipients

would then be free to build as their means permitted and they chose.

There are problems with limiting the federal obligation (the mirror image of the current set of problems, which derive from the fact that the program is open-ended). Among much else, such a shift would likely require a fairly high degree of regulation of the insurance and/or managed care markets to make sure that the sickest among the elderly and disabled weren't stranded. The fundamental issue would be how to adjust the value of the voucher each year to meet both of its twin purposes—yes, impose greater fiscal discipline on the program, but not in such a way as to destroy the level of coverage. John Rother, principal lobbyist for the American Association of Retired Persons, was quoted the other day as warning that without sufficient adjustment a voucher system “gradually turns into something that looks a lot like food stamps, rather than Medicare, so that's the end of Medicare as we know it.”

But Medicare as we know it is too costly to be sustained, and the problem will only grow worse as the baby boomers begin to retire in the next century. The Republicans are right that it has to be restructured; the questions are how drastically, at whose expense and how. Vouchers won't magically solve the problem all by themselves—they can't—but they might be part of a tolerable solution. The idea deserves some thought.

July 21, 1995

MEMORANDUM TO PATSY AND JEFF

From: Vanessa Potkin and Rachael Smith

Re: News, July 21

"Sneak Attack on AIDS Research" (New York Times, 7/20)

Congress is scheduled to vote on a proposal that would forbid NIH to designate any money for AIDS research. This would have extremely adverse affects on the Office of AIDS Research at NIH.

"Abortion Foes Prevail In House Panel Votes" (Washington Post, 7/21)

The House Appropriations Committee voted yesterday to eliminate the government's family planning program and to prohibit federal research on human embryos created outside the womb. The family planning program was to have provided \$193 million next year, to provide grants to public and private nonprofit agencies, serving approximately 4.3 million people.

"Can Health Care Be Reduced to the Terms of an Equation?" (Washington Post, 7/21)

In an effort to control the costs of health care, the U.S. Public Health Service is studying a new method of comparing the cost effectiveness of different treatments. In short, the method provides a dollar cost per life--year saved, that is then compared across a spectrum of conditions.

"Democrats Charge Republicans With 'Stealth' Plan for Medicare Vouchers" (Washington Post, 7/21)

Democrats charge that the GOP is attempting to finance tax cuts promised in its budget resolution through changes in Medicare that would make the elderly pay more and get less.

Sneak Attack on AIDS Research

By David Baltimore
and David Ho

In his effort to cut spending on AIDS, Senator Jesse Helms caused a furor this month by attributing the epidemic not to a virus but to "disgusting, revolting conduct." But a more subtle and menacing Congressional attack on Federal financing for AIDS research has gone largely unnoticed.

Today, the House Appropriations Committee is scheduled to vote on a proposal that would forbid the National Institutes of Health to designate any money for AIDS research. The bill would effectively emasculate the Office of Aids Research, which coordinates the national effort against the disease. If the committee passes the proposal, as is expected, then Speaker Newt Gingrich, who has called for letting scientists, not politicians, make research decisions, should squash it.

The Office of AIDS Research was created by Congress two years ago to organize scientists in the fight against H.I.V. Previously each of the 24 institutes at the National Institutes of Health had separate AIDS programs

David Baltimore, who won the Nobel Prize in medicine in 1975, is professor of biology at the Massachusetts Institute of Technology. David Ho is director of the Aaron Diamond AIDS research center in New York City.

and no common strategic plan; now the office coordinates the effort, eliminating overlaps in research and evaluating every program.

Before the office took charge, the \$1.4 billion annual AIDS research enterprise was like a house being built with plumbers, roofers, carpenters and painters working away, but with no architect or general contractor to direct them.

This year the coordinated effort was initiated. A task force of 100

The target? An office that works.

scientists, many not previously involved in AIDS research, is evaluating the state of the AIDS program and creating a blueprint for fighting the disease. This plan will specify how much money should be spent on developing vaccines, designing drugs, studying the virus's genes and carrying out clinical studies.

Regrettably, we are still without a vaccine against the leading killer of Americans between 25 and 44. The handful of drugs available like AZT can only delay death.

But instead of admitting that AIDS is a national tragedy, many conservative leaders prefer to bury their heads in the sand or rail against

homosexuality and drug abuse. They pretend not to see the huge economic and emotional toll of AIDS.

The public has invested more than \$100 billion in general biomedical research over the last decade. Scientists have a responsibility to show that we have made the most of this money, and we will be judged in large part by our success against AIDS. It would be cataclysmic to be turned away and sacrifice the gains we have made.

Some critics of AIDS research claim it receives a disproportionately large amount of money compared with budgets for other diseases that kill more people. But they neglect the consideration that unlike cancer and heart disease, AIDS is a developing epidemic and a communicable disease.

One notable conservative seems to understand the situation. Mr. Gingrich said we should "depoliticize research decisions about biology" and let scientists set priorities.

This is exactly what scientists are trying to do: 45 leading researchers have signed a letter to Congress insisting that the Office of AIDS Research is the rudder that steers us in the right direction against the disease.

The House should not let this research effort drift. If the bill is passed, we scientists will go back to making exciting individual discoveries on AIDS, but there will be no central plan for conquering our tiny but wily foe — the virus. □

Abortion Foes Prevail In House Panel Votes

Appropriations Committee Rejects Family Planning, Embryo Research

By Dan Morgan
Washington Post Staff Writer

The antiabortion movement scored two major victories in the House yesterday when the Appropriations Committee voted for the first time to eliminate the government's principal family planning program and prohibit federal research on human embryos created outside the womb.

The committee action came a day after the House voted to reinstate a ban on the funding of most abortions by the federal employees' health insurance program. All the items are high on the legislative agenda of the Christian Coalition, which has been stepping up pressure on Republicans finally to deliver results.

"We're taking this one step at a time," said Rep. Christopher H. Smith (R-N.J.), a leader of antiabortion forces. "We're not going to underwrite the killing of unborn children."

Appropriations Committee Chairman Bob Livingston (R-La.), who offered the amendment ending the family planning House Republicans passed their "Contract With America," the antiabortion movement and its allies in the Christian right are beginning to collect the political debts from helping Republicans win control of Congress in the 1994 elections.

"Today is payback time," Livingston said after he introduced his amendment folding the \$193 million for family planning into block grants to the states.

Members allied with the abortion rights cause charged

See ABORTION, A14, Col. 1

A14 FRIDAY, JULY 21, 1995 ... R

House Panel Approves Antiabortion Measures

ABORTION, From A1

that the GOP leadership had been taken over by the radical right. "The Christian Coalition is here to collect," said Rep. Nancy Pelosi (D-Calif.), after the committee quit work for the day on the bill funding the Labor, Education and Health and Human Services Departments starting Oct. 1.

"This proves that the agenda [of the antiabortion movement] is anti-family planning," said Rep. John Edward Porter (R-Ill.), who led the GOP opposition to what he called the "very misguided" elimination of the family planning program.

Whether the movement's gains will be sustained by the House were uncertain. Porter, who will manage the labor and education spending bill on the floor, predicted many moderate Republicans would vote against it because of the elimination of the family planning program, which has had bipartisan support in the past.

Defeat of the bill would create an extremely delicate situation for the GOP leadership, which would have to resolve an impasse between party moderates and antiabortion conservatives to get the bill through the House.

President Clinton said yesterday he would veto the bill.



REP. NANCY PELOSI

... abortion foes "here to collect"

affected by the political calculations of Majority Leader Robert J. Dole (R-Kan.), who is maneuvering to garner presidential primary support from Christian conservatives.

The 25-year-old family planning program was to have provided \$193 million next year, to provide grants to pub-

served in 1995 through a network of 4,200 clinics providing pelvic exams, Pap tests, screenings for sexually transmitted diseases and other tests.

Funds cannot be used for abortions, but antiabortion forces have targeted the program because some \$30 million a year goes to Planned Parenthood clinics, which advise patients about "pregnancy management options," including abortion.

Planned Parenthood does not use federal funds to perform abortions, but does operate separate abortion clinics. Smith, leader of the House antiabortion caucus, charged that the family planning program "subsidized the filthy rich abortion industry."

Planned Parenthood said in a statement that "members of the House have capitulated to far right extremists."

The amendment approved yesterday shifts the family planning money to two state block grant programs for child and maternal health and community and migrant health centers. But recipients will not be required to spend money on family planning services.

Three Democrats supported elimination of the program and seven Republicans were opposed.

The amendment to bar federal researchers from using human embryos

ey (R-Ark.) and Roger Wicker (R-Miss.) and passed 30 to 23.

The Clinton administration already has prohibited the federal government from creating embryos for research purposes from in vitro techniques. But the National Institutes of Health has not reached a decision on whether to allow the use of two-, four- and eight-cell embryos that are a byproduct of private fertility clinics.

Porter pleaded with the committee to allow the NIH to keep that option open, citing the value of the material in research on contraception, birth defects and diseases. His attempt to substitute a less comprehensive amendment was defeated on a tie vote.

A representative of the National Right to Life Committee, present in the room, hailed the action. "These are live human embryos," said Maureen Malloy.

When the committee resumes work today, abortion foes plan to offer more initiatives, including one that would restrict medical schools from teaching abortion procedures.

FOR MORE INFORMATION

For the full text of the federal budget, see Digital Ink, The Post's on-line

Can Health Care Be Reduced To the Terms of an Equation?

By Spencer Rich
Washington Post Staff Writer

Although spending for public and private health care has slowed somewhat in recent years, health care costs are still growing faster than the overall economy. The United States in 1993 spent \$884 billion, 13.9 percent of gross domestic product, on health care, a higher proportion of its annual output than in 1992 and the highest figure for any developed nation in the world.

As the nation struggles to slow these costs, comparing the "cost effectiveness" of different medical services will be crucial to the effort so that money is not wasted.

A treatment for one disease may be expensive yet save only a few lives. A treatment for another disease may be relatively cheap and save many lives or substantially improve the quality of life of many people.

To make good policy, a reliable, standard method is needed to compare the costs of achieving various health improvements, such as averting premature births or saving the lives of heart attack victims.

Cost effectiveness studies are supposed to make those standard comparisons. Academics, government agencies ranging from the Office of Technology Assessment to the Agency for Health Care Policy and Research, and drug companies have produced scores of studies on how much bang society gets for its buck in the health field.

Although it is imprecise and crude in many ways, at least one standard method of comparing the cost effectiveness of different treatments has been developed by health economists from academia, and is being studied by the U.S. Public Health Service in an effort to make it more useful for future policy.

The method examines large blocs of population with various health problems and calculates how much it costs on average to extend the life of a sick person for a year using different treatments for different illnesses. The dollar cost per "life-year saved" then can be compared across a spectrum of conditions.

To make the calculation, it is necessary to know the cost of screening and treatment for everyone involved, the number of people who survive, and the total years survivors live.

A recent article in the New England Journal of Medicine illustrates the outcome of such studies. It estimated that universal use of one drug in heart attacks in place of a cheaper drug would increase the number of heart attack survivors by 2,750 people a year, at a cost of \$32,678 per added life-year saved.

Is this expensive? It depends on the comparison. Therapies routinely used for many ailments cost about

"It's a question for society to decide."

— Marthe Gold, physician,
U.S. Public Health Service

the same. For example, treatment for severe high blood pressure has been calculated at \$10,900 to \$72,100 per life-year, depending on drugs used.

Still, even if the cost effectiveness studies were perfect, they cannot answer the ethical or policy questions of whether it makes sense to pay for the treatment. For example, is it more worthwhile to spend \$60,000 per life-year to extend the life of a child or that of an older person?

Public Health Service physician Marthe Gold said academic researchers who are studying the issue for the service caution that while life-year cost analysis allows for easier comparison of the cost effectiveness of different treatments, no statistical measurement can answer the ultimate question: How much is it worth in dollar terms to save a life or measurably improve a person's quality of life?

"It's a question for society to decide," Gold said.

For example, the New England Journal of Medicine article said costs that exceed \$100,000 per life-year are "generally considered too high."

It is one thing to do cost analyses of diseases that have been detected. It is quite another to develop meth-

ods of examining the life-year costs of programs to detect and treat hidden diseases in people who have no symptoms and appear healthy.

First, researchers estimate the costs of screening large numbers of people, most of whom will prove to have no hidden condition and will never get the disease. Then they figure out the costs of treatment for those discovered to have the disease. They then calculate from health surveys how many lives will be saved and how many added years people are likely to live in the aggregate. The total costs for screening and treatment are divided by the total years of life added for everyone involved. Result: the cost per life-year saved.

Using this method, David Eddy, a leading researcher, estimated in the 1980s that if every woman 20 to 75 were given a Pap smear every three years to detect cervical cancer, it would cost \$13,300 in 1985 for every year of life saved. Eddy judged that amount "well worth it." Screening every three years would detect more than 90 percent of invasive cervical cancers. Screening annually would detect only a few percent more.

Gold said one problem in cost effectiveness analysis is the difference of perspective based on who is doing the analysis. For example, in calculating the cost of a new treatment, some insurance companies might count only costs they pay, ignoring costs others might incur.

Another problem: Some people, while kept alive by a treatment, may not regain the level of health they had before becoming ill. Therefore, some analysts believe that this change in "quality of life" should always be taken into account in the cost-per-life-year consideration.

If quality of life is likely to be reduced for large numbers receiving a particular treatment, the argument runs, the number of life-years gained should be adjusted downward to reflect the lesser value people place on years of survival with pain and reduced functioning. The cost per life-year adjusted for quality will be greater than if quality of life is ignored.

Democrats Charge Republicans With 'Stealth' Plan for Medicare Vouchers

By Spencer Rich
and Judith Havemann
Washington Post Staff Writers

Senate Democrats yesterday attacked what they called a Republican "stealth" plan for Medicare, charging that the GOP would make the elderly pay more and get less in order to finance tax cuts promised in its budget resolution.

"Thirty years ago the Republicans tried to kill Medicare aborning," said Sen. Tom Harkin (D-Iowa). "Now they want to destroy it with \$270 billion in cuts." The Democrats charged that in order to help pay for the tax cuts, GOP lawmakers plan to offer Medicare patients a limited "voucher" for health care instead of guaranteed full payment for services.

Minority Leader Thomas A. Daschle (D-S.D.), reacting to a GOP options paper, called it a "ticket to disaster." Sen. John D. "Jay" Rockefeller IV (D-W.Va.) said putting millions of Medicare recipients into the private insurance market "could not possibly work." Sen. Bob Graham (D-Fla.) said that nearly 80 percent of Medicare patients spend less than \$2,000 a year on health services, while 10 percent spend more than \$20,000. "How would a voucher operate with these extreme differences?" he asked.

House Ways and Means health subcommittee chairman Bill Thomas (R-Calif.) responded angrily that Republicans do not intend that seniors be "handed vouchers and shoved out into the cold." The GOP is looking at the

Medicare program to save it from bankruptcy in 2002, Thomas said. The options paper, he said, was just that—a list of options.

Health and Human Services Secretary Donna E. Shalala charged that the Republicans were backing away from the options in the Ways and Means Committee's preliminary list "so quickly it was as if their proposals were written by gremlins in the middle of the night."

"I don't know of any way to construct a voucher that maintains the quality of benefits and takes that much money out of health care system," she said. Locking in vouchers would "break the promise we made 30 years ago" to guarantee health benefits to the elderly and disabled.

The Democrats, showing a united

front, spoke at news conferences on Capitol Hill, in interviews and in testimony before the Ways and Means health subcommittee.

Medicare administrator Bruce C. Vladeck told the committee that the cuts in the program's growth required by the congressional budget resolution are so huge over such a short period that annual increases in the value of the voucher to make up for inflation and other increases in health care costs would be limited to "an incredibly tight 4.9 percent per capita" from 1996 to 2002.

He said Congressional Budget Office data indicate that private sector health plans will grow 7.1 percent annually. Assuming costs for caring for Medicare patients also go up 7.1 percent, beneficiaries would have two

choices, Vladeck said: pay the difference out of pocket, or sign up for policies with inferior benefits and/or quality of care.

Vladeck said that people might seek to avoid this by choosing to stay in the traditional Medicare plan, another choice in the Republican options paper. But these people would have to pay more in copayments, deductibles and premiums than they do now.

GOP aides said comparing the 4.9 percent Medicare voucher growth figure with the 7.1 percent private sector growth rate is misleading because private sector plans generally offer more benefits. Republicans believe that to compete for voucher customers, private plans will improve efficiency and get rid of waste and overutilization, holding down cost increases.



BRUCE C. VLADECK

... vouchers would fall short

JULY 17, 1995

MEMORANDUM TO PATSY AND JEFF

From: Vanessa Potkin and Rachael Smith

Re: News for 7/15 & 7/17

"Advisors Back Baboon Human Cell Transplant : FDA Urged to Approve AIDS Patient Experiment" (Washington Post 7/15)
After a two day meeting a federal advisory panel recommended allowing researchers to proceed with an experimental procedure that involves injecting marrow cells from a baboon into AIDS patients. Baboons are not infected by HIV. FDA official cautioned that the many potential risks of cross species transplants should be better understood. There is also concern that viruses could pass from animals to humans who already have defective immune systems.

"Attempted Murder Conviction Upheld in HIV-Related Rape Case" (Washington Post 7/15)
Maryland Court of Special Appeals ruled that a Prince George's County man that has AIDS can be convicted of attempted murder for raping a woman. This ruling adds to the debate of what crimes, if any, warrant additional penalties if they place someone at risk of HIV infection.

"AIDS Fears Bring Suspension" (Washington Post 7/15)
A letter carrier was suspended after he refused to deliver mail to a couple with AIDS because he was afraid of cutting himself on the home's metal mail slot and becoming infected from envelopes or stamps the couple had licked.

"Rivlin: Clinton Will Use Veto Unless More Government Funds Allocated" (Washington Post 7/15)
Rivlin told a group of reporters that Clinton will veto spending bills unless Congress increases overall discretionary spending. Rivlin said the Clinton Administration is planning a month-long public relations blitz to demonstrate to voters the differences between the Clinton budget and those advocated by congressional Republicans.

"Merck to Provide New AIDS Drug: 1400 in Disease's Late Stages Will Be Chosen for Free " (Washington Post 7/17)
Merck & Co. announced it would make the drug indinavir sulfate, also known as Crixivan, available to 1400 PWAs for free. The drugs reduce the amount of HIV in the body to 1% or less of its previous level and they raise the level of critical immune cells depleted in AIDS. People will be chosen through a lottery system, for it was the most fair way to decide who will get their drugs. Merck said they are still awaiting the results of clinical trials.

"The Guardians: Who'll Care for the Kids If the Parents Die?"
(Washington Post 7/17)

This article discusses the issue of guardianship in the event of one or both parents dying while children are young. According to this article, more and more attorneys are advising parents to make arrangements in the event of death so that guardianship will not be determined by the courts. It is believed that "disaster-planning" is more relevant today than ever before with more babies being born to single mothers with AIDS. The article mentions the recent passage of a New York state law that allows AIDS-infected and other terminally ill single parents to choose "standby" guardians for their children.

"Death Without Dignity in D.C. Jail" (Washington Post 7/15)

Richard Johnson, a D.C. jail inmate with AIDS, was left unattended to for ten days while he lay curled up on the floor of his cell, dying from AIDS. According to the author of this article, because of Johnson's stench medical staff refused to treat him. A spokesperson from the Washington Legal Clinic for the Homeless said District jails have become a prime breeding ground for tuberculosis and AIDS. Since his death, three medical employees were suspended pending an investigation and a fourth was fired.

Advisers Back Baboon-Human Cell Transplant

FDA Urged to Approve AIDS Patient Experiment

By John Schwartz
Washington Post Staff Writer

A federal advisory panel yesterday recommended allowing researchers to proceed with a controversial AIDS experiment that calls for transplanting a baboon's bone marrow into a human patient.

The procedure involves taking marrow cells from a baboon and injecting them into the patient. Researchers hope that the simian cells, specially treated to reduce the chance of rejection by the recipient, will provide the immune response that the patient's body cannot. Baboons are not infected by HIV, the virus that causes AIDS. Citing safety concerns, the Food and Drug Administration blocked the experiment earlier this year.

The experiment would be conducted in San Francisco by University of California AIDS specialist Steven G. Deeks. This week's two-day meeting of the FDA's Biological Response Modifiers Advisory Committee at the Bethesda Holiday Inn was held to discuss the concerns in a public forum.

Panel members seemed moved by the impassioned testimony of friends and family of Jeff Getty, the 38-year-old San Francisco AIDS activist who is the most likely subject of the test. Physicians have estimated that he has less than a year to live; his health is too precarious to allow travel.

Getty's family went to the meeting ready to face down a room full of dilatory bureaucrats. Getty's sister, Kim, barely holding back tears, said, "If I don't do my job fast enough, I lose customers. If you don't do your job fast enough, people die. . . . What if you are sitting on a solution to my brother's life, and he dies?"

But the members of the advisory panel, while insisting that strong precautions be taken to ensure that the potential for cross-species infection do not introduce new diseases into the human population, were unanimous in supporting the preliminary experiment.

After the panel's vote, Getty's mother, Susan, said, "I'm so happy . . . we never dreamed this would happen."



ASSOCIATED PRESS

Susan Getty, left, and daughters Kim, Jennifer and Carrie, at FDA advisory panel session with poster of Jeff Getty, 38, an AIDS patient and the most likely transplant recipient.

The panel, however, did not share the family's optimism about the experiment's potential benefits to Getty. Although several members said it would provide valuable information for future attempts to bolster the human immune system, panel member Hugh Auchincloss Jr., of the Massachusetts General Hospital, grimly predicted that "the likelihood that this will work is extremely small." He added that the difficult procedure "will probably hasten his death and not prevent it."

FDA officials warned that many potential risks of cross-species transplants, known as xenotransplants, should be better understood before more patients undergo similar treatments. Some voiced worries about viruses that could pass from animals into humans: "xeno-zoonoses." They noted that because AIDS patients already have defective immune systems, and because the treatment calls for further immunosuppression to keep the body from rejecting the baboon cells, the risk of bringing new diseases into the human population could be increased.

The agents of several human diseases are believed to have evolved from viruses that first infected other species, including some strains of influenza, AIDS and the Ebola virus. Researchers said the two baboons that have been selected for the transplantation experiment are known to have five viruses that theoretically could infect the patient, and that breeding completely "clean" baboons would take several years and would be prohibitively expensive. The patient and researchers working with him will have to submit to regular screenings for disease.

Members of the panel discussed safety precautions at length, including a strong recommendation that the patient be required to sign a pledge that he will engage in safe sexual practices for the rest of his life in order to minimize the chance of transmitting of any potential new pathogens. (In an interview earlier this week, Getty said he has already volunteered to sign such a pledge. "I don't have that great a sex life anymore," he said. "To tell you the truth, it's shot.")

W. French Anderson, a gene therapy pioneer and member of the advisory committee, said that the time required by the FDA for extra consideration paid off in an improved, safer plan for the experiment. "This is the way pioneering science ought to be done," Anderson said. "I believe it should be approved now."

Although the agency is not bound by advisory panel recommendations, it usually follows them, and in this case agency officials were careful to underscore the point. "It's most unusual that we would overrule such a suggestion," said Jay P. Siegel, director of the FDA's division of therapeutics in the Center for Biologics.

If the FDA decides to let the experiment go forward—a decision could be made within weeks—and if Getty still meets the physical criteria, then the injections could begin by the end of the summer.

Getty's mother said her son was aware of the risks, but wanted the chance to be part of a possible cure for AIDS. "He doesn't want to die in a hospice; he wants to go out fighting."

Attempted Murder Conviction Upheld in HIV-Related Rape Case

By Fern Shen
Washington Post Staff Writer

Maryland's second-highest court has ruled that a Prince George's County man infected with the AIDS virus can be convicted of attempted murder for raping a woman, the first appellate ruling in the state on whether rape can constitute attempted murder when the rapist carries the lethal virus.

The 2 to 1 decision, filed Thursday by a three-judge panel of the Court of Special Appeals, added fuel to the national debate over whether additional penalties should be imposed on a person whose criminal actions place someone at risk of HIV infection.

Law enforcement officials and lawmakers in other states have argued that an HIV-positive person who scratches, bites, spits at or rapes another should be charged with attempted

murder. AIDS activists and civil libertarians maintain that murderous intent should not be presumed in such cases and that behavior such as biting and spitting rarely, if ever, transmit the AIDS virus.

The appellate court's 17-page opinion upheld Dwight Ralph Smallwood's October 1994 conviction for attempted murder in sexual attacks on three women during a 1993 crime rampage. Police said Smallwood, of Temple Hills, and an accomplice abducted the women at gunpoint and forced them to withdraw money from bank teller machines before sexually assaulting them.

Smallwood pleaded guilty to charges of first-degree attempted rape and robbery with a deadly weapon and received a life sentence, but he appealed an attempted murder conviction, which could yield an additional 30 years in prison and affect when he becomes eligible for parole.

"HIV is a significant public health matter, and we think there should be grave consequences imposed on a person who knowingly puts someone at risk," said Maryland Attorney General J. Joseph Curran Jr., whose office argued the case on appeal.

Smallwood's attorneys, from the state public defender's office, could not be reached yesterday for comment or to say whether they will appeal the decision to the Maryland Court of Appeals.

Both sides agreed that Smallwood was found to be HIV-positive on Aug. 29, 1991, and that he told a psychiatrist at the Prince George's County jail that he would not have intercourse without informing his partners.

Also, a social worker told Smallwood in February 1992 that he must practice "safe sex," and in 1993, while receiving HIV-related treatment at Children's Hospital, he told medi-

cal personnel that he "always used condoms during sex," according to the majority opinion, written by Judge John J. Bishop Jr.

"Appellant proffered no evidence suggesting that he did not understand that HIV could be transmitted through sexual contact."

But in a tartly worded nine-page dissent, Judge Theodore G. Bloom wrote that it is unlikely that Smallwood had a specific intent to kill. Smallwood merely wished to rob and rape, Bloom argued, and did so with "the wanton reckless indifference that signifies a depraved heart."

If Smallwood's desire was to murder, Bloom wrote, he "was armed with a gun, which is a far more effective weapon."

An attorney for the New York-based Lambda Legal Defense Fund called the Maryland opinion "miserable," saying it unfairly stigmatizes those with HIV and will discourage people from getting HIV and AIDS diagnosed and treated.

AIDS Fears Bring Suspension

■ CHARLESTON, W.Va.—A letter carrier who refused to deliver mail to a couple with AIDS was indefinitely suspended with pay after an educational class failed to change his mind.

Tim Snodgrass, a 10-year mail carrier, refused to serve Fred and Pat Grounds after they moved into a home for people with AIDS. They are the first and only residents at the home, which is run by a charity.

Snodgrass said he was afraid of cutting himself on the home's metal mail slot and becoming infected from envelopes or stamps the couple had licked, but the federal Centers for Disease Control and Pre-

vention says there are no known cases of AIDS being spread through saliva.

"His job was not what I was after," said Pat Grounds. "I was trying to raise AIDS awareness."

Rivlin: Clinton Will Use Veto Unless More Government Funds Allocated

By Clay Chandler
Washington Post Staff Writer

Office of Management and Budget Director Alice M. Rivlin said yesterday President Clinton will veto spending bills unless the Republican Congress allocates more money overall for government programs.

Rivlin, in a luncheon meeting with a small group of reporters, said Clinton will demand more spending for government programs overall than Congress put in its budget plan in addition to insisting that the distribution of that spending more closely reflect his priorities for job training, education and protecting the environment.

If Republican spending plans fail either of those two tests, she warned, Clinton is determined to reject them—even if that means there would not be any money to run the government

after Sept. 30, the end of the current spending year.

"In the end, there is going to have to be a negotiation that we hope will put more money into discretionary spending," she said. Voters would be more likely to blame Republicans than Clinton for a budget standoff, she contended, because "everybody knows the Republicans are in charge of the Congress."

Increasing overall discretionary spending—the money that Congress must appropriate each year for everything from government salaries to paper clips—would require congressional Republicans to accept spending bills that would bust the budget they approved earlier this month. Lawmakers are using that plan as the basis for the 13 annual appropriations bills required to fund the government in the next fiscal year, which begins Oct. 1.

Rivlin said the administration has had no

substantive discussions with Republican congressional leaders about the possible outlines of a budget compromise. She stressed that Clinton does not plan to work out differences between the two sides at a "budget summit" similar to the marathon closed-door bargaining session held between Bush administration officials and Democratic congressional leaders at Andrews Air Force Base in 1990.

"People who have in their head that everybody goes to Andrews Air Force Base for two months—we're very eager not to do that," she said.

Instead, the administration is launching a month-long public relations blitz to demonstrate to voters the differences between the Clinton budget and those advocated by congressional Republicans, Rivlin said.

The primary aim of the campaign, she said, will be to show the public that it is possible to

balance the budget more gradually while protecting programs that aid poor and middle-class families. "The public has to hear that debate and the Congress has to engage in that debate," she said.

Rivlin declined to discuss details of the administration's approach for slowing the growth of Medicare spending, saying only that it would affect health care providers but—unlike Republican proposals—have no impact on Medicare beneficiaries.

The administration also opposes Republican plans to scale back Medicaid by lowering spending totals and turning administration of the programs over to the states in the form of block grants. The block grant approach, Rivlin said, would pit nursing homes against poor children—probably to the disadvantage of the children.

Merck to Provide New AIDS Drug

1,400 in Disease's Late Stages Will Be Chosen for Free Treatment

By Justin Gillis
Washington Post Staff Writer

An experimental AIDS drug will become available soon to a limited number of people in the late stages of the disease under a program announced over the weekend by the manufacturer.

Merck & Co. said it would make the drug indinavir sulfate available free by lottery to about 1,400 people in the United States. Indinavir sulfate, also known by the brand name Crivivan, is one of a promising new class of drugs designed to attack the AIDS virus at a critical point in its life cycle.

Merck, of Whitehouse Station, N.J., becomes the second big drug company in recent weeks to announce an expanded access program for this group of drugs, known as the protease inhibitors. Hoffman-La Roche Inc., of Nutley, N.J., announced a similar program June 21 for its drug, known as saquinavir or Invirase.

Although the drugs are still experimental, demand outstrips supply.

The companies are awaiting the results of clinical trials and have not gone into full production. In the meantime, tens of thousands of sick people with few other options would like to take the drugs. For instance, Roche has only 2,280 slots available in its "compassionate use" program but has already received more than 10,000 calls. The company says that number could double before registration closes this week.

The companies say the drugs are exceedingly difficult to make, and they will not be able to meet the demand until they have built bigger factories.

The new drugs work by blocking a key enzyme used by the human immunodeficiency virus in its reproductive cycle. In the short term, the drugs reduce the amount of HIV in the body to 1 percent or less of its

previous level, and they raise the level of the critical immune cells depleted in AIDS. It's not clear yet how long these favorable responses will last, or whether they will im-

The announcement was a response to the pleas of AIDS activists.

prove the long-term health and survival of people with AIDS.

The announcement by Merck, like the earlier one by Roche, was a response to the pleas of AIDS activists who argued for broader access. Some people are getting the drugs through research programs, but the enrollment criteria for such trials are strict, and not everyone in the advanced stages of AIDS can qualify.

No announcement of expanded access has been made by Abbott Laboratories, of Abbott Park, Ill., the third company with a drug of this class in the late stages of testing. AIDS groups are pressing the company for an announcement.

"There's a large population of people who in the next year or two, without access to these drugs, will surely die," said A. Cornelius Baker of the National Association of People with AIDS. The question is, what can the companies do to help prevent those deaths?"

Abbott said in a statement Friday that it has only enough drug for its clinical tests. It said it would reevaluate the situation in several months, when more drug is available.

Both Merck and Roche decided that a lottery was the most fair way to decide who will get their drugs. Merck mailed letters Friday to about 130,000 doctors in the United States announcing its program.

The Guardians

Who'll Care for the Kids If the Parents Die?

By Beth Frerking

Michelle Weiner-Davis is a shrink, so you'd think that she and her husband, Jim, would have sat down years ago and thrashed out one of the most emotional decisions parents can make: Who raises the children if both parents die?

They talked about it for years. She wanted her mother. He wanted his parents. But reasoned discussion degenerated into arguments whenever the subject arose. They'd snipe at each other's nominees. Eventually, they avoided the topic altogether. Death ruled.

Today, their children are 14 and 9, and the Chicago-area couple is only now nearing settlement of the guardianship issue. If they don't get around to it, and they die before the kids are grown, they virtually ensure that strangers in a courtroom will decide the fate of their children.

"The court is making a decision that should have been made by the biological parents"—determining whether a guardian has a stable life, will provide a good home, shares the parents' views on religion, morality and education, Judge Louis D. Laurino, a retired surrogate in Queens County, N.Y., said.

And, while judges find it fairly straightforward to divide an estate, appointing a guardian is an entirely different matter.

"You're not dealing with property or personal assets," Laurino said. "You're dealing with human beings."

Yet the Weiner-Davises have a lot of company. Few couples ever go through the legal process of naming guardians for minor children, betting instead that at least one parent will survive to shepherd the kids to adulthood.

But this most basic, if unpleasant, disaster planning may be more relevant today than ever, as more couples opt for late parenthood, as many live far away from extended family, and as more babies are born to single mothers with AIDS. The latter circumstance recently spurred passage of a New York state law that allows AIDS-

infected and other terminally ill single parents to choose "standby" guardians for their children.

"I normally tell people if they have small children, it's the single most important thing they can do," said Catherine Hughes, a Washington, D.C., attorney who practices estate and probate law.

That may be, but estimates of how many parents actually designate guardians are alarmingly low: from 5 percent to 25 percent, say probate lawyers and financial estate planners.

Who does it, and why? Often, a planned anniversary trip—sans children—sends parents scurrying to a lawyer to provide for the kids in case the jet disappears into the Bermuda triangle. A terminal illness or upcoming surgery prompts others to do it.

And the wealthy have always addressed guardianship issues as part of

While judges find it fairly straightforward to divide an estate, appointing a guardian is an entirely different matter.

their complicated estates. Who gets what—and how family loyalties shift and affect fortunes—have been the stuff of legends since Shakespeare.

But the average two-earner couple or single parent isn't King Lear, worrying about the nettlesome postmortem division of assets. Most people simply try to have enough life insurance to cover the bills and pay for college should they suddenly and unexpectedly depart this world.

All in all, most people prefer not to think about guardians for their children. It's hardly surprising. Selecting

a guardian means contemplating one's own death, a subject so emotionally charged, said Weiner-Davis, "that it colors everything that you talk about."

"People . . . don't want to consider the possibility that they may not raise this child to adulthood," said Anna Beth Benningfield, a family and marriage therapist in Dallas. "It kicks in a lot of our sense of helplessness, and not being able to give to our children what we want them to have."

"And, few of us can contemplate for very long our not being here."

Then there's the disagreeable task of picking among families.

With children at stake, the name-calling ensues. Your brother is a couch potato. Your sister is a hush. Your mom is a religious nut and your dad is crazy. Suddenly, all those submerged feelings about the in-laws come bubbling out like emotional toxic waste, fueled by not-unrealistic fears that the child's ties to the "losing" side may wither without the parent around to nurture them.

Benningfield saw this happen to a couple she counseled a few years ago. As they began to discuss who would best raise their children, the wife revealed that she had serious reservations about her husband's brother—something she'd never had reason, or inclination, to express until then.

Questions

By Beth Frerking

In his "Pre-Mortem Planning Checklist," New York attorney Edward Schlesinger offers parents some guidelines in choosing guardians for their children.

Some are basic: Are the nominees in good financial shape? Are they healthy enough to raise children? Are they employed? Do they like the child or children? And does the child, if he's old enough, approve of the choice?

But in going through Schlesinger's checklist, a parent will realize that the factors that can

influence the choice of guardian are endless. Among considerations that might not immediately come to mind:

- Does the guardian have a similar education level and share the parents' views on education of the child?
- Do they share religious and moral beliefs?
- Does the guardian share the parents' views on discipline?
- If the proposed guardian is married, is the marriage stable? And, who gets the child if there's a divorce?
- Should some of the money in the estate go to equalize the living standards of the proposed

guardian and the child in case the child is left with a lot of money?

- If there are several children, should they all have the same guardian? What happens if one guardian cannot raise all the children, such as might happen in a large family?

- And, should the parents tell all close relatives who they have chosen and why, so a postmortem custody battle doesn't ensue?

Schlesinger acknowledges that the questions are tough, but he advises parents to confront them directly for the children's sake. Doing so, he says ruefully, will help parents make "the least lousy choice."

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Californians Lynn Weingarden and her husband, Richard Wilbur, have named her brother as guardian of their son, Harris, 4, in the event of their deaths.

BY SCOTT ANDERSON
NORTHWEST NEWS SERVICE

The couple struggled through the debate, comparing the strengths and weaknesses of various relatives, Benningfield recalled. In the end, they took what probably was the most revolutionary (and incendiary) route: They chose a close friend who had been in their wedding.

Their experience is instructive in that they broached the subject at all and thoroughly examined the possible choices from emotional and practical angles.

Many people who begin the work of choosing a guardian haven't given it nearly enough thought, say lawyers who specialize in probate matters.

Often, a couple will reflexively name grandparents. But with many people postponing childbearing until into their mid- and late-thirties, they forget that grandparents may be unwilling or unable to care for young children, said Edward S. Schlesinger, a New York attorney. Do parents really want to expose children to the possible loss of their replacement "parents" a few years down the road, he asked.

Then, parents often don't examine all aspects of the proposed match, said Schlesinger, who moderated a videotaped course on guardianship issues for the American Law Institute-American Bar Association Committee on Continuing Professional Education.

Parents usually cover the basics, he said, such as the nominee's financial well-being. But they often fail to address philosophical concerns: Does the nominee share the parents' religious, educational and moral values? If the guardian is already a parent, will the two sets of children get along?

"The heart of it is, you are replacing yourself when you make that designation. . . . You're cloning yourself," said attorney Rhonda H. Brink of Austin, Tex., and one of the participants on Schlesinger's videotape. "It's a shame that it's often done with no more deliberation than it's given."

Finally, some parents forget to ask the single most obvious question of all: Is the nominee willing to raise the children?

Lynn Weingarden and Richard Wilbur of Redwood City, Calif., had all but closed on their decision to name

Lynn's brother guardian of their son, Harris, when it occurred to them they had never asked, "I would drop a little hint, like, 'What if? Would you guys consider taking care of him?'" Weingarden said recently. When the time came to formalize matters, however, they asked outright, and her brother agreed.

Harris already was 4 years old when they began working with San Francisco attorney Robert A. Goldman to set up a living trust. Still, they feel ahead of the curve. Weingarden could think of only one other couple they know who has named a guardian for their child.

She's not sure whether people procrastinate to avoid painful issues or because they're lazy.

"It's just easier not to do," Weingarden said. "It's like sitting down and paying your bills, or figuring out if you have the right homeowners insurance."

Indeed the legal angles can be daunting. For starters, states vary widely on how guardians can be named. Many require that guardians be listed in wills. Others, like Texas, require only a "written declaration." In New York, parents can designate a guardian in a deed filed with the county clerk's office or through a will.

And, at least 15 states have adopted the Uniform Guardianship and Protective Proceedings Act, which allows

someone to serve as an agent with parental rights and responsibilities should a parent suddenly die or become incapacitated. Many of those states have imposed strict time limits with the law.

Parents also must decide just how far to reach from beyond the grave to influence their children's lives.

Some stipulate that a second guardian take over if the first choice divorces, for example. Others make detailed financial plans, down to providing money and directions for a child's summer camp. Still others chose the minimalist route, appointing someone they trust to make the best decisions for the child in their absence.

All guardians must be approved by a court, and in rare cases, a judge will overrule what was stipulated in a will, perhaps because the named guardian

"Few of us can contemplate for very long our not being here."

—Therapist Anna Beth Benningfield

has become incapacitated or because relatives are contesting the choice.

Nonetheless, the lawyers who write wills and the judges who put them into effect agree that something on paper is better than nothing.

Armed with that truth, Michelle Weiner-Davis came to a decision over the Christmas holidays. In part, she was motivated by an impending three-week book tour. But that wasn't what clinched the deal. Watching her children in Colorado with several of her husband's nieces and nephews did it.

"Of course, I think my mother is more nurturing in the way that I'm nurturing," she said, stepping gingerly through her rationale, "but they'd be part of a larger clan" with their paternal cousins.

She was, in a way, practicing the words she would use on her husband. "See, I'm telling you this before I even tell him," she said, laughing.

The next job will be asking, or telling, or both, the chosen relatives, making sure they're up for the job.

And what about telling the children? Her answer showed in a heartbeat why so few parents even approach this prickly topic, let alone decide it: "Oh, God!" she said nervously. "I don't want to talk to them about it."

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Answers

By Kate Moore
Washington Post Staff Writer

A number of common issues come up for people with children. The following guidelines are based on Maryland, D.C. and Virginia laws:

- If the married couple has minor children and one of the parents dies, the living parent will be responsible for the children.
- The parents of minor children can designate either a blood relative or a nonblood relative to

be the guardian of the children's money.

■ If there is only one parent left and he/she dies, the children can go to a blood relative or a nonblood relative—for example, friends, godparents, cousins. This stipulation is honored by most courts.

■ If the parents are divorced and one dies, the children go to the surviving parent.

■ If the parents are divorced and one dies, provisions for the children's money can be made that require the surviving parent to provide child support without using money that was left specifically for the children.

Colbert I. King

Death Without Dignity in D.C. Jail

For 10 days, Richard Johnson lay curled up on his D.C. Jail bunk in soiled bedding, his body ravaged with AIDS. He urinated in milk cartons that were left on the floor of his cell because he was too weak to walk to the toilet. He was incontinent.

Before he died, other inmates on work detail refused to clean his urine and feces-filled cell, hoping the odor would force the medical staff to respond. It didn't.

At one point, corrections staff, for reasons that defy comprehension, decided this severely ill man should be sent back to Maximum Security. Johnson had to crawl to the door of his cell before he was placed in a makeshift wheelchair for transfer. It then dawned on them that if Johnson was too weak to walk, maybe Maximum wasn't where he belonged.

Johnson was dying; he couldn't care for himself. Yet, because of his stench, no medical staff would treat him. His final hours on this earth were his worst.

Richard Johnson died tied to a wheelchair with a urine-stained sheet. He had been left seated there for two hours, unmedicated, leaning to one side, saliva dripping from his mouth, limbs limp, and eyes open in a blank stare. It was AIDS that took Johnson down. But it was his government, that made him suffer.

When Johnson's story hit the news, D.C. officialdom did its number. "Outraged and appalled" was the way Corrections Director Margaret Moore put it. Four of the jail's medical staff took hits.

Three medical employees were suspended pending an investigation. A fourth, a physician's assistant on contract, got fired. Deserving, perhaps, but not enough.

What about the warden and other brass on whose watch this travesty occurred? Where were they as Johnson languished for days within their jail? What and when did they know and what, if anything, did they do? Those questions haven't been answered, at least not publicly. They need to be, and soon.

There are other shocking and disgusting stories about inmate mistreatment at D.C. Jail, where the suicide rate is three times the national average.

A court-appointed special master's report on the department's tuberculosis prevention and treatment program is downright frightening in its implications for public health in Washington. District jails have become prime breeding grounds for tuberculosis and AIDS, reported the Washington Legal Clinic for the Homeless. Those are communicable

Moore denounced Johnson's treatment as "inhumane." Don't limit that description to his death. You want negligence and unkind treatment? Consider D.C. Village. Or foster care, juvenile services, public housing or the accounts of sexual harassment in the jails.

These are programs with official failure at their core. If the D.C. government were a foreign nation, say critics, it might be up on charges as a violator of internationally recognized human rights.

Confront city hall with these abuses, however, and the first thing you're likely to hear are the strains of "Mo' Money Blues." Tune it out. The District's fiscal woes didn't cause Richard Johnson's suffering, or make those jail suicides possible, or consign the elderly and disabled to live in squalor. Credit those horrors to callousness, cruelty and indifference.

And those are problems that money won't solve.

Moore cites her staff's lack of training as a major agency deficiency. She's undoubtedly right. The American Corrections Association recommends 40 hours of training annually for staff having direct contact with inmates. D.C. Corrections staff get only eight hours a year.

But the government also has an attitude problem. Senior U.S. District Judge William Bryant has been presiding over civil lawsuits involving the jail for more than 20 years—and with the patience of Job. But this week he'd had enough. At Monday's hearing on a special master's report about the horrific conditions at the jail, Judge Bryant seized control of the jail's medical and mental health services. Some corrections officials, he concluded just "don't give a damn." "They have jobs, titles, they get paid, and they do nothing," he said.

That judgment could apply elsewhere in the government. Make no mistake, most D.C. government employees do their jobs as best they can. They're honest and take pride in their work. But they can't make up for that other band of workers who have been hired on the basis of "dumbed down" standards that ignore skills and personal qualities the government really needs.

We're talking here about certain basic values that employees ought to bring with them from home when they first report to work. Notions of respect and concern for others, of accepting responsibility for one's actions, of using authority to do what is right and expected—these are values that government shouldn't have to teach adults.

But the employees bereft of those values are the very ones who have become part of the D.C. government's "getting over" work culture. That is a culture where the thought of getting to the job on time, of regarding work as a legal and moral obligation, and treating the public with respect is held up for private ridicule. I hope these will be the workers who will fill the ranks of the 2,000 employees the financial control board wants gone.

They represent a culture that is bringing down this city. It was that culture that left Richard Johnson to die without dignity.

The writer is a member of the editorial page staff.

July 20, 1995

MEMORANDUM TO PATSY AND JEFF

From: Rachael Smith

Re: News 7/20

"Fear of Contagion Prompts Recall of Blood Products in Canada"
(Washington Post 7/20/95)

The Canadian Red Cross is in the midst of its largest recall of blood products ever. The reason for the recall is that two donors have been diagnosed with Creutzfeldt-Jakob disease (CJD), a rare, fatal disease of the brain. While there is no evidence that CJD is transmittable by blood, there is no evidence to suggest otherwise. The Red Cross is taking drastic precautions as a result of their delayed reaction in dealing with HIV tainted blood in the mid 1980s. In the U.S. and FDA advisory committee recommended that blood products containing CJD be removed from the market to maintain confidence in the blood supply.

"Medicare As We Know It" (Washington Post 7/20/95)

This editorial explores the idea of giving Medicare recipients vouchers to buy what would presumably amount to private insurance. The author of this editorial believes Medicare as we know it, is too costly to be sustained and therefore, must be restructured.

July 18, 1995

MEMORANDUM TO PATSY AND JEFF

From: Rachael Smith & Vanessa Potkin

Re: News for 7/18

"House GOP Medicare Plans Would Raise Copayments, Deductibles" (Washington Post)

House Republican plans to overhaul Medicare include creating substantial financial incentives to encourage people to join Health maintenance organizations or other type of managed care. The changes in Medicare detailed in the House GOP plan could add up to many hundreds and even thousands of dollars a year.

"Richmond to Honor Ashe Alongside Rebel Heroes" (Washington Post)

The Richmond City Council voted to erect a memorial to tennis star Arthur Ashe alongside statues of Confederate war heroes on Monument Avenue. The decision came after weeks of polarized debate.

"Promises to Keep: Disability Policy Past and Future" (Washington Post) Bob Dole discusses the evolution of the Americans with Disabilities Act and charts the progress of disability policy.

"Louis Harris/N.O.D. Survey Finds Employers Overwhelmingly Support the ADA - And Jobs" (Washington Post) Survey concludes corporate America strongly endorses the Americans with disabilities act and its goals and has taken some steps to improve employment practices.

"Fallacy and Truth About the ADA" (Washington Post) This article attempts to dispel some of the myths associated with disabled people in general and with the ADA specifically. Issues highlighted are: cost of ADA; litigation and frivolous claims; regulations on businesses and communities; definition of disability.

"Federal Disability Policies: At Cross Purposes" (Washington Post) This editorial is skeptical that the ADA will deliver on its promise of jobs to disabled people. This author believes that there is good reason to assume the ADA will be harmful to the employment opportunities of people who are most disabled because the ADA imposes "costly and uncertain obligations on employees contemplating hiring people with disabilities, yet does nothing to enhance the skills disabled people bring to the job market."

"Enforcing the ADA: Calls for Commonsense Compliance Should Precede Litigation" (Washington Post) An editorial by Janet Reno and Deval L. Patrick suggests that the ADA is a fair and reasonable law. The Attorney general states the primary objective has been to enlighten the public and encourage voluntary compliance, rather than simply litigate.

House GOP Medicare Plans Would Raise Copayments, Deductibles

By Spencer Rich
and Judith Havemann
Washington Post Staff Writers

Under House Republican plans to overhaul Medicare, elderly Americans would have to ante up a lot more of their own money if they chose to enroll in a traditional fee-for-service Medicare program that allows them to choose their own doctors, according to an outline of the plan circulating on Capitol Hill.

The outline memorandum makes clear that the Republican plan would create substantial financial incentives to encourage people to join a health maintenance organization or other types of managed care plans that are designed to reduce the growth of medical costs. Those electing not to take one of the new options would face a slew of higher copayments, premiums and deductibles.

Depending on what services an individual used, the changes in Medicare described in the House GOP document could add up to many hundreds and even thousands of dollars a year.

House Speaker Newt Gingrich (R-Ga.), Ways and Means Chairman Bill Archer (R-Tex.) and House Medicare subcommittee chairman Bill Thomas (R-Calif.) have all pledged that anyone who wants to be in the existing fee-for-service plan, including future retirees, will be able to join it even after the Republicans enact plans to cut the growth of Medicare spending nearly in half.

As money-saving alternatives, the Republican plan would create what amounts to a government-funded voucher that could be used to pay for a wide variety of private plans such as HMOs.

Rep. Fortney "Pete" Stark (D-Calif.) said the outline makes clear that a large portion of the \$270 billion savings Republicans want to squeeze from the program over the next seven years comes "out of the pockets of seniors."

Critics of the GOP's proposed cuts in Medicare spending argue that the elderly have been reluctant to sign up for HMOs for fear they will not be able to choose their own doctors, and that as a result, many might see no advantage to joining

HMOs under the GOP plan unless traditional fee-for-service care is made unattractively expensive.

Finding a means to reduce the growth of Medicare spending is the keystone of the Republicans' plans to balance the budget by the year 2002. Indeed, the stakes are so high that Gingrich recently boasted, "if we solve Medicare, I think we will govern for a generation."

However, changing a program that has proved very popular among the influential elderly population could have disastrous political consequences.

The Medicare plan drafted by the House Ways and Means Committee staff "is far from a final version and very substantial changes are highly likely," said a GOP leadership aide, noting that the House Commerce Committee has jurisdiction over part of Medicare and may have plans of its own.

For those who chose traditional Medicare insurance, the GOP plan would increase the portion of most doctor bills that the individual must pay from 20 percent to 25 percent. It would raise the annual \$100 deduct-

ible that a patient must pay on doctor bills before Medicare benefits kick in and would increase it each year. Similarly, the Republican plan would require copayments of 20 percent for home health services, for the first 20 days in a skilled nursing home (now the first 20 days are free), and for clinical laboratory services. It would also raise Medicare premiums faster than now projected.

As an alternative to these increased costs, the memorandum, first reported in the New York Times, outlines a plan to give Medicare beneficiaries what amounts to government-funded vouchers and let them buy their own insurance on the private market from a list of government-approved HMOs and private insurance plans. The theory behind this idea is that HMOs restrain the costs of medical care because they receive an annual fixed premium and then must provide all specified services all year for little or no additional payments. As a result, they have every incentive to fight wasteful or marginal services.

The plan envisions that competition by HMOs and private insurers to win enrollees will force these groups to be

more efficient and thereby keep waste, overutilization and prices down. In the existing Medicare fee-for-service system, according to the theory, a person can choose any doctor he or she likes and go for repeated treatments. The doctor now has incentives to pile on extra, marginal services since he gets paid more for each added service.

According to the American Association of Retired Persons (AARP), raising the \$100 out-of-pocket deductible in the doctor-insurance part of the program to \$150 and then increasing it annually would boost it to \$270 a year by the year 2002.

Raising the co-insurance payments on doctor bills could cost beneficiaries billions of dollars over the next seven years, but how much is not clear since no one knows how many would stay in the fee-for-service program.

Raising the premium so that instead of covering 25 percent, as is now law, of the doctor-insurance program costs, it would rise to 31 percent, as proposed in the outline, would boost the premium from \$46.10 a month to \$97.70 a month by 2002, the AARP said.

Richmond to ... for Ashe

Alongside Rebel Heroes

City Was Split Over Memorial to Tennis Great

By Peter Baker

Washington Post Staff Writer

RICHMOND, July 18 (Tuesday)—After weeks of polarizing debate, the Richmond City Council decided early today to erect a memorial to tennis star Arthur Ashe alongside statues of Confederate war heroes on the city's famed Monument Avenue.

In a symbolic break with its past as the Capital of the Confederacy, the leaders of Ashe's home town approved a 24-foot bronze and granite monument to the late native son just blocks from statues honoring the likes of Robert E. Lee, Stonewall Jackson and J.E.B. Stuart.

The 1:15 a.m. vote culminated a seven-hour council meeting that saw hundreds of black and white residents pack the council chamber to speak out on an issue that touched many in a personal way, even if they had never met Ashe. The surprise appearance of some of Ashe's relatives turned around what seemed to be a movement to abandon the Monument Avenue site, and in the end, seven council members voted for it,



BY DEAN HOFFMEYER FOR THE WASHINGTON POST

The face of Arthur Ashe is portrayed in a casting model for the statue.

with no negative votes and only one abstention.

"I think this is our finest hour," said Mayor Leonidas B. Young, who switched positions, "because it shows that we have grown. It is painful to grow, but if you do not grow, if you do not experience the pain, you will not become everything

See ASHE, A8, Col. 4

Created Odd Allies as It Divided Virginia's Capital

ASHE, From A1

you can become." For those not present, Young added, "you missed the healing of a city."

In a city that regularly divides along racial lines, the emotions became especially raw as Richmond debated the meaning of art, race and history under the glare of the international media.

To its supporters, led by L. Douglas Wilder, the Democrat who was the nation's first elected black governor, the plan to honor Ashe on Monument Avenue was a powerful symbol of racial reconciliation in a city that barred Ashe from playing on its whites-only tennis courts. But opponents included an odd mix of whites who considered it nothing short of heresy to the Lost Cause and blacks who considered it nothing short of heresy to Ashe.

"Richmond's venting, and the world's getting to watch," Paul Di Pasquale, sculptor of the \$400,000 monument to a man he met only once, said before the vote. "Hopefully, Richmond's venting for other people in other places, as well, and they're hearing Arthur Ashe's message."

After leaving segregated Richmond as a young man, Ashe went on to become the first black man to win the U.S. Open and Wimbledon titles. Yet it's not so much as a tennis champion that he is remembered here but as a champion of education, human rights and, ultimately, the fight against AIDS. Complications from the disease claimed him in 1993 after he had contracted it through a heart-bypass operation.

Before his death at age 49, he outlined his wishes for the monument. In it, he grasps a tennis racket in his left hand but holds books in his right hand, which he used to play. The books are held above the racket, to symbolize the importance of education.

That he is a hero is generally acknowledged by both sides. Whether he belongs with the likes of Lee and Jackson is another matter.

The famed Monument Avenue is Richmond's premier boulevard, often referred to as the Champs Elysees of the South for its wide, tree-lined median and fashionable turn-of-the-century houses.

The idea of adding Ashe originated with Wilder, a friend who has made the issue a crusade and who

broadcast his daily radio talk show live from the corner of Monument and Rosemeath Road Monday morning. "Every time we think we've crossed the bridge, we see that there's more water than we ever thought," the former governor said.

Sitting on the front porch across the street, however, was Mary Carr, a 20-year resident of Monument Avenue who thinks it's a bad idea and resents the implications that her being white has anything to do with it.

"It's really not racial. It's really more artistic," she said. "I just think it's an informal sports statue, and that's fine for what it is, but it doesn't fit into the cohesion of the rest of the avenue. . . . I think we should have a statue to the blacks who fought for the Confederacy. And I think we should build the sports hall of fame he wanted built and put his statue there."

On the other side of town, back in the Northside neighborhood where Ashe grew up, Eugene Price came to a similar conclusion for different reasons. To Price, who went to school with Ashe, Monument Avenue isn't good enough. "The only way we could go to Monument was to run across it," he said recently.

While most opponents disavowed race, the thoughts of some whites were clearer than those of others.

"We need to protect our heritage," a man identified as Ken said on WVGO-FM, a rock-and-roll radio station that took calls on the issue all day. "We don't need no blacks on Monument Avenue. . . . They've taken over our city; they've tried to take over our government. If you've got daughters like I've got daughters, they're trying to take them over, too."

Ashe's family largely tried to stay out of the issue, but his younger brother flew from Atlanta to weigh in on the side of the Monument Avenue site. "These guys were generals," Johnnie Ashe, 47, said of the current bronze denizens. "They were in the background with thousands in front of them. Arthur did what he did on his own."

For the City Council, which sat through six hours of testimony, the issues are about as difficult as they come.

More than 250 people showed up, with many of each race on each side, expressing reasons ranging from aesthetics to traffic. One opponent was escorted out by police after repeated outbursts, and a few supporters suggested tearing down the statues of the generals, but most of the discussion was more sober.

In the end, Young, who is black, abandoned his own compromise that would have put the statue at Byrd Park, where Ashe was not allowed to play tennis as a boy because of his race, and renamed the adjacent city thoroughfare Arthur Ashe Boulevard, which would lead north to the existing Arthur Ashe Jr. Athletic Center.

A separate memorial, he had suggested, then could be built along Monument Avenue to commemorate African Americans who fought for civil rights.

That wasn't good enough for some City Council members. Vicki Baskerville said this is an issue that touches the soul of a city.

"Ghosts still haunt us," she said earlier. "And we haven't resolved that."



BY DEAN HOFFMEYER FOR THE WASHINGTON POST

Sculptor Paul Di Pasquale stands in his Richmond studio with part of the casting model for his monument to tennis star Arthur Ashe.

"Promises to Keep": Disability Policy Past and Future

BY BOB DOLE

As we approach the 5th birthday of the Americans with Disabilities Act, the future has never been brighter for people with disabilities. As a nation, we are increasingly committed to an accessible society — not only our buildings and our environment, but our hearts and minds as well.

The ADA is an important part of our nation's commitment to the full participation of people with disabilities. I know many in the disability community are worried about criticism of the ADA. There have been some crazy stories in the press, but some fair concerns as well. In my view, thoughtful debate is always healthy — it means that people are paying attention. In 1973, Congress passed the Rehabilitation Act, which required that federally funded programs be accessible. But for many years little happened. No one can say that's the case with the ADA.

Let us remember the ADA asks something of most Americans — usually not a lot, but sometimes a great deal. We should expect questions and concerns will be raised. We must make it our job to make the ADA work for both people with and without disabilities.

A quick tour of disability policy past and future will show how far we have come, and the distance we have yet to go.

FIRST SENATE SPEECH

Twenty-six years ago, I was elected to the U.S. Senate. After several months of careful thought, on April 14, 1969, I rose to give my first speech. I spoke not just about disability, but as a person with a disability myself. During World War II, on another April 14th, I was wounded in combat and joined the disability community.

I talked about values in disability policy — of independence, dignity and security. And how society had shut out people with disabilities: "As a minority, (people with disabilities have) always known exclusion — maybe not exclusion from the front of the bus, but perhaps from even climbing aboard it; maybe not exclusion from pursuing advanced education, but perhaps from experiencing any formal education; maybe not exclusion from day-to-day life itself, but perhaps from an adequate opportunity to develop and contribute to his or her fullest capacity."

continued on next page

BIG CHANGES — AND NEW ISSUES

Since that first speech, there have been big changes. Congress has passed dozens of laws to help promote the full participation of people with disabilities — culminating with the ADA.

But many gains have come from the hard work of people with disabilities themselves. Today, across America there are hundreds of independent living centers and advocacy groups serving people with disabilities.

The issues are changing though, and are, in some ways, tougher. For example, this year is the 20th anniversary of the Federal special education law — the Individuals with Disabilities Education Act. It was needed, and I was proud to vote for it. It was unconscionable that thousands of children with disabilities were barred at the school-house door.

Although access in education remains a fundamental issue, new and more complicated issues often dominate the debate — school violence, competing demands on school budgets, and even allegations that students are mislabeled as disabled for financial or other reasons. Such complex problems often require careful arguments and often good data to address them.

Unemployment of people with disabilities also remains a big problem. Despite billions spent by the Federal government over the past decade, the job outlook for many has not improved, and is maybe even worse. In my first Senate speech I also said, "We in America are far from the half-way point of assuring that every (person with a disability) can become as active and useful as his abilities will allow." I believe we will reach that point only when employment among people with disabilities is at least half that of people without disabilities.

THE PROMISE OF TECHNOLOGY

Perhaps the most exciting avenue for progress is technology. On June 15, the Senate passed a sweeping telecommunications bill that will deregulate markets and spur innovation. We did not forget people with disabilities. We asked that all equipment and services consider the needs of those with disabilities. In my view, no group may benefit more from this legislation than people with disabilities.

The poet Archibald MacLeish once wrote, "America was always promises." There still is much work to do, but never have America's promises been within closer reach for people with disabilities.

Bob Dole (R. Kansas) is the Majority Leader of the Senate and a candidate for President of the United States.

Louis Harris/N.O.D. Survey Finds Employers Overwhelmingly Support The ADA — And Jobs

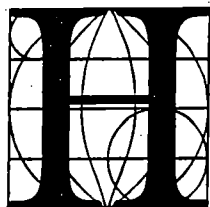
BY HUMPHREY TAYLOR

Hopes have always run high within the disability community for improvement in employment with the passage of the ADA, but over the first five years, how has the new law been accepted by those who do the hiring — under its anti-discriminatory provision? To find out, the National Organization on Disability (NOD) commissioned Louis Harris Associates, Inc. to survey 404 employers, operating businesses both large and small, and ascertain what changes the ADA had brought as legal guide or goad to their employing people with disabilities.

The Harris pollsters chiefly concluded that Corporate America strongly endorses the Americans with Disabilities Act and its goals, and has taken some steps to improve its own practices in relation to the employment of people with disabilities.

At the same time, the pollsters found that, even with this staunch support for the ADA, the number of corporations actually hiring people with disabilities has scarcely changed over the last nine years.

Their research also refutes two misconceptions about the ADA that have become politically current. The first misconception is



NOD
NATIONAL
ORGANIZATION ON
DISABILITY

that many companies have incurred heavy additional costs, or have been badly mired in litigation because of the ADA. This is only true of a very small fraction of employers.

The second misconception is that Corporate America is not supportive of the ADA. The reverse is true. The overwhelming majority of senior corporate executives strongly support the ADA and do not favor weakening it in any way.

Since 1986, and a previous Harris survey of employers, the environment for the employment of people with disabilities has improved — although this change has been modest. More corporate programs geared toward the employment of people with disabilities have been put in place, and dramat-

ically more accommodations have been made by corporate employers.

These changes have resulted in some increased costs, though the costs seem to be modest. The employers feel that this effort has been worth it, and in the next three years there is likely to be an increased effort to hire people with disabilities. Whether any of this can be directly attributed to passage of the ADA has not been definitively proved by this survey. Other highlights:

The number of corporate employers with policies and programs for hiring people with disabilities has increased substantially, from 48 percent to a current 57 percent.

• One of the most dramatic findings of this survey is that the number of companies that say accommodations have been made in the workplace has almost doubled since 1986. More than eight out of ten (81%) managers now say changes have been made as compared to 51 percent in 1986.

• However, the number of companies who have hired people with disabilities has scarcely changed. The number is up only very slightly to 64 percent in 1995 from 62 percent in 1986. While this overall increase is insignificant, among the larger and medium sized companies the change has been more pronounced. On the other hand smaller companies show a decrease from 54 percent to a current 48 percent.

• Corporate managers attitudes toward the job performance of employees with disabilities are generally very positive. Very few (3% say only fair) give these employees negative marks. Furthermore, bringing more people with disabilities into the workforce is seen as being a real boost to the nation.

• The survey confirms the findings of earlier research that people with disabilities represent an untapped

potential; fully 73 percent of employers see it that way. Comparatively few numbers of employers also say that their employees would support policies to increase the number of people with disabilities.

• Three quarters (75%) of the managers say they are likely to make greater efforts to hire people with disabilities in the next three years. Almost all corporate managers say that there will be at least the same amount of opportunity for people with disabilities. No one said that these opportunities would lessen.

The picture painted by this survey not all positive towards employment people with disabilities. The most important negative result involves costs.

• Twice as many managers today compared to 1986 (27% vs. 14%) say the average cost of employing a person with a disability is greater than employing a person without a disability. However, by an 82 percent to 5 percent margin, the top managers and EEO managers also say that these costs will be worth it.

• It is important to note that the costs of accommodation seem to be fairly modest. Among those executives who could provide figures, the median figure per accommodation is \$223 per employee.

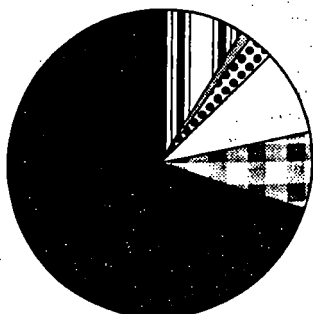
The direct impact of the ADA is difficult to gauge. However, the overwhelming majority of corporate employers are strongly supportive of the ADA. Knowledge and awareness of the law are nearly unanimous, as is support for its basic provisions. However, most managers also say that it has had no direct impact on their companies as yet.

• A large majority thinks that the ADA should not be changed. Only 12 percent think that the law should be weakened or even repealed. Eight percent say it should be strengthened.

• Those surveyed say that because of the ADA their costs to accommodate people with disabilities have increased. However, most say that the costs have increased only a little. This echoes the other results in the survey.

Generally, the corporate managers are strongly supportive of the basic ideas of the ADA even if they also say that the law has had little direct impact. Contrary to some reports in the media, there is no sign of corporate backlash against ADA. Change has occurred and seems likely to continue to do so in the future.

BUSINESS OWNERS WERE ASKED: Should the ADA Be Changed?



70% Keep As Is
8% Strengthen
9% Weaken
3% Repeal
1% Refused To Answer
9% Not Sure

Humphrey Taylor is president of Louis Harris Associates, Inc. To obtain a copy of the NOD/Harris 1995 survey of Employment of People with Disabilities, write to: National Organization on Disability, 910 16th St. NW, Washington, DC 20006.

Fallacy and Truth About the ADA

BY JUSTIN DART

All of the current attacks on the ADA pander to one basic fallacy which is seldom spoken, but deeply rooted in the attitudinal heritage of every culture.

Fallacy: People with serious disabilities are not fully human. They form a small minority whose fate is only marginally relevant to the concerns of ordinary people. The old approach: They are possessed by devils. Kill them. Banish them. Let them starve. The "enlightened" approach: They are tragic victims. Take care of them through welfare and charity. Give the presentable ones something to do, hire the handicapped. Keep the ugly and the "crazy" ones out of sight.

Truth: Science is creating a new human being. We live twice as long as we once did. Disability used to signal the end of active life. Now it is a common characteristic of a normal lifespan. Sooner or later it will occur in the lives of most people, surely in the life of every family.

Almost all new humans, including those with severe disabilities, have the potential to achieve far greater levels of productivity and prosperity than our strongest, smartest pre-science ancestors. Yet for the vast majority, with and without disabilities, that magnificent potential remains unfulfilled, because we allow obsolete attitudes to limit new abilities.

Fallacy: The ADA costs too much. It will bankrupt businesses and communities.

Truth: There have been no bankruptcies, no serious economic problems caused by the ADA. Not one. There never will be. The ADA specifically states that no public entity or business can be forced to do anything that will result in an undue financial burden. The ADA states that when necessary alternative services can be delivered to citizens with disabilities in ways that are equitable and cost effective.

Seventy percent of working age Americans with disabilities are unemployed. Millions are forced to depend on public or private welfare. President George Bush estimated that this costs our nation almost \$200 billion cash every year. Who pays? Who else? Individual tax payers, businesses, families.

Historically, every time America has extended civil rights to another oppressed minority, the entire nation has prospered. The ADA clears the way for the members

of our poorest, most welfare dependent minority to work, to pay taxes, to be customers and full, contributing participants in their communities.

Fallacy: The ADA will cause an avalanche of litigation and frivolous claims.

Truth: No avalanche. As of January 1, 1995, less than one fiftieth of one percent of the entities covered by the ADA had actually been sued under the law. Of course there have been a few frivolous claims. Every new law is tested. Every right Americans have is subject to occasional abuse.



Justin Dart

Fallacy: The ADA signals "The Death of Common Sense." It imposes rigid, irrational regulations on businesses and communities.

Truth: Written in cooperation with the business oriented Bush administration, the ADA is a model of common sense, free enterprise civil rights law. It provides regulatory guidelines, but gives business owners

and local community officials unprecedented discretion to ask and to answer the most important questions: "Can we afford this accommodation?" "Is there another way to provide equality cheaper?" "Is this the most qualified person for the job?"

Fallacy: The ADA definition of disability is "loosely written." All kinds of people are claiming to have disabilities that do not fit traditional definitions.

Truth: The traditional definitions are wrong. There are far more people with real disabilities than Americans thought - 49 million and going up. There are far more kinds of disabilities and discrimination than Americans thought. The major component of the ADA definition of disability is simple and clear: "a physical or mental impairment that substantially limits one or more major life activities." It allows courts, public officials, businesspersons and ordinary citizens to make common sense decisions based on individual reality.

The truth is that ADA does not need to be trashed — or rewritten. It needs to be implemented. The world is watching. Will we use science and free enterprise to empower the new human? Failure is unthinkable. Success will mean the culture of our dreams. ■

Justin Dart, one of the earliest proponents of the ADA, was head of the President's Committee on Employment of People with Disabilities.

Issue Forum

YEAR FIVE *of the*
ADAFEDERAL
DISABILITY POLICIES:
At Cross Purposes

BY CAROLYN L. WEAVER

Five years ago, proponents of the ADA — the most sweeping piece of legislation in history for people with disabilities — said that the legislation brought the promise of jobs as well as independence, freedom of choice, and access to "mainstream" America. Since work is the key to economic well-being in our society, whether the ADA delivers on its promise of jobs will be critical to its overall success.

While it is too soon to point to any empirical findings, there unfortunately is little reason to believe that the effect of the ADA on the employment and wages of people with disabilities will be nearly as great as envisioned. On the contrary, there is good reason to believe that the ADA will be harmful to the employment opportunities of people who are most disadvantaged in the job market. The reason is quite simple: the ADA imposes costly and uncertain obligations on employers contemplating hiring (or laying off) people with disabilities, yet does nothing to enhance the skills disabled people bring to the job market.

People with less severe disabilities, who already have jobs or who are well equipped to get them — especially those who are willing and able to press their claims before the EEOC — will no doubt benefit. But for people with severe disabilities, poor education, few work skills, and little or no work experience — those most in need of a "leg up" in the job market — the ADA runs the very real risk of undermining employment prospects.

This is not to disparage the worthy goals of the ADA. Few would deny that disabled Americans should have the same rights and opportunities as other Americans to compete in the job market. So too, few would question the occurrence of outright discrimination and the potential benefits of a civil rights measure to rectify that discrimination. But there is a hitch in applying traditional civil rights measures to people with disabilities. Unlike race, the minority classification that gave rise to the 1964 Civil Rights Act, the condition of disability itself generally (not always) limits work ability. Disabilities tend to reduce productivity on the job, limit the time that can be devoted to the job, or limit

work place, a disabled individual may be unable to perform all the job-related tasks, or even the essential tasks, of the job as well as other workers or applicants.

Congress failed to face this issue head-on, either by measures to enhance the skills or capabilities of people with disabilities, reduce the barriers to part-time or low-wage work, or subsidize employers' adjustment costs. Instead, Congress simply mandated that employers provide "reasonable accom-

modations" to "qualified individuals with disabilities." (Needless to say, armies of federal bureaucrats, labor attorneys, personnel managers, vocational experts, and a newly emerging industry of ADA consultants, along with more than a few federal judges, are busy trying to sort out the meaning of these terms.) While some disabled workers will surely benefit, there are no assurances that these benefits will exceed the social costs. And sadly, the employment opportunities of low-skilled workers with disabilities — whose employment prospects are already restricted by minimum wage laws and other mandated benefits — will be further diminished.



Carolyn L. Weaver

The early experience at the EEOC is revealing. Of the 45,000 complaints involving employment discrimination under the ADA (filed as of March 31), fully half allege wrongful discharge by people who already had jobs and were attempting to hold onto them. This compares to 11 percent alleging

in the popular press has become the stereotype of a person with a disability — someone who has, say, blindness or deafness, a mobility impairment requiring the use of a wheelchair, or mental retardation — people alleging back impairments are at the top of the list of complainants, accounting for one out of five cases filed to date. (Interestingly, of the 25,000 cases thus far resolved, one-third were found to have no reasonable cause and close to half were closed for administrative reasons.)

Ironically, as private businesses are burdened with the responsibilities attendant to carrying out a law intended to promote employment, the Social Security Administration is busy writing disability checks to ever-growing numbers of people who do not work and, in all probability, never will. In Year Five of the ADA, the number of people receiving cash benefits from SSA based on a disability stands at 10 million, up from 7 million in 1990, at an annual cost of \$64 billion. Including the costs of publicly-funded health care, the federal tab now hovers around \$100 billion.

Despite improvements in science and medicine, in technology, in rehabilitation, and in the labor market itself, people are finding their way onto the disability rolls earlier in life (generally on the basis of mental rather than physical impairments) and staying longer. For these people, the ADA amounts to an entitlement to something they will not use — at least not until the gains from work relative to non-work are altered sufficiently.

As it stands, the nation's two biggest commitments to people with disabilities — the ADA and the Social Security disability programs — operate at cross purposes. The ADA is based on the premise that people with disabilities, even severe disabilities, can, if provided the right environment, work and make lives for themselves and their families, and participate in "mainstream" America. SSA's disability programs are based on the premise that people with disabilities cannot work and need to be provided cash assistance, very likely for the rest of their lives. Surely the reality lies somewhere in between.

ENFORCING THE ADA:

Calls for Commonsense Compliance Should Precede Litigation

**BY ATTORNEY GENERAL JANET RENO
& ASSISTANT ATTORNEY GENERAL
DEVAL L. PATRICK**

The ADA is a fair and reasonable law. It strikes a careful balance between the legitimate rights of individuals with disabilities and the resources and capabilities of private businesses and government. The law's requirements for access are grounded in reasonableness and flexibility.

Common sense and fair play have guided our enforcement of the ADA since its enactment in 1990. Our primary objective has been to teach the public about the law. By using our resources to enlighten rather than simply litigate, we have encouraged voluntary compliance. Our nationwide education effort includes public service announcements, a toll-free ADA information line, materials distributed to 15,000 libraries and 6,000 local Chambers of Commerce, and grants to business and trade groups to educate their members.

We work hard to accommodate the interests of businesses, particularly small businesses. But we have been and remain committed to using all of the enforcement tools that the law provides — including civil penalties — when appropriate to achieve compliance.

We avoid unreasonable and frivolous litigation. Instead we focus on the fundamental thrust of the ADA: providing equal access to goods and services that are necessary to daily life. Each case we pursue, and each settlement we reach, makes a real difference in the lives of millions of persons with disabilities.

We have settled over 350 cases since the law went into effect. In the process barriers have been removed in schools, courts, town halls, banks, grocery stores, restaurants, retail stores, service sta-



Janet Reno

tions, and movie theaters throughout the nation.

But as we all know, compliance with the ADA is just beginning. Much remains to be done. Too many Americans do not yet recognize the attitudinal and physical barriers that block the advancement of people with disabilities. Too many see the ADA only in terms of costs, and not in terms of changed lives, expanding opportunities, and economic growth.

We should not expect the ADA to change America overnight. Decades of indifference cannot be undone in five years. We are committed to the long-term effort through vigorous enforcement and through partnerships with businesses, state and local governments, and all persons of good will who recognize that common sense and justice require us to expand opportunities for Americans with disabilities. ■

August 4, 1995

MEMORANDUM TO PATSY AND JEFF

From: Rachel Garfield

Re: August 4 news

"AIDS Council Calls on Clinton for Leadership" (Blade 8/3/95)

The Presidential Advisory Council on HIV/AIDS held its first meeting with President Clinton on July 27. The Council stressed their recommendation that executive leadership- including action on the Council's suggestions- is essential not only to help wage a battle against the disease, but also to prove that Clinton is genuinely interested in doing something about AIDS.

"Being Under the Microscope Tough for D.C. General Clinic." (Blade 8/4/95)

The HIV/AIDS clinic at D.C. General Hospital is still getting the job done, despite the fact that there is only one full-time doctor and one full-time social worker on staff. The clinic has been under public scrutiny ever since its director and specialist in infectious diseases resigned three months ago. The D.C. General clinic treats some of the poorest and sickest patients in the city.

"HIV/AIDS Media Campaign Tailored to Fit" (Blade 8/4/95)

Koba Associates, Inc. has launched a new HIV prevention model that seeks to reach out to D.C.'s African American, African, and Caribbean population. The campaign includes HIV prevention and testing brochures, Metro bus ads, and radio public service announcements and involved planning by members of the black community.

"Dr. John Stansell Talks Frankly About Efforts to 'Aid in Dying'" (Blade 8/4/95)

Dr. John Stansell, head of San Francisco General Hospital's AIDS Clinic, announced six months ago that he practiced physician-assisted suicide with some of his patients who were in the final stages of AIDS. Stansell says that he is simply "treating pain" in providing prescriptions for medication to relieve pain, knowing that the patient will use it to end his life. Though physician-assisted suicide is illegal in 49 states, a large proportion of doctors that treat patients with AIDS practice it.

"Helm's Arguments Gaining Wider Acceptance" (Blade 8/4/95)

Sen. Jesse Helms' (R-N.C.) argument that too much funding is going to battle AIDS- a disease he says is spread by "deliberate, disgusting, revolting conduct"- is gaining steam among those who feel more money should go towards combating other diseases (like heart disease, cancer, and alzheimer's). The idea that AIDS receives a disproportionate amount of funding, however, is false.

"Hill Update" (Blade 8/4/95)

- The House of Representatives passed a \$79.4 billion FY96 Veterans Affairs/ Housing and Urban Development bill with a provision to increase funding for the Housing Opportunities for People With AIDS. The amendment restored the loss of funding to HOPWA from the 23% decrease in the HUD budget that the House Committee on Appropriations approved on July 18.
- On July 21, the House Appropriations Committee unanimously approved report language offered by Rep. Nancy Pelosi (D-CA) that would grant authority to the National Institutes of Health's director to adjust the allocation of AIDS funding to the NIH's 24 institutes.
- On July 19 the House of Representatives approved an amendment proposed by Rep. Ron Packard (R-CA) which could limit the scope of the Clinton administration's federal AIDS training initiative. The amendment states the no federal funds may be used for "unconventional" federal employee training.

AIDS Council calls on Clinton for leadership

by José Zuniga

Members of the newly formed presidential Advisory Council on HIV/AIDS told President Bill Clinton and Vice President Al Gore in a July 27 White House meeting that presidential leadership is desperately needed to wage an effective battle against the AIDS epidemic.

"We were very specific about our concerns ... that there can be no real and significant campaign against this epidemic without some desperately-needed leadership from President Clinton," said Dr. Scott Hitt, a Los Angeles physician and the council's chairperson. "I'm optimistic ... but I guess in a few months from now we'll know if this panel was formed simply as a political ploy or if he is genuinely interested in doing something about AIDS."

The 23-member presidential advisory council, in town for its first meeting since it was formed five weeks ago, presented Clinton with a list of specific recommendations during the half-hour White House meeting. The advisory council recommended President Clinton:

- Hold a national summit before year's end that "encompasses the scientific, medical, social, and political aspects of the AIDS epidemic." The council said the summit, on the scale of the national economic summit held shortly after Clinton's inauguration, should consider the impact of race, culture, poverty, disability, region, gender, sexual orientation, and age, "on our ability to develop an effective national AIDS strategy."

- Address the nation, "declaring the battle against HIV a national health priority and laying out his vision for the end of this epidemic."

- Make HIV prevention programs at the U.S. Centers for Disease Control and Prevention (CDC) an "investment priority" in the White House's FY 97 budget. The council noted that, in past years, areas in which the president has placed investment priority — such as biomedical research and the Ryan White CARE Act — have received significant increases in funding. "HIV prevention efforts, such as specific population-based targeted pro-

grams, demand a similar level of commitment," advised the council.

- Continue to support the Ryan White CARE Act, the Housing Opportunities for People with AIDS (HOPWA) program, and other federal housing programs that serve people with AIDS. The council urged the president to make housing for people with AIDS an FY 97 budget priority.

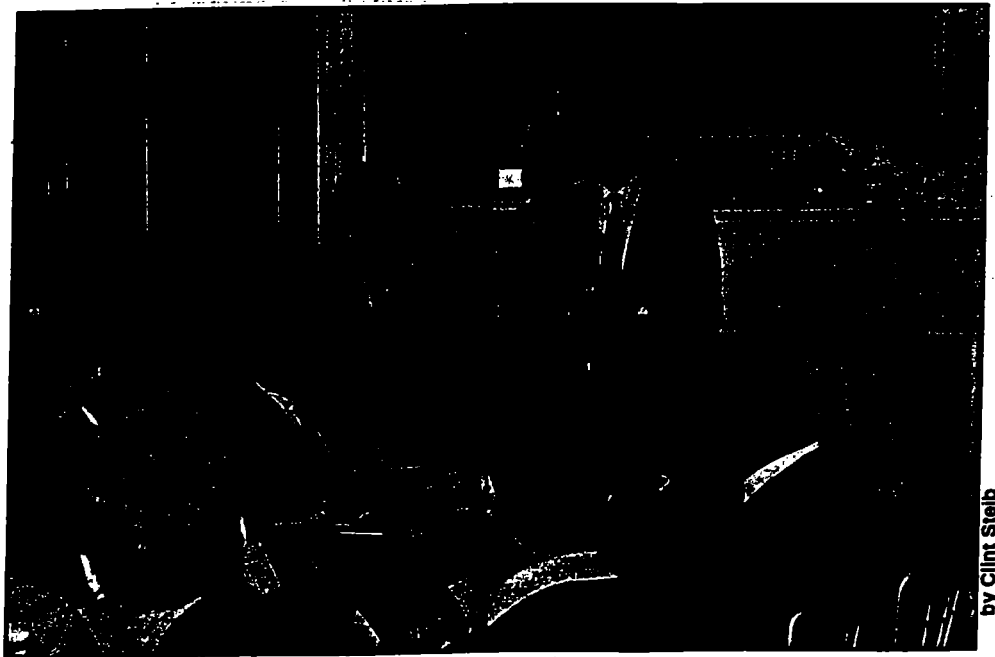
- Continue to support a coordinated federal approach to AIDS research and show support for the Office of AIDS Research (OAR). In a move AIDS activists condemned, the House of Representatives last month stripped away the OAR's responsibility to distribute AIDS research money to the National Institutes of Health's 24 institutes, and failed to earmark any research money specifically for AIDS research.

- Should "speak out against HIV-related discrimination and condemn prejudice based on race or ethnicity and sexual orientation." In an apparent response to anti-Gay comments made last week by Sen. Jesse Helms (R-N.C.) during Senate debate on the Ryan White CARE Act's reauthorization, the council urged Clinton to oppose amendments to AIDS-related legislation "that are designed to divide the American people along lines of sexual orientation, substance abuse history, race or ethnicity, or other factors."

Advisory Council member H. Alexander Robinson, an openly Gay man living with HIV, said he knows there is some belief in the AIDS community that the council is a political ploy by the Clinton administration to save face with the Gay community.

Robinson said that council member made clear to Clinton that presidential action on their recommendations is a condition for their ongoing participation on the advisory council.

"I know there is cynicism and maybe some doubt and skepticism; but be assured, we're not here to be window dressing or to supply the White House rhetoric that sounds good," said Robinson, who is co-chair of the National Organizations Responding to AIDS (NORA) coalition. ▼



President Bill Clinton addresses members of the newly formed presidential Advisory Council on HIV/AIDS.

by Clint Stelb

Being under the microscope tough for D.C. General clinic

Staff at HIV/AIDS clinic wants to 'get on with the business of patient care'

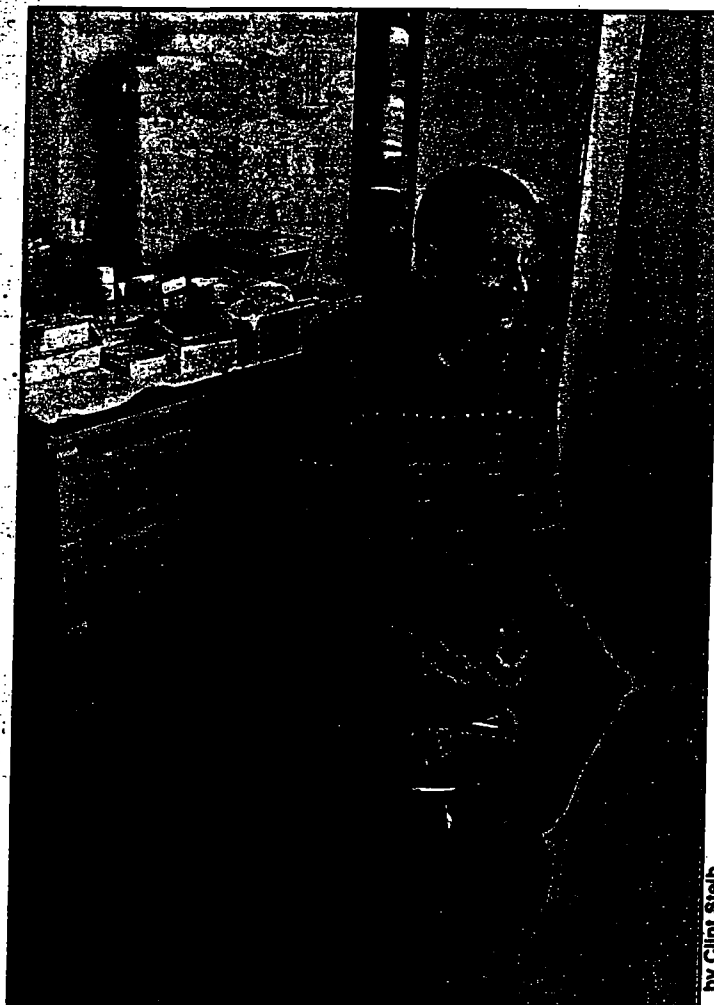
by Sue Fox

For a clinic that serves more than 800 patients with only one full-time doctor, the halls of the HIV/AIDS outpatient center of D.C. General Hospital are oddly quiet. There is no mad stampede of vexed part-time physicians scrambling through the unit, phones are not ringing off the hook, and clients do not seem to be overflowing the waiting room. In fact, hardly anyone is around.

That's because it's Friday afternoon, according to Dr. Ana Maria Espinoza, the sole full-time physician left at the AIDS center. Mondays, explained the soft-spoken doctor with a shy smile, are much livelier.

Three months after the exodus of the clinic's former director, Dr. Joseph Timponi, and another specialist in infectious diseases, Dr. Joseph Toerner, it's business as usual for the staff and patients who stayed. Patients continue to be seen by Espinoza or one of the four part-time doctors filling in until additional physicians are hired. New clients are accepted, and doctors this week said the clinic's waiting period for an appointment is generally only a couple days long. The center is still grossly understaffed, to be sure, but the unit's staff radiates the resolved serenity of those prepared to dig in for the long haul rather than the fevered disquietude of a team in crisis.

"Outside health clinics were under the impression that we were going to close, so they stopped referring patients here," Espinoza said last week. But the HIV center is now accepting same-day referrals, over-



by Clint Steib

"They treat me real good," said James Wilson, a bisexual man who has been coming to D.C. General since another clinic began charging him.

booking to squeeze in acute cases, and even taking walk-in clients from time to time.

Continued on page 10

At D.C. General c'n'c, li e under the m'croscope

Continued from page 1

"They treat me real good," said James Wilson, a bisexual man and a former intravenous drug user with AIDS who has been coming to D.C. General's clinic for two years, since another clinic began charging him for his visits. According to Espinoza, about 30 percent of her clinic's patients are Gay or bisexual men.

No one here appears to be ready to throw in the towel, having made it this far. Those who remain at the clinic are recovering from the hot glare of publicity surrounding the April resignations, a sudden exposure which "decimated the entire morale of the institution," according to Dr. Robin Newton, interim chair of the hospital's department of medicine.

"You really find out what you're made of in that environment," Newton said in an interview with the *Blade* last week. "You've got to ask yourself over and over again, 'Why are you here?'"

Instability persists

Though temporary measures have been taken to insure the viability of HIV outpatient services, instability continues its reign at D.C. General.

The lack of job security at the District's only public hospital reportedly initiated the current upheaval at the HIV/AIDS clinic. In a front page article in the May 10 *Washington Post*, departing doctors Timponi and Toerner cited a warning from D.C. General's medical director Lawrence Johnson that their jobs were in danger of being eliminated as part of a medical staff reduction. At the time, Johnson disputed the account, saying that although he could not provide the AIDS physicians with "an airtight guarantee," it was very unlikely they would be dismissed.



By Clint Steib

"Ultimately, the patients suffer," said Fred Pardo. "Every new patient that comes into the HIV center should be seen by a social worker for a psychosocial assessment, but I can't see everyone."

Three months later, the doctors have yet to be replaced with full-time physicians. The clinic's \$630,000 grant this year from the D.C. Agency for HIV/AIDS also calls for three social workers and other support staff, including nurses. Fred Pardo, the only social worker currently assigned to the unit, has been carrying the caseload single-handedly for almost six months now.

"Ultimately, the patients suffer," said Pardo. "Every new patient that comes into the HIV center should be seen by a social worker for a psychosocial assessment, but I can't see everyone."

Pardo now has an active caseload of 98 clients. That figure alone is enough to make most social workers quake, but several unique circumstances at D.C. General's AIDS clinic exacerbate the impact of the already cumbersome caseload.

The patients who show up at D.C. General's AIDS clinic are some of the poorest in the city. Sixty-seven percent are without any medical insurance, according to Newton. Only three to four percent are covered by private health plans, while the rest receive some type of government assistance.

The patients are also, according to Espinoza, some of the sickest. Sixty percent of the HIV clinic's clients have progressed to AIDS, requiring frequent visits and complex procedures such as intravenous blood transfusions and spinal taps not offered by other health clinics such as Whitman-Walker. Many clients also sorely need the services of a social worker to ad-

dress a melange of concerns that may be affecting their health care.

"Here people are homeless, they don't have food, they may be substance abusers, there are mothers with lots of children," explained Espinoza. "There are lots of social issues on top of the medical issues."

The optimal caseload for a social worker serving people with HIV is 30 to 40 clients, according to Pardo. With a full staff of three social workers, he believes they could each manage 75 cases.

"If I had 50," he added, "I would be in heaven."

The intense care required by people with late-stage HIV, particularly poor people who may lack access to strong home support systems, does not mix well with the hurried constraints of an overburdened system.

"One of the reasons the [AHA] grant is so important is that [caregivers can] take an hour if the patient needs an hour, since most patients have advanced disease," Newton said. "If you can pick up on more subtle signs, you can prevent hospitalization or more serious illness."

Newton, who sometimes fills in at the HIV center to make up for the shortfall in staff, said that many of her clients have no home support, making it impossible for her to prescribe treatments that demand in-home services. Instead, she keeps them in the hospital.

"They have to be self-sufficient. If they're not, they wind up back here, so there's no point in discharging them in the first place A lot I keep a full six weeks or more," she said.

A revolving door

James S. Brooks has been a patient at the hospital's HIV/AIDS clinic since 1991. He's had four different doctors during that time, but Brooks is generally positive about the care he has received there.

"There's only about one or two things I really don't like," he said. One is that the clinic sometimes reschedules his appointments without notifying him. Brooks said he is difficult to reach by telephone because he resides in the annex of a local church where his brother once served as pastor.

Another complaint Brooks has with the clinic is the long delay patients often en-

dure while waiting to be seen by a doctor.

"It's disturbing when you have a set time for an appointment and then you get here early and have to sit for an hour to be seen — and if you're 15 minutes late they won't see you," he said.

Brooks also dislikes having to explain his medical history over and over again each time he is assigned a new doctor. The irregularity of the clinic's full-time staff troubles employees as well.

"I have been here just under three years — longer than anyone else here," said Loretta Owens, a health technician at the clinic. "That in itself should raise a flag. Why is there such a revolving door here?"

Since Owens, a 23-year-veteran of D.C. General, has been stationed at the AIDS clinic, she has witnessed the comings and goings of at least a dozen staff members — half of them doctors.

"This clinic could do so much," Owens said. "It's really, really sad."

But then, it takes an exceptional sort of person to make it in the HIV/AIDS clinic of D.C. General, according to Newton and Espinoza. It takes someone who has a committed interest in taking care of people with HIV/AIDS, particularly indigent clients, someone who is "willing to push all other infectious disease [interests] to the back burner," someone undaunted by the hospital's tarnished reputation, who doesn't mind that the job pays a good 20 percent less than that offered by most hospitals. And it takes someone who is licensed to practice medicine in the District of Columbia and someone who plans to stay.

"Just because we are D.C. General, we have a black mark against us," asserted Newton. "If [a patient] has one negative experience here, the black mark grows ... [and] that word goes out into the community. We have to be very picky [about who is hired.]"

Newton said the clinic hopes to secure a second full-time doctor by Sept. 1. She and Espinoza have so far identified two strong candidates for the position, but the hiring procedure at the clinic stipulates that their recommendations be approved by officials at Georgetown University Hospital, one of D.C. General's two affiliate hospitals. The HIV clinic is affiliated with Georgetown's AIDS clinical trials. Things are already looking up; on July 17

a new part-time physician who plans to stay at D.C. General's HIV clinic, Milton Mills, began work on the unit. Newton and Espinoza have also started interviewing social workers with the intent of hiring two more.

The shortages of staff and other woes have spawned suggestions that D.C. General Hospital be converted into a private institution — or closed. The main concern hospital employees have about privatization is the potential loss of retirement benefits, according to Newton. "But there are some things about being hooked into the D.C. government that we could do without," she said, such as the inability of hospital staff to set salaries or hire in a timely manner.

"Yes, everything's in the process, but because of the bureaucracy at the D.C. government and the bureaucracy here, it takes months [to hire new doctors and social workers]," Pardo predicted wearily. "When I came on board [in April 1994], it took three and a half months to hire me, and that's when everyone was here, doing what they were supposed to be doing."

Forging ahead

Last month, James Wilson was hospitalized twice with pneumonia. Diagnosed with HIV in 1987, Wilson said his CD4-cell count is now under 100. These days, he visits the AIDS clinic at D.C. General at least once a month.

"I plan to be here for the whole day," said Wilson. "I'm not impatient like I got something to do I'm not picky and saying, 'Doctor didn't come in till 1 or 2.' She's doing her work She has a whole lot of patients and I know I'm not the only one, so why should I complain. She's a good doctor. She gives me what I need."

Christine McMurray learned she was HIV-antibody positive in September 1994 and has been a patient at the clinic ever since. Aside from a few minor complaints, she is very satisfied with the care she has received there.

"It's great," she said. "I'm still getting the proper care, but now I have to wait longer. But that's about it. I wouldn't know what to do if I didn't have my social worker [Pardo] in my life He's always there."

As the media continues to dissect D.C. General and politicians consider the hospital's future, Pardo, Espinoza, and the rest of the staff at the HIV/AIDS clinic try to keep focused on the task of caring for the people depending on them.

"The negative publicity frightens away patients," Newton said, noting that some clients have told her if they had known about the good treatment they would receive at the HIV center, they would not have waited so long to come.

Newton and Espinoza, glancing at each other with the knowing smiles of those who have spent many a trying hour side by side in the trenches, agree they are looking forward to the day that the spotlight of public interest recedes from D.C. General.

"We have a commitment to HIV patients," Newton said. "Hopefully, in 30 days we will have stopped putting out fires, the city will take us from under its microscope — and we can get on with the business of patient care." ▼

HIV/AIDS media campaign tailored to fit

by Sue Fox

It's a safe sex admonition that may not hit home with everyone — "Just be careful where you swing your ding-a-ling"—but that's the point. This message, along with an array of public service announcements, ads, and brochures, was designed to target a specific population that is often unreached by conventional HIV prevention models, many of which were developed within white Gay communities.

The "ding-a-ling" advice was delivered by David Ellis, the lead rapper of the Northeast Groovers, a local black "go-go" band recruited by the HIV/AIDS mass media campaign to get the prevention message out to the city's black youth. Judging from the number of African American teenagers who endured a press conference last week just to see the Groovers and hear Ellis's brief *a cappella* riff, he seems to have struck a chord.

"The community knows exactly what it wants, what message will be effective," said Claudia Thorne, an HIV/AIDS mass media campaign organizer at Koba Associates, Inc. In September, Koba secured a \$200,000 contract with the D.C. Agency for HIV/AIDS to develop media products targeting the city's African American, African, and Caribbean populations.

According to statistics provided by the Agency for HIV/AIDS, approximately eight out of ten reported AIDS cases diagnosed in 1993 among D.C. residents were African American. Black Gay and bisexual men continue to represent the largest category of cumulative AIDS cases (32 percent), and from 1989-1994, the infection rate among black men who have sex with men increased 83 percent in the past five years in the statistical area which includes D.C. and parts of Maryland, Virginia, and West Virginia.

Last week, Koba presented the results of the yearlong campaign: two colorful HIV prevention and testing brochures, three Metro bus ads proclaiming "Get the 411 on HIV/AIDS," and two

radio public service announcements. The materials, the culmination of a unique collaboration between campaign organizers and many members of the black community, will be disseminated throughout the city.

To insure input from all groups, Koba set up a community advisory committee that represented "the entire mosaic of the African American community," according to Thorne. Evidence of the people's suggestions is everywhere, from the Northeast Groovers to pictures of Eban, an African symbol of "safety, security, and love," on the campaign brochures. HIV is referred to as "one more river to cross" for African Americans. Two of the three bus ads urging people to get tested for HIV feature mothers with children, because, according to Thorne, "women will do things for their children that they wouldn't do for themselves."

Thorne said 20,000 brochures and 450 Metro bus ads will be produced and the two radio announcements will be sent to numerous stations. Other media products such as posters targeting black men and youth and a television announcement are in the works and should be out within a month, according to campaign director Dana Olds.

AHA director Mel Wilson affirmed that the contract with Koba, which expires Aug. 31, will be renewed for another year, but declined to say at what level the campaign would be funded. Koba president Ford T. Johnson told the *Blade* he had been informed that District officials were considering cutting \$95,000 from the contract. The project is funded by D.C. appropriated, not federal, funds.

Wilson confirmed that there had been "preliminary discussions" about scaling back funds for the media campaign but he emphasized that no decision had been reached. "The case is not closed on this," Wilson said. "As it stands now, there is no commitment to cut anything." ▼

Dr. John Stansell talks frankly about efforts to 'aid in dying'

by Sidney Brinkley

SAN FRANCISCO — San Francisco General Hospital's Dr. John Stansell rocked the medical establishment six months ago when he publicly acknowledged putting into practice what other doctors only talked about in private: physician-assisted suicide.

"It's a very moral thing that physicians choose to provide release from pain at the end of natural life," said Stansell, 46, who calls it "aid in dying."

Physician-assisted suicide is illegal in 49 states. Oregon voters narrowly passed a measure last year legalizing the practice in that state, but it is currently under a temporary restraining order as a judge considers if it is constitutional. The Hippocratic oath, used for centuries to guide the moral and ethical behavior of physicians, specifically forbids physician-assisted suicide.

"To please no one will I prescribe a deadly drug, nor give advice which may cause his death," the oath states. "If I keep this oath faithfully, may I enjoy my life and practice my art, respected by all men and in all times; but if I swerve from it or violate it, may the reverse be my lot."

But Stansell firmly believes to do otherwise would not be upholding what he feels is the core principle of the physician's oath, and that is to treat the patient.

"What I am talking about is not the Dr. Jack Kervorkian type of suicide," Stansell told the *Blade* in an interview conducted in his office at San Francisco General Hospital. "I am talking about treating pain, whether psychic or physical pain, with medication to relieve that pain at the same time knowing that the patient is going to use that medication to abbreviate their suffering. I have absolutely no problem with that in the case of a terminal illness, with incredible suffering. We would be less than physicians, less than adherent to our oaths as physicians, if we didn't treat that kind of pain."

In his practice, Stansell sees a great deal of pain and suffering. He is head of San Francisco General's renowned AIDS clinic, and the people to whom he provides aid in dying are his patients in the final stages of AIDS.



John Stansell: "I treat their pain, bearing in mind the treating of pain may entail some abbreviation of the life they have remaining to them but that is the trade-off."

A report on pain in AIDS published in the March 1995 issue of *BETA* magazine, said a review of pain in a hospitalized population of AIDS patients reported that abdominal pain, peripheral neuropathy (destruction of the peripheral nerves), and Kaposi's sarcoma were the three most frequent pain problems. In addition, pain can occur as a result of AIDS therapy including the use of antivirals (AZT, ddI, ddC) and chemotherapy. Opiate analgesics, such as morphine, Dilaudid, and Demerol, are among the most frequently used drugs for moderate to severe pain.

"The majority of AIDS patients were in favor of physician-assisted suicide and euthanasia as options," the report concluded. "The presence of pain was highly correlated with endorsement of physician-assisted suicide or euthanasia."

Stansell, however, says he only offers aid in dying to patients he knows very well and has treated for a very long time.

"The key in any decision revolving around end of life, abbreviating suffering, has to come from a long-term physician-patient relationship," he said. "People need to get to know one another, get to know what is appropriate, how aggressive that person wants to be when faced with the inevitable demise. That absolutely is the key."

And when the demise is inevitable and the pain unendurable, Stansell will provide a prescription for pain killing opiates or barbiturates. When mixed with alcohol, the drugs become lethal. The patient falls into a deep sleep and respiratory cardiac arrest follows.

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"I treat their pain, bearing in mind the treating of pain may entail some abbreviation of the life they have remaining to them but that is the trade-off. It is the double effect of treating pain."

Stansell is a pulmonary specialist—"I love the lungs"—and has always been interested in health care and enjoyed working in a hospital environment. Before becoming a doctor he was a registered nurse at George Washington University hospital in Washington, D.C. After working in the coronary unit he went to graduate school at GW to study physiology. He was close to finishing a Ph.D. when he had a revelation.

"I was walking down New Hampshire Avenue from where I lived on Dupont Circle, to the university and thinking about a life of poverty as a Ph.D. because there were no jobs available. Then it hit me at the corner of L Street and New Hampshire like a ton of bricks, 'Hey, maybe I could go to medical school!' I had never thought about it prior to that moment."

Stansell was 29 at the time and broke. With no money to interview anywhere else, he applied to GW's medical school and was accepted.

"I loved every minute of medical school," he said. "I was in my element from the start. I love learning, and they offered the environment that made my medicine a joy."

During his stay in Washington, Stansell met the man who would be his longtime companion, a law student and Gay activist named Clint Hockenberry.

They became interested in the Gay health care movement and formed the Gay Men's Venereal Dis-

Continued on page 19

Doctor 'aids in dying'

Continued from 14
ease Clinic in the basement of a church in Georgetown. Hockenberry served as president.

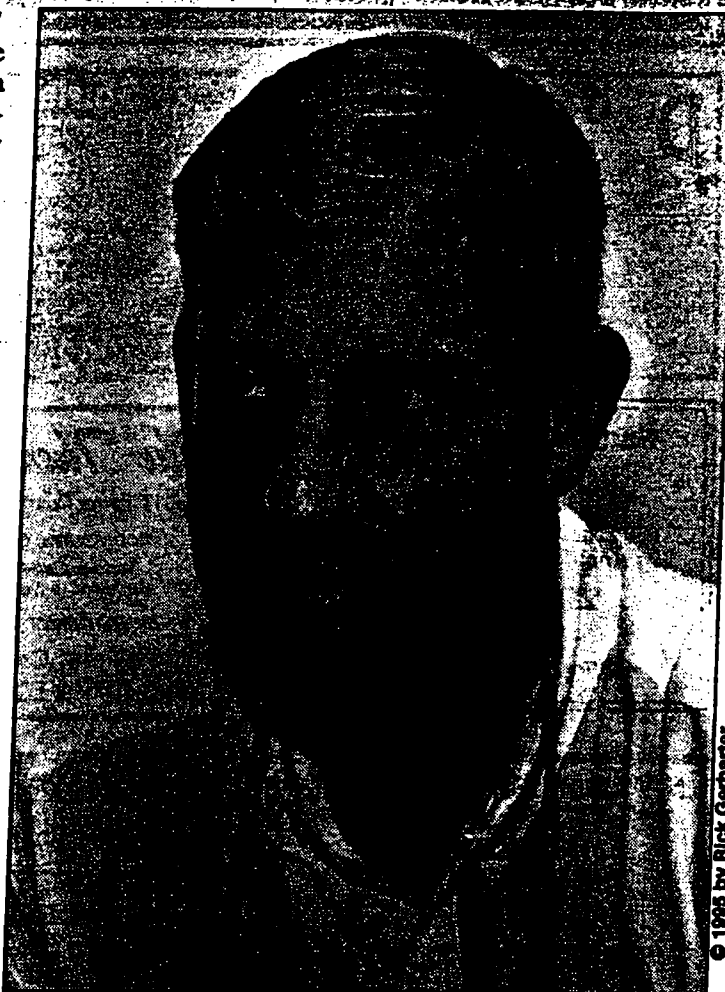
"When we were kicked out of the church basement, we formed a new clinic. The Whitman-Walker clinic was born on the floor of Clint's and mine's living room in D.C. I served as president for two years before Jim Graham came on board."

After medical school, Stansell and Hockenberry moved to California where he did his residency at Stanford University Hospital. He then moved on to the University of California at San Francisco as a pulmonary fellow, and then was offered the position as head of the AIDS clinic at San Francisco General which is a branch of UCSF. He has been in that position for three years.

Stansell has seen suffering in his personal life as well. Hockenberry died of AIDS in 1992. They had been together 17 years together and Stansell was devastated.

"I adored Clint," Stansell said. "Clint and I fell in love when we were children. We put each other through grad school. I worked to put him through law school and he worked to put me through medical school. Every marriage has its ups and downs, but I adored him."

The AIDS clinic at San Francisco General has been ranked the top facility for AIDS care in the country for the fourth year in a row according to a survey published by *U.S. News and World Report*. Stansell is one of the most prominent AIDS doctors in the country and it was inevitable that his acknowledgment of physician-assisted suicide would attract wide attention.



Dr. John Stansell: I got tremendous support from all over the country, from families, lovers, friends, and other professionals."

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Did he ever consider the consequences?

"I did consider the consequences. The only negative feedback I got was from the University of California lawyers who were worried about the liabilities of the university, and not inappropriately so, but I got tremendous support from all over the country, from families, lovers, friends, and other professionals."

According to a recent poll conducted by Dr. Donald Abrams of the San Francisco Consortium of Physicians, a group of doctors that treat primarily patients with HIV infection, over 50 percent reported giving patients medication strong enough to be lethal, knowing that the patients were going to use it in that

manner.

Despite that high figure, there have been no prosecutions in San Francisco for physician-assisted suicide. Dr. Boyd Stephens, the San Francisco medical examiner, told reporters he has never found sufficient evidence to refer such a case to the district attorney's office for possible prosecution.

Still, some physicians do have ethical issues about helping someone end their life.

"I can't say whether I'm in favor of or opposed to physician-assisted suicide," said pioneer AIDS researcher Dr. Marcus Conant.

"I have certainly come across patients who have made the decisions that they want to end their lives and I have understood why they have made that decision. However, I've seen other men who have just become depressed, withdrawn, and have inappropriately decided they wanted to end their lives. It is a very charged issue, but I don't think that we aren't capable, as a society, of dealing with something that is this important. Stansell may be telling us, from the heart, that he is anguishing over this issue and he wants to see it discussed in a public forum."

Stansell acknowledges that it is, in part, anguish — "I can't tell you the number I've watched die over the years, both patients and personal friends" — but his position is more informed by a belief that every individual has some basic human rights.

"Everyone should have some control over how they die," he said. "What could be more central to the individual than that last vestige of control. I have no difficulty at all to bringing a patient to that." ▼

He's arguing with acceptance

Sen. Jesse Helms (R-N.C.) held up reauthorization of the Ryan White CARE Act because he wants the federal government to spend less money for treatment of AIDS patients. Helms wants to cut the money because HIV is spread by "deliberate, disgusting, revolting conduct." He and others — including lobbyists for some non-AIDS health groups —

Hastings Wyman Jr.

claim that more money is spent on AIDS than on other diseases that kill more people.

It doesn't take a genius to figure out, of course, that Helms's motivation is *not* more equitable distribution of health-related funds. His anti-Gay record, along with his bigoted rhetoric, strongly suggest that the right-wing senator's goal is to withhold research, treatment, and prevention dollars so that Gays will die off more quickly — sort of passive genocide.

Helms's latest volley on this issue is nothing new. It was for such as this that Texas columnist Molly Ivins recently referred to Helms as "that poisonous old hate sow, suckling all the little hate pigs." And *The New York Times*, in its article on Helms's stand on Ryan White funding, was quick to identify the senator as a lawmaker "who has vigorously fought homosexual rights."

Recently, however, and of greater concern, more respectable sources than Senator Hate Sow have begun to express similar sentiments. Some heart disease groups, according to one AIDS lobbyist, are now taking the position that AIDS is getting more than its fair share of federal funds. "This is the first time," the AIDS lobbyist told me, "that one of the other health groups has used that argument" — a trend probably inspired by the shrinking federal pie. Presumably the heart lobby doesn't care as much about

"unnatural acts" as Sen. Helms, but it smells a good argument that might increase its own coffers. Moreover, I have heard friends who are not homophobic, but who are concerned about breast cancer or other diseases, echo the Helms argument.

While no one is likely to persuade Sen. Helms that AIDS programs should be fully funded, other concerned folks out there are more open-minded, so it's important that the facts about AIDS funding get more distribution.

First, the short answer is that AIDS is *not* disproportionately funded. Figures from the U.S. Department of Health and Human Services on treatment, research, and prevention indicate that the federal government spends \$47.1 billion for heart disease, \$19.3 billion for cancer, and \$6.6 billion for AIDS.

Second, while AIDS is slightly ahead of some in the research category, the government still spends \$2.1 billion on cancer research, compared to \$1.6 billion on HIV/AIDS research. Since AIDS is relatively new, large sums have been needed to provide basic knowledge about the disease, a research base that already exists for other diseases.

Third, unlike other major diseases, HIV is infectious and continues to spread. Between 1992 and the year 2000, deaths from heart disease are projected to decline by six percent and deaths from cancer to rise by 14 percent. But deaths from HIV infection are projected to increase 100 percent, and AIDS is a heavy killer of young people. Therefore, when you look at something health statisticians call "years of potential life lost," or YPLL, you see a different dimension to the AIDS threat. While AIDS ranks eighth among diseases in total deaths, it ranks third in YPLL. In 1992, the YPLL per 100,000 people for all cancers was 836 (105 for breast cancer and eight for

I have heard friends who are not homophobic ... echo the Helms argument.

prostate cancer); for heart disease, it was 625; for HIV infection, 386.

Fourth, it makes little sense for anyone to divide the country on the basis of risk for a particular disease. Most health problems affect the entire society to some extent. I had a heart attack three years ago; I want the government to spend money on heart research, and find a cure that involves neither diet nor exercise. At age 56, my annual physical includes checking to see if I have prostate cancer, so cancer research is important to me. While breast cancer rarely strikes males, I don't want my mother, my two sisters, or my daughter to suffer from that disease because of a lack of research. (Notably, much HIV/AIDS research, because it involves the immune system, provides knowledge that is helpful in finding cures and treatments for other diseases, especially cancer.)

Fifth, much of the motivation for claiming that too much money is spent on AIDS comes, of course, from the fact that homosexual males are the highest risk group. However, critics of AIDS funding must consider that the epidemic is no longer just wiping out queers. AIDS is now the leading killer of all

Americans between 25 and 44 — that includes women and heterosexual men, as well as those of us who engage in "deliberate, disgusting, revolting conduct."

Sixth, while Helms gets exercised by the voluntary acts that transmit HIV, he doesn't advocate cutting health funds for treatment of lung cancer, which is caused by the voluntary — and some say disgusting — act of smoking. That may have something to do with the fact that he represents North Carolina, the nation's leading tobacco-growing state. Also, when syphilis — spread mainly by heterosexual activity — was incurable and eventually fatal, federal and local governments devoted enormous resources to its prevention and treatment.

Finally, Helms and company, including his fellow travelers in other disease groups, are not riding the wave of popular support they may think. A national opinion survey taken for the Human Rights Campaign Fund by the Democratic firm of Celinda Lake and the Republican firm of Lance Tarrance, found that seven out of 10 voters believe federal funding to care for people with AIDS should be maintained or increased. More than 60 percent of Republicans likely to vote in primaries — i.e., self-identified conservatives, born-again Christians, and active churchgoers — agree that AIDS treatment funds should remain steady or be increased.

So when all is said and done, what we're hearing about AIDS funding from Senator Hate Sow is so much hogwash. And the public isn't feeding at that trough.

Hastings Wyman Jr.'s column on Gay issues in American politics appears monthly in the Blade. He has published Southern Political Report, a nonpartisan newsletter, since 1978.

Hill Update

HOUSE UPS HOPWA FUNDING:

The House of Representatives Monday night passed a \$79.4 billion FY 96 Veterans Affairs/Housing and Urban Development (HUD) appropriations bill with a provision to increase funding for the Housing Opportunities for People with AIDS (HOPWA).

The House Committee on Appropriations approved July 18 an appropriations bill for VA/HUD which slashed the overall HUD budget by 23 percent, from its FY 95 level of \$26.1 billion to \$19.1 billion. The bill also consolidated Section 202 (housing for the elderly), Section 811 (housing for people with disabilities), and HOPWA, a \$186 million program that subsidizes housing for people living with AIDS who have low incomes, into a "special needs" account. Overall "special needs" funding was reduced by 47 percent to \$1 billion.

The aggregate total spent on the three "special needs" programs had been \$1.86 billion in FY 95. But an FY 95 rescissions bill, recently signed into law by President Clinton, cut spending to \$1.2 billion.

An amendment passed July 27 provides for a \$441 million increase to the "special needs" housing account in FY 96, which increases funding for the three programs by \$2 million more than the post-rescissions FY 95 level, explained AIDS Action Council's Aimee Berenson.

"It's all very confusing ... but this amendment means more than just restoring HOPWA funding," Berenson said. "If we compare this year's \$1.44 billion funding level with the post-rescission FY 95 funding level of \$1.2 billion, HOPWA fares well."

PELOSI HELPS RESEARCH:

The House Appropriations Committee July 21 unanimously approved report language offered by Rep. Nancy Pelosi (D-Calif.) that would grant authority to the National Institutes of Health's director to adjust the allocation of AIDS funding to the NIH's 24 institutes.

Although a House subcommittee on appropriations voted July 12 to increase the NIH budget by \$642 million, or 5.7 percent, it also voted to remove from the NIH's Office of AIDS Research (OAR) the responsibility to disburse AIDS research dollars to the 24 institutes conducting AIDS research. The subcommittee also did not earmark any of the NIH's research budget specifically to AIDS research, but instead left it to each individual institute to determine its own priorities for AIDS research.

Pelosi's report language, added to the FY 96 House Labor, Health and Human Services appropriations bill, allows the "[NIH] Director transfer authority to reallocate funds among appropriations accounts" and "encourages NIH to use this authority whenever it believes that an adjustment in the allocation of AIDS funding between Institutes is appropriate to

achieve scientific objectives or to facilitate promising research efforts."

Winnie Stachelberg, senior health policy advocate for the Human Rights Campaign Fund, said that Pelosi's "[v]ery short words will make such a difference for people living with AIDS."

The FY 96 House Labor, Health and Human Services appropriations bill was still before the full appropriations committee as of *Blade* deadline.

AMENDMENT PASSES: The House of Representatives approved July 19 an amendment proposed by Rep. Ron Packard (R-Calif.) which one AIDS advocate explains could significantly limit the scope of the Clinton administration's federal AIDS training initiative.

The amendment, approved 283-138 in the course of debate on a \$23 billion FY 96 Treasury/Postal Service appropriations bill, calls for no federal funds to be used for "unconventional" federal employee training, or training which "contains elements likely to induce high levels of emotional response or psychological stress in some participants." Packard explained on the House floor that unconventional training, in his eyes, includes training on the proper use of condoms.

The flap over "HIV/AIDS in the Workplace Training" began almost four months ago when the *Washington Times* reported an increasing number of complaints from federal employees who said the training was either "too graphic" or pushed people to "accept homosexuality as a viable lifestyle." The article, according to House Subcommittee on Civil Service Chairperson Rep. John Mica (R-Fla.), spurred his subcommittee to hold hearings June 23 on federal AIDS training.

Gay civil rights advocates said the hearings were more a "lynching" than fair and objective debate.

Nancy Buermeyer, policy advocate at the Human Rights Campaign Fund (HRCF), said the Packard amendment is an extension of the ignorance surrounding AIDS prevention.

"You can't teach people about AIDS without teaching them how to prevent contracting the virus. We're obviously disappointed with the passing of Packard's amendment," Buermeyer said.

She added that "at a time when White House guards feel they need to wear gloves to greet Gay elected officials, it makes no sense to have an amendment that could put up major barriers to how AIDS training is conducted in the federal workplace."

A substitute amendment proposed by Rep. David Hobson (R-Ohio) would have allowed federal employees to "opt out" of any training they deemed objectionable, but would not have prohibited such things as training on the proper use of condoms. The substitute amendment was defeated 223-201.

— José Zuniga

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INSIDE THE WHITE HOUSE
The Night Vince Foster Died

CAPPUCCHINO VS. COWBOYS
The New War for the West

Newsweek

Bisexuality

Not Gay. Not Straight.
A New Sexual
Identity Emerges.

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WASHINGTON DC 20008-2827



TO:

FROM: HRCF COMMUNICATIONS

ATTN: JOHN PAUL GURROLA

TO: FAX PHONE#: 202-632-1096

TIME: 07/27/95 14: 11: 49

JOB NUMBER: 16883814-007-121-0052

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News from the largest national gay and lesbian political organization

NEWS

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FOR IMMEDIATE RELEASE:

Thursday, July 27, 1995

RYAN WHITE CARE ACT PASSES SENATE BY STRONG BIPARTISAN VOTE

Helms' Anti-Gay Efforts Thwarted by Kassebaum/Kennedy

WASHINGTON -- The Ryan White CARE Act Reauthorization of 1995 -- providing essential, life-sustaining medical and support services to women, men, and children living with HIV and AIDS -- passed the U.S. Senate today by a vote of 97 to 3. Sen. Jesse Helms (R-N.C.) offered several amendments designed to gut the bill and keep gay people from receiving medical care. Helms' anti-gay attack was reversed by an amendment offered by Sens. Nancy Kassebaum (R-Kan.) and Ted Kennedy (D-Mass.).

"The vote on Senator Kassebaum's amendment was a victory over Jesse Helms' efforts to gut the Ryan White CARE Act," said Elizabeth Birch, Executive Director of the Human Rights Campaign Fund. "Helms was stopped in his tracks. The Senate made a clear choice by adopting language that does not single out anybody for discrimination or exclude gay Americans from much needed medical care."

When the Ryan White CARE Act passes the House, the legislation will go before a House-Senate conference committee, which will reconcile the House and Senate versions. The conference committee will be in a strong position to deliver a bill solidly focused on providing treatment to men, women, and children living with HIV and AIDS.

A summary of amendment votes is listed below (bold indicates the position of the Human Rights Campaign Fund and the National Organizations Responding to AIDS):

1854 - Helms **PROHIBITION/HOMOSEXUAL** YES: 54 NO: 45

Prohibits funds to be used for programs that directly or indirectly "promote homosexuality," effectively denying medical care to gay people.

1858 - Kassebaum **REVERSES HELMS AMENDMENT** YES: 76 NO: 23

Prohibits programs that promote sexual activity or intravenous drug use but protects the delivery of essential medical and support services.

RYAN WHITE - PAGE TWO

1855 - Helms **FUNDING CAP** **YES: 32 NO: 67**

Freezes Ryan White spending at FY '95 levels for five years despite rapidly growing case loads and cuts spending below level already approved by House Appropriations Committee and Senate Budget Committee.

1857 - Helms **FUNDING LEVEL RESTRICTIONS** **YES: 15 NO: 84**

Fails to acknowledge the epidemic nature of AIDS and the total amount of federal spending on cancer.

1856 - Helms **FEDERAL WORKPLACE TRAINING** **YES: 99 NO: 0**

Allows Federal employees to opt out of AIDS training.

1860 - Kassebaum **FUNDING EQUITY** **PASSED VOICE VOTE**

Ensures that Congress considers all federal funds in ensuring equity in spending for cancer and AIDS.

"Jesse Helms' amendments were extreme and born of supreme ignorance. They were based on faulty and nonsensical information. The programs Helms was attacking are not in the business of promoting sexuality -- they are in the business of saving lives," Birch said.

The Ryan White CARE Act is the federal government's leading program for providing care and treatment to more than 350,000 women, men and children living with HIV and AIDS. AIDS is the leading cause of death among all Americans aged 25 to 44. A bipartisan poll of American voters commissioned by the Human Rights Campaign Fund found that 78 percent of voters support maintaining or increasing federal funding for the care of people with HIV and AIDS. The poll was cited during Senate debate on the bill. HRCF lobbyists worked closely with other HIV/AIDS advocates to gather bipartisan support for the bill and to turn back Helms' amendments.

"Today's Senate action bodes well for advancing this legislation in the House," said Daniel Zingale, Political Director of the Human Rights Campaign Fund. "The bipartisan outcome of today's vote creates momentum for its final passage in the House."

The Human Rights Campaign Fund (HRCF), the nation's largest lesbian and gay political organization, works to end discrimination, secure equal rights, and protect the health and safety of all Americans. With a national staff, and volunteers and members throughout the country, HRCF lobbies the federal government on lesbian, gay, and AIDS issues, educates the general public, participates in election campaigns, organizes volunteers and provides expertise and training at the state and local level.

Memorandum to Patsy and Jeff

From: Rachel Garfield

Date: July 27, 1995

Re: July 27 news

"Board Upholds Hill Staffer Fired Over AIDS Fear" (Washington Post 7/27/95)

The Office of Fair Employment Practices ruled Tuesday in favor of Bruce Taylor, former aide and press secretary to Barbara-Rose Collins (D-Mich.); the grievance board found that Taylor was fired in 1994 because Collins and her chief of staff thought he was HIV-positive. Taylor was seeking back pay, legal fees, and \$50,000 in damages under the Americans With Disabilities Act. Collins denied discriminating against Taylor and plans to appeal the decision.

"Top Allen Aide Pushes No-Sex Message for Teens" (Washington Post 7/27/95)

Kay Coles James, Virginia's Secretary of Health and Human Resources, has pulled \$100,000 from a federal anti-drug initiative to fund the "Best Friends" program, a statewide campaign to counsel girls to abstain from sex. The action is part of a movement by Gov. George Allen (R) to reshape Virginia's health, education, and family planning programs to promote abstinence over contraception as the way to reduce teenage pregnancies.

Board Upholds Hill Staffer Fired Over AIDS Fear

A grievance board for congressional employees has ruled in favor of a homosexual man who complained he was fired by Rep. Barbara-Rose Collins (D-Mich.) because she feared he had the AIDS virus.

Bruce Taylor, 31, a former aide and press secretary to Collins, was earning \$40,000 when he was fired Dec. 9, 1994, two days after his partner died of AIDS complications.

In a confidential decision, the Office of Fair Employment Practices ruled Tuesday that Taylor was fired because Collins and her chief of staff, Meredith Cooper, thought he was HIV positive.

"The Office of Fair Employment Practices finds that [Taylor] was terminated because he was perceived to be HIV positive or to have AIDS and would require time off for health reasons," wrote hearing officer Edward Hosken Jr.

Collins's press secretary, Lillian German, said Collins was appealing the decision.

"I am disappointed that Mrs. Collins has chosen to appeal," Taylor said yesterday. "But nevertheless, this victory is not just for me and my partner but for all caregivers throughout the country who are dealing with a loved one with a catastrophic illness."

Taylor's attorney, Martha Wolford, did not return telephone messages seeking comment.

Taylor was seeking back pay, legal fees and \$50,000 in damages under the Americans With Disabilities Act. The office ruled he should get back pay and pay up until July 31, unless he finds another job before that date, along with reimbursement for legal fees.

Collins has denied discriminating against Taylor.

Collins testified at a closed-door hearing of the fair employment office in June that she never thought Taylor was ill with AIDS or HIV positive, according to official minutes of the proceedings obtained by the Associated Press.

The Democratic congresswom-

an said Taylor was fired because the office was cutting six positions after the Republican election victory, and it was decided that a press secretary was not needed.

Taylor said Collins and chief of staff Cooper were aware his partner was dying. He said Collins had asked him if he had AIDS, and he said no.

Top Allen Aide Pushes No-Sex Message for Teens

Funds Shifted From Federal Anti-Drug Program

By Peter Baker and Amy Goldstein
Washington Post Staff Writers

Kay Coles James, Virginia's top health official, wanted to launch a statewide campaign to counsel girls to abstain from sex. Even when the General Assembly told her no last winter, James was undeterred. The secretary of health and human resources simply pulled \$100,000 from a federal anti-drug initiative and went ahead with her plans.

Diverting the money to pay for "Best Friends" was only one step that aides to Gov. George Allen (R) have taken recently to reshape Virginia's health, education and family planning programs to promote abstinence over contraception as the way to reduce teenage pregnancies.

Through federal grants, state projects and directives to local health officials, the administration is deemphasizing typical strategies it deems overly permissive in favor of a more conservative approach.

"I happen to believe that abstinence-based sex education does

work," James said. "The evidence is continuing to come in that these programs can be and in fact are successful. We certainly know that in health policy, it's in the best interest of youngsters."

The shift represents a turning point in the decades-old debate in Richmond over what to teach the state's youth about sex, and critics complain that Allen is catering to his supporters in the Christian right. Many public health officials, while agreeing that abstinence is the best way to avoid pregnancy and disease, say that most teenagers will disregard such advice and continue to need to know about birth control.

"Those people who want to shield teenagers from responsible information aren't living in the real world," said Rosann Wisman, president of Planned Parenthood of Metropolitan Washington. "We know education and information in this society is good. Everything Kay James is doing is contrary to that."

See ABSTINENCE, C5, Col. 1

Allen Aide Pushes for Abstinence

ABSTINENCE, From C1

Long before Allen named her to his Cabinet last year, James had become known nationally as a champion of conservative family values. During stints in the Bush administration and with the National Right-to-Life Committee and the Family Research Council, she consistently opposed contraceptive-based programs as unwise and unhealthy.

In an autobiography published in 1992, she derided the idea of "safe sex" by noting the failure rates of prophylactics. She even cited personal experience on this point, calling two of her children "condom kids."

The Allen administration is redefining the state's approach to family planning at a time when fewer teenagers are becoming pregnant in Virginia and nationally.

About 74 out of 1,000 Virginia teenagers ages 15 to 19 became pregnant in 1993, the most recent year for which figures are available, compared with about 90 per 1,000 in 1990. Nationally, the rate among the same age group has fallen from 254 per 1,000 sexually active teenagers in 1972 to 208 in 1991, according to a study last year by the Alan Guttmacher Institute, a nonprofit group that researches sexual activity and contraception.

Even so, teenage sex remains widespread. More than half of all girls and about three-quarters of all boys have had intercourse before age 18.

For most of the last decade, Virginia subscribed to the prevailing approach to family planning by requiring schools to teach about contraception, a move that sparked furious debate that continues to this day. Allen tried last winter to repeal the statewide requirement but was rebuffed by the legislature.

His administration has been more successful in redefining other programs. It persuaded the federal government to allow part of a family planning grant

to be used to promote abstinence, and health departments and nonprofit clinics that receive funds are being asked to provide abstinence counseling to teenagers, including those already sexually active.

Just last week, state health officials asked local directors to buy posters urging abstinence from the Family Research Council, the Washington think tank where James once worked.

In addition, the state's newly revised family planning manual notes that saying "no" is the only 100-percent reliable method of birth control. The manual, however, instructs local health departments to provide all federally approved birth control methods.

But in several state-funded projects, not all teenagers will continue to have access to contraceptives, according to guidelines written by Virginia's deputy health commissioner, a former employee of the Family Research Council. The guidelines suggest contraception may "undermine the desired goal of abstinence until marriage" and should be dispensed only when health officials can "present data about the retrenchment of sexual behavior" in a girl's life.

The Best Friends program may be what most shows James's determination, however.

The program was started eight years ago by Elayne Bennett, wife of William J. Bennett, who worked in the Bush administration along with James. James asked the General Assembly for \$150,000 to bring it to Virginia, but lawmakers took it out of Allen's budget.

James and her staff got around the roadblock by finding \$100,000 in grants under the federal drug-free school program. Although William Modzeleski, director of the federal program, said states have great flexibility to determine how they will spend the money, several key Virginia lawmakers objected when they learned of the move recently.



BY LARRY MORRIS—THE WASHINGTON POST

Key Coles James derided the idea of "safe sex" as being unreliable in a 1992 autobiography.

"To my way of thinking, taking drug-free school money and converting it to abstinence instruction is an abuse," said Del. Jay W. DeBoer (D-Petersburg), chairman of the state Joint Health Care Commission. "She clearly has an agenda that is her own . . . and she's going to pursue it in any way or any form that she has available to her."

Best Friends will serve as many as 200 middle school girls in four cities. It provides mentors and role models in an effort to teach girls to wait until marriage for sex and to stay off drugs.

"If it's a good program and can stand on its merits and it's within the principles and values of this administration," James said, "I really don't see any problem with it."



¿sirven los condones?

pueden los condones salvar vidas?

Claro que sí. A pesar de la controversia que aun persiste en cuanto a si los condones son una forma efectiva de prevenir la transmisión del Virus de Inmunodeficiencia Humana (VIH), tener fácil acceso a los condones, promocionados en forma eficaz y usándolos todo el tiempo y correctamente, juega un papel importante en el área de salud pública y en la prevención del SIDA.

La abstinencia o las relaciones sexuales entre una pareja mutuamente fiel es lo mas efectivo para prevenir la infección del VIH. Sin embargo, en una encuesta nacional de jóvenes, el 63% entre las edades de 14 a 21 años de edad reportaron haber tenido relaciones sexuales.¹ Usar condones reduce el riesgo de contraer enfermedades venéreas o Enfermedades Transmitidas Sexualmente (ETS), incluyendo el VIH en aquellas personas que no practican la abstinencia.

No hay estrategia de salud pública que pueda garantizar la protección total. Por ejemplo, la vacuna de la influenza es efectiva "sólo" de un 60 a un 80 por ciento previniendo la influenza, sin embargo miles de muertes podrían prevenirse anualmente a través de el uso mas amplio de esta vacuna "imperfecta".² La verdadera pregunta de salud pública no es si los condones son 100% efectivos, mas bien debería ser: De que forma podemos usar el condón de forma mas eficaz para ayudar a prevenir la transmisión de enfermedades?

son los condones barreras efectivas?

Si. En el laboratorio, los condones latex son efectivos bloqueando la entrada del virus del VIH ya que los poros del latex son tan pequeños que no permiten su entrada. Los condones no solo han demostrado ser una barrera efectiva contra el VIH, el virus que causa el SIDA, tambien para el Herpes, CMV, la hepatitis "B", la clamidiosis, y la gonorrea.³

Fuera del laboratorio, la efectividad del condón disminuye al introducirse el "factor humano". La razón por la cual las personas no usan el condón correctamente es porque la educación con respecto al condón no se ha hecho como es debido. La falla del condón se debe mas que a una falla en el producto, a una falla por parte de quienes lo usan. Los usuarios pueden fallar al: 1) no usar un condón en cada acto sexual 2) no ponerse un condón antes de que ocurra cualquier contacto genital o 3) no desenrollar por completo el condon al ponérselo.³ El uso del alcohol puede tambien impedir tanto el buen juicio como el uso apropiado del condón.⁴

Para una mayor eficacia del condón, lo siguiente se debe evitar: el uso de lubricantes hechos a base de aceite (vaselina, manteca, cremas) esto debilita el latex, guardar los condones en contacto muy directo con el calor o con el sol, usar condones que han estado en paquetes rotos o dañados o con muestras de ser viejos (arrugados, pegajosos o descoloridos).³

porque las personas no usan condones?

Principalmente por reacciones emocionales o malas interpretaciones. Los resultados de una encuesta telefónica a heterosexuales en 23 áreas urbanas con alta incidencia de SIDA descubrió que la desconfianza asociada con el uso del condón se ve mas acentuada entre los varones, los afro-americanos y los que tienen un bajo nivel de educación. De los que respondieron a la encuesta el 54% creyeron que los condones podían fallar durante el acto sexual, el 41% se quejó de una reducción en la sensación sexual, el 35% se sentían incómodos al comprarlos y el 21% se sentían incómodos al ponérselos.⁵

Los jóvenes que pedían ayuda al comprar condones, en una encuesta realizada en 1988 en tiendas del área de Washington, D.C., encontraron cierta resistencia y desaprobación por parte del cajero(a) un 40% del tiempo.⁶

En un estudio a los estudiantes de un colegio canadiense, los factores asociados al no uso del condón incluyeron pena o vergüenza al comprar condones, dificultad en discutir el uso del condón con la pareja, el uso de anticonceptivos orales, falta de conocimientos sobre el VIH y de las Enfermedades Transmitidas Sexualmente y la creencia de que los condones interfieren con el placer sexual.⁷ La vergüenza se puede contrarrestar con la educación, las pláticas francas acerca de la sexualidad, y un mejor mercadeo y distribución de condones.

¿quien lo dice?

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3. Centers for Disease Control and Prevention. Condoms for prevention of sexually transmitted diseases. *Morbidity and Mortality Weekly Report* 1988;37:133-137.

4. Stall R, McKusick L, Wiley J, et al. Alcohol and drug use during sexual activity and compliance with safe sex guidelines for AIDS: the AIDS Behavioral Research Project. *Health Education Quarterly* 1986;13:359-371.

5. Choi KH, Rickman R, Catania, JA. What do US heterosexual adults believe about condoms? (letter). *New England Journal of Medicine* 1994;331:406-407.

6. Center for Population Options Teen Council. Teens' survey of stores in the District of Columbia on accessibility of family planning methods. Washington, DC 1988.

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se puede promover el condón de manera mas efectiva?

Definitivamente. Las barreras que impiden un mayor uso del condón apenas se están empezando a tratar en los E.U.. Por ejemplo, en Suecia, el programa "STOP AIDS" (PARE el SIDA), envió un panfleto a cada hogar en 1986, esto seguido por una campaña masiva de televisión promoviendo el uso del condón. Las personas sexualmente activas entre las edades de 17 a 30 años de edad reportaron un incremento de un 8% a un 50% en el uso del condón al tener contacto sexual casual en 1991. Para el grupo mas joven, entre las edades de 17 a 20 años de edad, el uso del condón se incrementó de un 19% en 1987 a un 73% en 1990.⁸

Los esfuerzos del mercadeo social del condón han incrementado dramáticamente las ventas de los condones. En Zaire, por ejemplo, después de un cuidadoso estudio al consumidor se produjo "Prudence" o Prudente, un condón diseñado y valuado de manera que fuera culturalmente sensible, atractivo y económico. La venta total de "Prudence" se incrementó hasta un 443% de 1988 a 1989, y en muchas regiones de Zaire, "Prudence" ha sustituido a la palabra condón.⁹

La televisión es uno de los medios de comunicación mas populares en los E.U., sin embargo, la mayoría de los canales de televisión continúan prohibiendo la promoción del condón en horarios claves. Una encuesta a los usuarios de drogas intravenosas de Baltimore demostró que el 47% aprendieron mas acerca del SIDA a través de la televisión; el average de horas que una persona mira en una semana es de 28 horas.¹⁰ La televisión pudiera alcanzar a millones de norteamericanos con mensajes de como prevenir el SIDA.

Cada vez mas, los estudiantes tanto de primaria como de secundaria ponen a la disposición condones en las escuelas a través de programas especiales. En la encuesta "Roper" llevada a cabo en 1991 se descubrió que dos de cada tres adultos (64%) dijeron que debieran haber condones disponibles en las escuelas secundarias; el 47% estuvo a favor de que debieran haber condones en las escuelas primarias.¹¹

La forma en la que los condones se ponen a la disposición tiene un impacto enorme en cuanto a su adquisición. En una clínica para el tratamiento del abuso de drogas se dejaron condones tanto en los baños como en la sala de espera. En total, el 381% de los condones fueron tomados del baño.¹²

son los condones a prueba de fallas?

No. A como tampoco son los cinturones de seguridad, los cascos, las vacunas o las personas. Pero en el mundo real manejamos para ir al trabajo, vacunamos a nuestros hijos, y esperamos llegar al final del día sin ningún inconveniente. Ninguna estrategia para la prevención de enfermedades es perfecta, y toda estrategia, incluyendo la abstinencia, dependen de la habilidad y el conocimiento de quien la efectúa. Una amplia estrategia para la prevención del VIH utiliza muchos elementos para proteger a cuantas personas sea posible. La abstinencia y la monogamia mutua forman parte de esa estrategia, tanto como la promoción adecuada y un correcto del uso del condón.

En un estudio a 245 parejas heterosexuales donde una de las parejas estaba infectada con VIH y la otra no, ninguno entre 123 hombres o mujeres que en la pareja usaron un condón cada vez que tenían relaciones sexuales se infectó con el VIH. En contraste con 12 de las 122 hombres o mujeres que si se infectaron ya que usaron condones algunas veces o no los usaron del todo.¹³

El uso adecuado y consistente del condón puede en forma muy amplia reducir el riesgo de transmisión del VIH y de las Enfermedades Transmitidas Sexualmente. Con un millón de Norteamericanos actualmente infectados con VIH, y la mayoría de las infecciones que se transmiten sexualmente, la promoción del condón es un elemento crucial en cualquier estrategia de salud pública.

PREPARADO POR PAMELA DECARLO TRADUCCIÓN ROMY BENARD-RODRÍGUEZ

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9. Ferreros C, Mivumbi N, Kakera K, et al. Social marketing of condoms for AIDS prevention in developing countries: the Zaire experience. Presented at the VI International Conference on AIDS 1990; San Francisco, CA. Abstract SC 697.

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se obtienen resultados al prevenir el VIH?

puede la prevención hacer la diferencia?

Sin lugar a dudas la respuesta es sí. Si se espera que los programas de prevención del VIH protejan al 100% de la población de toda enfermedad el 100% del tiempo, entonces se les estaría condenando al fracaso.¹ No hay intervención con metas a lograr cambios de conducta para mejorar la salud que hasta hoy hayan alcanzado o puedan alcanzar el 100% del éxito. Las muertes ocasionadas por conductores ebrios bajó del 57% en 1982 al 45% en 1992, y esto se consideró una victoria. En 1964 el Ministro de Salud dijo al Congreso que fumar era peligroso; la advertencia en las cajetillas de cigarros no fueron mandatorias sino hasta 1984, 30 años más tarde, las campañas para dejar de fumar se consideran todo un éxito a pesar de que las enfermedades relacionadas con el uso del cigarro sean todavía la causa principal de muerte entre los Americanos.

*En San Francisco, CA la cantidad de casos nuevos por infección del VIH llegó a los 8,000 en 1982. En 1994, la cantidad estimada de casos nuevos por infección del VIH llegó a los 1,000. Los amplios programas comunitarios de prevención del VIH, que fueron dirigidos hacia hombres homosexuales y bisexuales desde comienzos hasta mediados de los 80, ciertamente contribuyeron a esta dramática reducción.*²

Una revisión a fondo a estudios que evaluaban programas de prevención del VIH, descubrió que en 20 de estos estudios se ha demostrado que los cambios de comportamiento a largo plazo ocurren a consecuencia de los programas.³ Las dudas sobre la efectividad de los programas de prevención del VIH no están basados en evidencia científica. Los siguientes son programas de prevención que al ser evaluados científicamente han probado ser efectivos.

que funciona entre los hombres gay/bisexuales?

Los pequeños grupos de apoyo. Presentaciones audio-visuales mostrando la práctica del sexo seguro en forma erótica. El entrenamiento de la habilidad para negociar el sexo seguro, entrenar o practicar la forma de reducir las tensiones, y las sesiones intensivas de grupos de apoyo han demostrado ser efectivas para obtener un cambio conductual de corto plazo. En Pittsburgh, PA, un estudio obtuvo como resultado un incremento en el uso del condón del 36% al 80%.⁴

*Intervenciones comunitarias. Educación sobre el SIDA a nivel comunitario dirigidas por miembros del mismo grupo han sido efectivas al atraer a aquellos hombres que en muy raras ocasiones participan en pequeños grupos de apoyo. En varias ciudades más o menos pequeñas, las personas más populares del ambiente social fueron entrenadas para llevar mensajes de reducción de riesgo a sus amigos y conocidos en cantinas "gay". Como resultado, menos hombres "gay" practican sexo sin protección.*⁵ Este estudio se ha repetido exitosamente en otra docena de ciudades.⁶

entre los que se inyectan drogas?

Atraer a la comunidad. En Chicago, los programas callejeros guiados por los mismos miembros del grupo cuyo propósito fue atraer grupos sociales de usuarios de drogas intravenosas (UDI) que no estuvieran en programas de tratamiento, encontró una reducción sustancial de compartir agujas de un 100% a un 14%. Un seguimiento por cuatro años de este programa encontró también un descenso en las tasas de seroconversión (esto es cuando la pareja sana se infecta con VIH), de un 5% a menos del 1%.⁷ Una campaña de prevención del VIH dirigida a un audiencia nacional a través de los medios publicitarios demostró ser efectiva al aminorar la conversión del VIH entre los Usuarios de Drogas Intravenosas (UDIs) del Norte de Italia.⁸

*Programas de intercambio de jeringas. Un reporte muy amplio preparado por los Centros de Control y Prevención reportó que diez de los programas de intercambio de jeringas, la vía más rápida para la transmisión del VIH, obtuvieron como resultado la reducción de compartirlas.*⁹

Quien lo dice?

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Financiado por fondos del



que funciona entre los adolescentes?

La educación sexual. Aunque la educación sexual para adolescentes está siempre envuelta en la controversia, los datos que predominan han demostrado que los programas escolares a una edad apropiada reducen las conductas de riesgo por un corto plazo, y pueden en la actualidad disminuir la actividad sexual entre adolescentes. Un programa experimental de educación sexual ayudó a estudiantes que se abstendían, a mantener la abstinencia por un año y medio. Entre aquellos que se volvieron sexualmente activos, se obtuvo un mayor uso de anticonceptivos, a consecuencia del programa.¹⁰

Pequeños grupos de apoyo y el entrenamiento de las habilidades. Para adolescentes a los cuales es difícil llegar y con alto riesgo de obtener el VIH, la educación repetitiva e intensiva, el entrenamiento de las habilidades y las sesiones de grupos de apoyo son efectivas. En Nueva York los jóvenes que han huído de sus casas y viven en casas de refugio que han recibido 15 sesiones o más, reportaron un aumento en el uso del condón del 33% al 63%, y una reducción en la conducta de alto riesgo del 20% a zero. A medida que las sesiones de intervención se incrementaban, el uso consistente del condón incrementó significativamente y envolverse en conductas de alto riesgo disminuyó significativamente.¹¹

entre los heterosexuales adultos?

Pequeños grupos de apoyo. Los pacientes de una clínica de salud de una área urbana que recibieron educación sobre el SIDA, entrenamiento de habilidades y grupos de apoyo reportaron un incremento en el uso del condón del 40%.¹²

Grupos de apoyo a parejas. Estudios entre parejas discordantes (esto es cuando uno de los dos está infectado con el VIH y el otro no) han demostrado que cuando a la pareja se le aconseja al mismo tiempo acerca de tomar precauciones para tener prácticas de sexo mas seguras, el uso del condón se incrementa, y la seroconversion del VIH (esto es cuando la pareja sana se infecta) se reduce. En un estudio, ninguna pareja de las que usaron condones se seroconvirtió.¹³ En otro estudio a parejas discordantes que recibían consejería antes y después de hacerse la prueba del VIH repetidamente mostró un incremento en el uso del condón de un 3% a un 57%.¹⁴

que tipo de programas funcionan mejor?

Las características de los programas exitosos son siempre las mismas.

- Intervenciones intensivas y perdurables son las que mas ayudan a mantener un cambio de conducta a largo plazo.
- Mejorar el acceso de los recursos necesarios para la práctica del sexo seguro.
- La creación de habilidades y la modificación de las normas comunales son elementos necesarios.
- Los mensajes de prevención del VIH al momento oportuno son importantes, a como se ha demostrado en programas de adolescentes, en donde haber proporcionado educación explícita sobre la prevención antes de que llegue el momento en que se vuelven sexualmente activos puede tener un mejor impacto que la educación proporcionada una vez iniciadas las actividades sexuales.
- Los programas que tratan con parejas discordantes (esto es cuando uno de los dos está infectado con el VIH y el otro(a) no) son especialmente efectivos entre los grupos donde predomina un alto nivel de infección con VIH.

Una estrategia completa de prevención del VIH utiliza muchos elementos para proteger al mayor número de personas a riesgo de contraer el VIH posible. Nosotros deberíamos de aprender y promover los programas efectivos de prevención del VIH que se están llevando a cabo, al mismo tiempo que se debe continuar la evaluación de los mismos. El standard para poder medir el éxito en la prevención del VIH deberá ser estudiado; un 100% de efectividad no se puede lograr. Finalmente, fundar programas de prevención e investigación en las ciencias de la prevención tienen que ir de la mano con la efectividad y la importancia en la salud pública. Ahora que ya sabemos que la prevención del VIH funciona, necesitamos ponerlo en práctica.

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July 28, 1995

MEMORANDUM TO PATSY AND JEFF

From: Rachel Garfield

Re: July 28 news

"Senate Votes to Continue AIDS Program" (Washington Post 7/28/95)
On July 27, the Senate voted to extend the Ryan White CARE Act, a \$633 million program that provides care and treatment to over 350,000 men, women, and children with AIDS and HIV. The Act passed despite several attempts by Sen. Jesse Helms (R-N.C.) to block the funding; Helms claimed that AIDS programs were an attempt to "restructure the values of American families in favor of the homosexual lifestyle."

Senate Votes To Continue AIDS Program

Helms Fails in Bid To Freeze Funding

By Helen Dewar

Washington Post Staff Writer

The Senate yesterday overwhelmingly approved legislation to extend the government's AIDS treatment program after blunting or finessing attempts by Sen. Jesse Helms (R-N.C.) to gut the program.

During two days of debate on the Ryan White CARE Act—a \$633-million program named for a young Indiana hemophiliac who died in 1990 after contracting AIDS from a blood transfusion—Helms repeatedly criticized homosexuals, as he often has done in the past, describing their conduct as “incredibly offensive and revolting.” He referred to AIDS prevention programs in schools and federal offices as “thinly veiled attempts to restructure values of American families in favor of the homosexual lifestyle.”

He also blamed gays for White's death, saying the teenager died of “blood that was tainted in the first place by homosexual conduct somewhere generations back.”

Few joined Helms in criticism of homosexuals. Conservative Sen. Orrin G. Hatch (R-Utah) praised the legislation as an opportunity to help people who are dying, without regard to “how those people got [the disease].” And the Senate reauthorized the measure by a vote of 97 to 3, with only Republican conservatives Helms, Robert C. Smith (N.H.) and Jon Kyl (Ariz.) in opposition.

“This legislation represents a compromise, and like most compromises, it is not perfect and will not please everyone,” said Sen. Edward M. Kennedy (D-Mass.), co-sponsor of the bill. “But on balance, it is a good bill, and its enactment will benefit all people living with HIV everywhere in the nation.” HIV is the virus that causes AIDS.

Helms did win some minor victories, however, including unanimous approval of a provision making attendance optional at workplace AIDS prevention programs that President Clinton has ordered for government offices.

Washington Post 28 July 1995

But he failed, 32 to 67, in an attempt to freeze spending levels for the Ryan White program through 2000. As approved, the bill puts no limits on spending for the program, allowing funding levels to be set in annual appropriations bills during the next five years. The House Appropriations Committee recently approved the spending of \$658 million for the fiscal year starting Oct. 1. The administration had requested \$723 million.

The Senate also approved, 54 to 45, a proposal by Helms to bar use of any funds in the legislation to promote or encourage homosexuality or intravenous drug use, directly or indirectly. The bill's supporters feared this could complicate delivery of care by gay-oriented programs.

But later, in what Helms criticized as an attempt to neutralize this provision, the Senate approved by a larger margin—76 to 23—a proposal by Sen. Nancy Landon Kassebaum (R-Kan.) to bar spending for activities that directly promote drug use or any sexual activity, heterosexual or homosexual.

“There is a great big odor rising from the manner in which Congress is falling all over itself to do what the homosexual lobby is almost hysterically demanding what Congress do,” Helms said during debate.

In the case of conflicting provisions, those adopted by the largest vote margin—and those that appear to be the final word on an issue—are given greater weight during House-Senate conferences to draft the final version of a bill.

A bid by Helms to limit federal spending for AIDS from exceeding amounts that Congress appropriates for cancer was rejected, 15 to 84. Helms had argued that cancer kills 18 times as many Americans as AIDS and therefore should receive more money. Kassebaum contended that it does, when money spent through mandatory programs such as Medicare and Medicaid is taken into account.

In action Wednesday, the Senate agreed to a compromise to encourage but not require more HIV testing of pregnant women and infants. By voice vote, it approved a provision to require the 11 states with the highest incidence of HIV infection in newborns to implement a program for encouraging testing of pregnant women.

The Ryan White bill, first passed in 1990, the year White died, currently provides care and treatment to more than 350,000 men, women and children with AIDS and HIV. It supports clinics in every state, 42 cities and many rural areas, paying for outpatient medical care for uninsured poor people infected with the virus.

The law expires at the end of September unless Congress reauthorizes it. The House is scheduled to consider its version of the legislation in September, shortly before spending bills for the next fiscal year are approved.

July 31, 1995

MEMORANDUM TO PATSY AND JEFF

From: Vanessa Potkin, Rachel Garfield, Rachael Smith

Re: News for 7/31

"New AIDS Treatment Lift Hopes" (Washington Post 7/31)

A recent proliferation of drugs to battle HIV infection is giving researchers new hope in the ability of combinations of drugs to treat AIDS. New treatments both increase CD4 counts and battle the virus directly. Though hopeful about the prospects of the drugs, researchers are still unsure how to fit these treatments into the "big picture" of AIDS treatment.

"AIDS Testing and Treatment in Pregnancies" (Washington Post 7/30)

This editorial is in response to the Post's July 11 editorial on AIDS testing for pregnant women. Philip R. Lee, assistant Secretary for Health, supports combined testing and treatment--not testing alone--as a method of reducing the risk of mother to child HIV transmission.

"AIDS Patients Paying A Price for Longevity" (Washington Post 7/30)

While people with AIDS are living longer due to different treatments, more people are now dying of the disease. Public health experts estimate 1 million HIV positive Americans do not know that they are infected.

AIDS Testing and Treatment in Pregnancies

The Post's July 11 editorial "AIDS Tests for All Pregnant Women" correctly notes that the Public Health Service has urged physicians to routinely counsel all pregnant women about the benefits of HIV testing early in pregnancy. But it includes several potentially confusing statements, one of which might suggest that giving children AZT after birth may prevent HIV infection.

After HIV counseling and testing early in pregnancy, women who are HIV-positive can then make informed decisions about taking AZT during pregnancy, labor and childbirth, and about giving it to their infants for six weeks after birth. Combined, testing and treatment—but not testing alone—can reduce the risk of mother-to-child HIV transmission by as much as 67 percent. This approach has been embraced by medical and public health professionals, including the American Academy of Pediatrics, the American College of Obstetricians and Gynecologists and the Pediatric AIDS Foundation.

This comprehensive "continuum of care" approach is already at work in several of our major cities. In fact, in Atlanta, at Grady Memorial Hospital, 95 percent of women who are HIV-positive choose to take AZT after discussing the risks and benefits with their health care providers. Similar results have been shown in places like Miami, Los Angeles, Chicago and New York City.

Women clearly want to do the best thing for themselves and their babies. The right information at the right time enables them to do so. The key to any successful effort to prevent maternal-child HIV transmission is making sure women have access to prenatal care and support services. But a significant num-

ber of women do not receive adequate prenatal care. That is why we need programs to ensure that women have access to testing and treatment prenatally or at delivery. Unfortunately, testing after delivery won't prevent the vast majority of HIV transmissions to babies.

Focusing primarily on newborns rather than on ensuring that pregnant women are in prenatal care—when there is still the opportunity to prevent HIV infection—is directing our efforts where they can't and won't do the most good. But in combination, these steps will provide the greatest level of protection for women and infants.

PHILIP R. LEE

Assistant Secretary for Health
Department of Health and Human Services
Washington

AIDS Patients Paying A Price for Longevity

*As Treatments Help Prolong Life,
They Also Protract the Challenges*

First of two articles

By Don Colburn
Washington Post Staff Writer

Fifteen years into the AIDS era, people infected with the virus are living years longer than the epidemic's early victims. But the price of those added years is often a tenuous existence marred by bouts of illness, drug side effects, financial worries and all the other realities of living with a fatal, chronic disease.

Early hopes for rapid discovery of a medical cure have largely faded. Although many promising experiments are underway in laboratories and drug trials, their outcomes are uncertain. Meanwhile, the nation must face a more mundane and sometimes overwhelming task: taking care of legions of patients who are growing old before their time.

"AIDS is a lot like geriatrics," said Hank Carde, 48, who was diagnosed with AIDS in June 1990. "You've got to embrace life."

Every day, the retired naval officer takes eight or nine different medicines. When he feels well enough, he goes out to do volunteer work for AIDS-related organizations, fighting fatigue and side effects of his medicines, such as headaches and nausea. Several times a week, he commutes to the National Institutes of Health to receive chemotherapy for an AIDS-related cancer.

Living with AIDS, he said, is "like living in a house with all the doors and windows open" in a high-crime area. "Theoretically you could live forever—or an opportunistic infection could come in the door and kill you tomorrow."

For people with the illness, and for the doctors who care for them, AIDS presents an energy-draining se-

See AIDS, A27, Col. 1

AIDS, From A1

quence of challenges—medical, social and emotional—that crop up relentlessly over the months and years.

"Patients are living longer—and having far more problems than they did in the past," said Donald M. Potts, an infectious disease specialist at Fairfax Hospital.

"In 1985, people went into the hospital and died five days later without a diagnosis of [AIDS-related pneumonia] even being made until the autopsy was done," said Peter Hawley, medical director of Whitman-Walker Clinic, the largest provider of AIDS services in the district. "That almost never happens today."

But despite the bewildering complexity of the disease caused by the human immunodeficiency virus (HIV), many researchers say they feel more optimistic than they did a few years ago. Experts compare the state of AIDS treatment now to the opening skirmishes of the war on cancer in the late 1960s, a time when doctors were first learning how to combine chemotherapy drugs to achieve better survival. They are hopeful that combinations of drugs that work against the virus will be found to boost life expectancy and at the same time improve quality of life.

"I think we're approaching a time when HIV is going to look much more like a long-term, chronic, manageable disease than it does now," said Jack Killen, head of the AIDS division at the National Institute of Allergy and Infectious Diseases.

A symbol of the epidemic's early years was actor Rock Hudson, who in 1985 shocked the world by disclosing he had AIDS—and died two months later. One of the most prominent symbols of the second decade of AIDS is basketball star Earvin "Magic" Johnson, who announced he had HIV, the virus that causes AIDS, in November 1991. Three months later Johnson was named the most valuable player in the NBA All-Star Game, and the following summer he led the U.S. "Dream Team" to a gold medal in the Barcelona Olympics.

The median time between infection with HIV and diagnosis with actual disease is about 10 years. That means half of all HIV-positive people come down with AIDS in less time than that; half take longer. The median time between an AIDS diagnosis and death is about two years.

Thus, a person can expect to live 12 years or more after becoming infected with the virus—about twice the life expectancy of an HIV-infected person in 1985.

But despite this improvement in life expectancy, more people are dying of the disease. AIDS has become the leading cause of death for Americans in the prime of life, ages 25 to 44. Researchers attribute most of the increase in life expectancy to the availability of treatments for AIDS-related infections, not to medicines that fight the virus itself. While various drugs appear to be active against HIV, no one has yet proven conclusively that any of these antiviral drugs extends life and health. Nor has research defined the best way to combine such drugs or determined at what stage of illness they should be administered to maximize the potential benefit.

There is also a growing "knowledge gap" between HIV-positive people who closely follow AIDS research and have access to doctors with the latest findings, and those who don't. The former are often white men, and the latter are often blacks, Hispanics or poor women, who make up a growing proportion of AIDS cases.

"There is still a stigma," said Alberto Avendaño, medical director for the National Association of People With AIDS in Washington. Among gay, white, middle-class Americans, it's nothing to be ashamed of. In African American and Latino communities, if you die from AIDS, your family still tries to say, "He died of lung cancer."

years without realizing it, potentially spreading the virus and perhaps missing the chance to take antiviral drugs at a point in the disease when they might have a better chance of prolonging survival. Public health authorities believe that more than half of the estimated 1 million HIV-positive Americans do not yet know they are infected.

The increased longevity is for some patients a mixed blessing: People with AIDS need more care and help than ever before. Patients who 10 years ago would have died within a few months of AIDS-related pneumonia are surviving longer but suffering more disabling complications, including dementia, cancer, depression and intractable vomiting or diarrhea. More patients are going blind from retinitis or wasting away from an inability to digest food.

The complications are economic as well as medical. The direct medical costs of treating HIV infection and AIDS were \$6.6 billion in 1994, according to the Public Health Service's Agency for Health Care Policy and Research. The estimated lifetime cost of treating an HIV-positive person from infection until death is \$119,000, according to a 1993 study by agency economist Fred J. Hellinger.

The National Commission on AIDS reported in 1991 that 29 percent of AIDS patients were covered by private health insurance, 40 percent by Medicaid, 2 percent by Medicare, and 29 percent had no health insurance. Even insured patients have huge out-of-pocket expenses at a time when they often cannot work.

AIDS care has become at least as much a matter of social work as medical treatment, said Joan Lewis, vice president of the D.C. Hospital Association. "We're seeing people who live a long time with a chronic disease, needing social services in many ways akin to the conditions of old age."

Internal Tug of War

HIV gradually disables the body's immune system by targeting CD4 T cells, the white blood cells that orchestrate the body's response to infections.

The CD4 cell count—the number of cells per microliter of blood—has become a standard measure of an HIV-infected person's stage of infection. A healthy person has a CD4 cell count in the 1,000 range. The count in an HIV-infected person typically falls by 60 to 100 T cells a year, but an individ-

FOR MORE INFORMATION

Treatments for HIV and AIDS

■ **General information and referrals:** Call 1-800-342-AIDS, a U.S. government hot line staffed 24 hours. For Spanish speakers, call 1-800-344-7432 from 8 a.m. to 2 a.m. For the deaf, use a TDD to call 1-800-243-7889.

■ **Clinical trials:** 1-800-TRIALS-A is a government hot line that can provide detailed information on ongoing research studies. Open Monday to Friday, 9 a.m. to 7 p.m. For the deaf, use a TDD to call 800-243-7012. International callers use 301-217-0023.

■ **Directory:** The National AIDS Clearinghouse can answer questions about prevention and research. It can send various publications, including one free copy of a written directory of HIV and AIDS treatment options published by the American Foundation for AIDS Research. Call 1-800-458-5231, English or Spanish.

■ **Treatment information:** The Carl Vogel Center in Washington distributes information on conventional treatments, nutrition and some alternative treatments, and sponsors workshops. Call 202-638-0700, Tuesday through Saturday from noon to 6 p.m., Wednesday till 9 p.m. The Whitman-Walker Clinic in Washington, 204-797-3500, provides an extensive array of AIDS-related services, hours are 9 to 6 Monday through Friday. AIDS Action Baltimore, 410-617-2437, publishes a treatment bulletin. Project Inform of San Francisco, 1-800-822-7422, will send a packet of treatment information.

THE WASHINGTON POST

ual may not develop serious symptoms of AIDS until the count drops below 200. A person with a CD4 cell count below 50 is in the advanced stage of AIDS.

Drugs may slow the progression to AIDS, but none have been shown to stop it. Eventually, AIDS leaves its victims defenseless against infections that a healthy immune system would fight off.

"What's happening is, we're not seeing any breakthroughs," said infectious disease specialist Poretz. "There's no polio vaccine coming out that's going to handle this disease. It's an incremental process of many little steps that allow us to treat AIDS as a chronic illness, with lots of medicines."

Some of Poretz's patients are taking 10 or 15 different medicines in a constant tug-of-war with their disease.

"AIDS is the only disease I've ever treated where you don't replace one medication with another," he said. "You add. And you add and you add and you add. You keep trying anything to suppress the disease."

Hank Carde said his CD4 cell count these days is around 10: "They each have names, that's how few there are," he jokes. He considers the nearly 20 pills that he takes each day a relatively manageable number; a few years ago, he took as many as 40.

"All are toxic," Carde said.

"That's part of having AIDS: You take your pills and live with the nausea, the headaches, the diarrhea. It's the cost of keeping going."

Four drugs active against the virus have been approved by the Food and Drug Administration: AZT, ddI, ddC and d4t. All have shortcomings, including potentially severe side effects, and none can be taken for long. Used in combination, they seem to help some patients, although exactly how to prescribe them—or even when to start treatment—remains a medical judgment call. When the approved drugs stop working, many patients face the dilemma of whether to enroll in studies to test experimental drugs—and of which study to enroll in.

Most AIDS experts agree that the increasing longevity of AIDS patients is due less to AZT and other anti-HIV drugs than to better treatment of the opportunistic infections that prey on their stricken immune systems. In the early days of the epidemic, most AIDS patients died of a pneumonia called *Pneumocystis carinii* pneumonia, or PCP. Today, several drugs are available to help prevent or control PCP. It is one of the biggest success stories of AIDS treatment.

In all, the FDA has approved 15 drugs for treatment of AIDS-related illnesses. Those include such

medications as ganciclovir and foscarnet to help prevent the blindness caused by a viral infection that afflicts AIDS patients; rifabutin to treat a common bacterial infection that produces chronic diarrhea, and fluconazole to treat fungal meningitis and thrush.

Experts also agree that some of the apparent increase in longevity is a mirage. With the advent of a test for HIV in 1985, people could find out about their infection long before symptoms appeared. Some of the apparent lengthening of survival after diagnosis with HIV infection may result simply from that earlier start of the prognostic time clock.

And while some of the increase is clearly real, people with the disease remain vulnerable to opportunistic infections, as well as to AIDS-related cancers. Any patient in the late stages of AIDS is at risk from even common bacterial infections.

"Instead of dying of massive opportunistic infections like PCP, they're dying bit by bit," said Richard A. DiGioia, a District internist with a large AIDS practice.

The Treatment Puzzle

Until scientists discover drugs that control the AIDS virus by keeping it from reproducing at each stage of its progression, "ultimately we lose," DiGioia said. "Yes, people are living longer, but if we're talking about doing, for example, what insulin did for diabetes, we're not anywhere close yet."

Many researchers are more optimistic, and dozens of labs around the world are pursuing different experimental strategies for defeating the virus. But scientific success is not the only critical factor; price is also important. Many in the AIDS community are wondering what will happen if a drug is devised that is enormously effective but enormously expensive, because cost of care is already a sensitive issue nationwide.

Painfully hard decisions arise about how intensively to treat a terminally ill patient when treatment is costly and its effectiveness uncertain.

For some patients who are wasting away because they can no longer digest or keep down regular food, the only alternative is a form of intravenous feeding called total parenteral nutrition, or TPN. But TPN is not always effective and is meant to be used only as a brief emergency stopgap. Its costs can run as high as \$30,000 a month.

Poretz said he and his colleagues

try not to use TPN except as a resort. A few years ago, he said, he would have ruled it out altogether for AIDS patients. "But when you have a young guy who wants to get back to work and has lost 40 pounds and is wasting away," he says, "Do something for me. You know TPN might help him." The question is: How much do you do for an individual who has a fatal disease? Is it reasonable to do this for a week? Two weeks? A month? Six months? A year? Those are philosophical questions I have no good answer for."

Despite the public perception of rapid death in AIDS patients, most people with AIDS "die a long, lingering death, usually related to malnutrition as much as anything else at the end," Whitman-Walker Hawley said. "There comes a point when, between you and the patient, you decide it's pointless to go on. The patient says, 'I don't want any more treatment.' It may be a period of weeks or months of going downhill."

AIDS patients used to be admitted to the hospital as soon as they were diagnosed. Often they were diagnosed in the late stages of the disease, when they already were very sick.

That pattern has changed dramatically, said Sandra Butcher, director of social work and nursing management at George Washington University Medical Center. "Patients are hospitalized for the complications, not for the disease itself, which is primarily treated on a chronic outpatient condition."

GW hospital no longer holds regular inpatient support groups for AIDS patients, Butcher said, "because most patients are taken care of on an outpatient basis, and the ones who are hospitalized are usually too sick to attend."

Keeping a Home

As in every aspect of medicine, there is growing pressure from insurance plans to keep patients out of the hospital and care for them in less intensive and less expensive settings. That may make fiscal sense, but doctors and social workers say it can also make care difficult for patients with as many complications as AIDS patients face.

People who take care of AIDS patients are increasingly concerned with the challenge of providing them what Butcher calls "the ordinary necessities of life," such as housing, housekeeping, cooking, laundry, transportation. It's less exciting than the quest for a vaccine, Butcher said, but no less vital to a person with a fatal, debilitating chronic illness such as AIDS.

About half of people diagnosed with AIDS have to move within a year, because they can no longer afford their homes or care for themselves, or both. Yet for people with AIDS, nursing home care "remains one of the least accessible options," according to the five-year comprehensive plan compiled in 1992 by the District's Agency for HIV/AIDS. Only six AIDS patients were admitted to a District nursing home between 1986 and 1989, and none in the following three years, the plan reported. The Whitman-Walker Clinic has referred only one person with AIDS to a D.C. nursing home in the past 18 months, clinic officials said. Placement in nursing homes outside the District has increased but remains difficult for very sick AIDS patients, they said.

One factor is the low level of Medicaid reimbursement. AIDS patients require more staff time and expensive care than most other patients in nursing homes. The cost of their care typically runs between \$250 and \$500 per day. In the District, Medicaid reimburses nursing homes between \$80 and \$190 per day, with no special rate for care of AIDS patients.

Another deterrent is that every District nursing home has a waiting list for patients who lack insurance.

"It's a waiting game," said Pauline Bourgeois, former director of AIDS services for the Whitman-Walker Clinic. "And with AIDS you can't wait."

Staff writer Kristin Ellis contributed to this report.

Tomorrow: Experimental drugs

THE CHANGING FACE OF AIDS

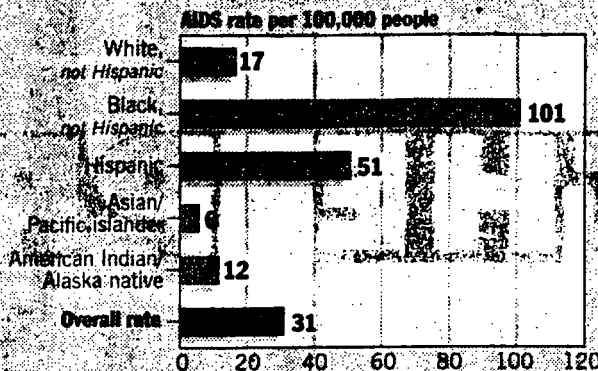
WHO IS AT RISK

Among adults, men who have sex with men still represent the largest group of AIDS cases, but they no longer account for a majority.

Proportion of all cases	1985	1994
Men who have sex with men	73%	44%
People who inject drugs	17	27
Men who have sex with men and inject drugs	5	5
Heterosexual contact	1	10
Recipients of blood transfusions, blood products or tissues	3	2
Risk not identified	6	12

MINORITY GROUPS ARE HIT HARD

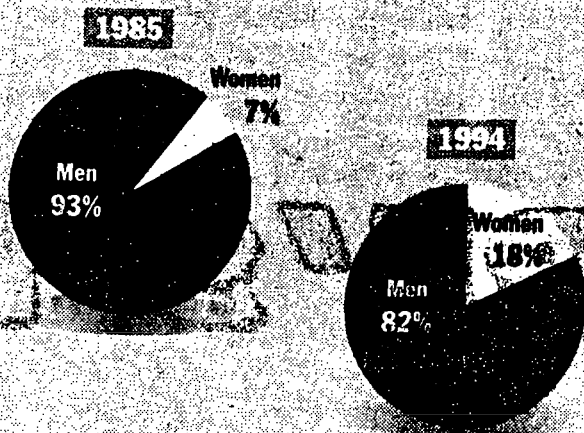
Overall, blacks and Hispanics are at greater risk of contracting AIDS in a given year than whites. This breakdown shows the number of new adult cases reported in 1994 per 100,000 people in each ethnic group.



SOURCE: Washington Post analysis of data from the U.S. Centers for Disease Control and Prevention

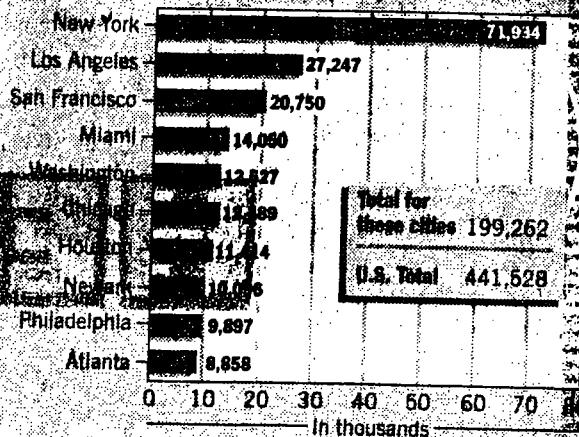
PROPORTION OF WOMEN INCREASING

Most adult AIDS cases are among men, but the proportion of cases among women has been growing.



WORST-HIT CITIES

Nearly half of all AIDS cases in the country have occurred in 10 metropolitan areas. Here are cumulative totals from the beginning of the epidemic to the end of 1994.



New AIDS Treatments Lift Hopes

Scientists on Way to Making Disease More Manageable

Second of two articles

By Justin Gillis

Washington Post Staff Writer

As people with HIV infection battle the slow but relentless progress of the illness, their eyes are trained on the nation's research laboratories. Top scientists in those labs have developed new, experimental treatments that they say are showing remarkable short-term effects.

The researchers caution against making too much of the latest findings. They acknowledge that much more needs to be learned about how well the new treatments really work, how best to use them and how long the improvements in the immune system will last.

Still, the gloom that has pervaded AIDS re-

search for more than a decade has begun to lift a bit. Progress is coming on several fronts. Although no one talks of a cure, some scientists in the lab and doctors treating the disease believe they may be drawing closer to a secondary goal.

They hope to slow the damage to the immune system enough to turn infection with the AIDS virus into a serious but manageable ailment. If it works—a big if—people might be able to live with the virus for a long time in relatively good health.

"I think we're about halfway there. And the road is set much more clearly," said Mathilde Krim, chairman of the American Foundation for AIDS Research. "This will be a disease that will never be cured in the sense of eliminating the

See AIDS, A8, Col. 1

Hope Lifts as Labs Develop Drugs to Make AIDS More Manageable

AIDS, From A1

virus from the body, but it will be a controllable disease."

Jerome Groopman, chief of an AIDS research lab at Harvard University, began seeing people with AIDS before the disease had a name. He believes that with new weapons against the virus soon to be in hand, doctors will greatly extend the lives of many infected people, possibly by decades. "I have a higher level of genuine optimism now than I've had for the last 15 years," Groopman said. "There are real, solid, scientific grounds for that optimism."

Treatments Proliferating

By late next year, the number of drugs on the market to attack the AIDS virus is likely to at least double, from four to eight or more. Doctors will try to identify infected people early and treat them with combinations of these drugs, hoping to keep the virus at bay.

This rapid proliferation of drugs complicates some issues surrounding AIDS treatment. Experts say learning how best to combine antiviral drugs is likely to require elaborate trials in large numbers of patients, and the results may take years to emerge. Meanwhile, with more and more treatments available, the potential market for each individual drug is shrinking. A federal task force recently expressed concern that companies may pull out of AIDS research, fearing they won't be able to sell enough of a drug to justify the high cost of bringing it to market.

Some of the experimental treatments have shown promising near-term effects. For instance, researchers at Merck & Co. are testing a drug, Crixivan, belonging to a new class of compounds called the protease inhibitors. In human tests, the drug has reduced the amount of AIDS virus in the body to less than 1 percent of its previous level and sharply boosted the specialized immune cells that are depleted by the disease.

Merck is spending \$100 million to expand a factory in Elkton, Va., and install a production line for Crixivan. Two similar drugs, from Abbott Laboratories and Hoffmann-La Roche, are also in the late stages of testing and have shown good results. The protease inhibitors seem to have few side effects. In recent weeks, the Food and Drug Administration approved programs offering expanded access to Crixivan and to the Roche drug, called Invirase, for people who are critically ill. Many scientists expect all three drugs to be licensed next year.

Researchers at the National Institutes of Health have pioneered another AIDS treatment using one of the body's natural chemical messengers, a form of interleukin. In some people, the treatment sharply boosts the count of CD4 cells (or T cells), the cells depleted by AIDS, producing twofold or threefold increases. H. Clifford Lane, the NIH researcher testing the therapy, cautioned that the ultimate usefulness of this regimen is not clear, but added that the results he and his colleagues are getting are "pretty unbelievable."

A decade ago, science could offer nothing to people with the AIDS virus. Soon, the problem may be the opposite. There will be anywhere from eight to as many as 10 or 11 partially effective drugs and treatments on the market, and many possible regimens for using them.

So far, scientists have produced little research to answer what is becoming the central strategic question: How should the treatments be used, in what order and in what combinations, at what stages of the illness?

With up to 20 million people around the world infected with the virus, and with millions of new cases projected by the turn of the century, the fates of large numbers of people could hang on the answer to that question.

Leaders responsible for battling AIDS are encouraged by the latest developments, though cautious.

"We've made some progress," said Donna E. Shalala, secretary of health and human services. "We have our research act together. But we have not done enough. No one in high office in this administration will ever say we have done enough until we have beaten this disease."

Drugs Have Limits

AIDS researchers are the first to admit that the latest treatments could ultimately prove disappointing. First, the virus can evolve rapidly in the body to become resistant to drugs, limiting how long even the best ones will work.

Second, most AIDS treatments, including the new ones, seem to work best in people who are not too sick to begin with. For the many thousands who have already progressed to severe illness, science does not hold out as much hope.

Finally, tapping into the latest developments is complicated and expensive. Those with access to

experimental treatments and nutritional counseling have largely been middle-class white men, while the virus is afflicting more and more

poor women and minorities. This "knowledge gap" is emerging as an enormous problem. Many people with the virus don't know they have it, much less what kinds of treatment are available.

Even for those with education, money and time on their side, AIDS is an extraordinary challenge. The promise of longer life is accompanied by the urgent need to keep up with the latest research. Being positive for the human immunodeficiency virus, the cause of AIDS, has become a full-time job for many people.

In the Washington metropolitan area, home to as many as 25,000 people with the virus, HIV-positive people file by the hundreds into classes on how to stay alive. Throughout the country, they enroll in studies, serve on committees, go to scientific conferences, work out in gyms, jog or bicycle assiduously, eat carefully, develop intense relationships with doctors and researchers, take scores or even hundreds of pills a week. Private or government health insurance often does not cover the cost of all these medicines, and about 30 percent of HIV-infected Americans have neither. They fret and scramble to figure out how to pay for it all.

In their bodies, HIV gradually disables the immune system by targeting CD4 cells, the white blood cells that orchestrate the body's response to infections. A healthy person has a CD4 cell count of roughly 1,000 per microliter of blood. People may not develop serious symptoms of AIDS until the count falls below 200. A person with a count below 50 is in the advanced stages of the disease.

Scientists have learned much more about how the AIDS virus causes that gradual decline. In the past few years, they have learned to prevent or treat many of the AIDS complications—such as pneumonia or intestinal infections—that actually kill people. For some people, that may buy time while drugs are developed that attack HIV itself. Scientists have learned that certain nutritional problems play a role in AIDS, and they are using that knowledge to attempt to slow the progression to serious illness.

Researchers believe the best strategy for prolonging survival is keeping the CD4 count high enough to allow a person to fight off infections. Studies with the compound interleukin-2 by Lane's team at NIH have made some progress toward that goal.

Interleukin-2, one of a family of chemical messengers in the body, stimulates production of the very cells that AIDS destroys. Researchers first tried the obvious: giving high doses of the substance to try to counteract the damage the AIDS virus was doing. It didn't work very well.

Then Lane and his group devised a new regimen. They gave the drug for a few days at a time, then let the body rest for several weeks before the next dose.

'The Bingo'

One of the first people to get this regimen, in 1993, was a man from New Mexico. At one point his CD4 cells were at 283, close to the danger zone. He started treatment, and Lane remembers the day some of his blood work came back from the lab.

"That was the bingo," Lane recalled. The man's CD4 count had jumped dramatically, to 1,998. Two years later, his CD4 count is still in the range seen in healthy people.

Since then, Lane and his colleagues have produced large CD4 increases in dozens of people. They have published their preliminary re-

sults and are now at work on other studies. But they have had one big disappointment. It turns out the treatment works best in those starting out fairly high to begin with. The people who are sickest, with the lowest cell counts, do poorly on it, perhaps because the immune system has already been irreparably damaged.

Still, being able to manipulate people's cell counts like this was science fiction not long ago. "Seeing someone's T4 count go from 400 to 2,000 is pretty unbelievable," Lane said. "In some instances, we can force the body to make T cells faster than the virus can destroy them."

Lane says the treatment is not ready for widespread use because doctors don't know enough about potential problems or about how to combine it with other therapies. "Right now, it fits nowhere in the overall strategy," he said.

The side effects of the drug are severe: a flu-like syndrome lasting several days that makes recipients

feel terrible, with shaking chills and high fevers. Not all patients respond to interleukin-2, but Lane said most of those who do have shown a sustained increase in CD4 counts.

Some patients—and some doctors—feel they can't wait for definitive answers to questions about how and when interleukin-2 should be used. Unlike many other experimental AIDS drugs, the treatment is already on the market for another purpose, treating a certain kind of kidney cancer. That means doctors can legally prescribe it, although insurance companies might refuse to pay.

Some doctors, such as Larry Bruni of Washington, have done exactly that. Bruni has run big advertisements in the Washington Blade, a newspaper for gay people, that are headlined: "RESTORING THE IMMUNE SYSTEM IN HIV DISEASE." He estimates he has given interleukin-2 to as many as 140 people.

One of Bruni's patients, Robert

Baublitz of Georgetown, heard about the experimental treatment two years ago. Baublitz's CD4 cells were falling, and he was getting scared. After Baublitz started the treatment, his CD4 counts rose dramatically, and are now close to normal. He takes the treatment every few weeks. It makes him sick for a few days, but otherwise he feels fine.

"I basically now am living with the virus, rather than dying from it," Baublitz said.

For people who don't get a good response, though, the side effects soon force them off the drug. To them it's a lot of pain for nothing.

The Battle Plan

When it works, interleukin-2 boosts immune cells directly. The protease inhibitor drugs work differently, by attacking the AIDS virus at a specific point in its life cycle.

Scientists used to think the virus infected people, then went into a semi-dormant phase for a decade or more before making them ill. Now, they know that for that entire decade, the body and the virus are engaged in heated battle: The virus is reproducing furiously, and the body is just as furiously killing the virus. In most people, the body loses just a little bit of ground, and the virus gains just a bit, each day.

As one of its reproductive steps, the virus uses an enzyme called HIV protease to wrap itself in a membrane of proteins snipped from the wall of a human cell. In effect, the protease is a kind of scissors that allows the virus to cut a coat for itself. Protease inhibitors are designed to block the enzyme's action, thereby reducing the virus's ability to escape from cells and infect new ones.

The aim is to tip the balance back in the body's favor, at least for a time, and to give the immune system a chance to produce more CD4 cells. The hope—not entirely proven for any AIDS antiviral treatment—is that boosting the cells will ultimately slow the progression to illness and death.

Three companies—Abbott, Merck and Hoffmann-La Roche—are in advanced stages of testing such drugs. Unlike some earlier AIDS drugs, they are not very toxic. And in most people, they seem to produce marked reductions in virus and concomitant boosts in the immune system.

For instance, with the Merck and Abbott drugs, a patient can typically expect to see virus levels plummet and CD4 counts rise by perhaps 100 per microliter of blood. That could be enough to lift many people out of short-term danger. Some patients get more dramatic responses, of 200 to 300 CD4 cells per microliter.

Brie Salzman, a writer in New York, had 32 T cells when he went on the Merck drug well over a year ago. His count has nearly quintupled, to 156.

"My health is excellent," he said. "I tell people who have just been diagnosed, and who have higher T cells, that I believe this will be a chronic, manageable disease before they are in serious danger."

While the toxicity of the new drugs has generally been low, not everyone can take them. Franklin Clemmons, of New York, worked for a year to get himself on Abbott's experimental drug. His blood work after he went on it looked great—but for reasons no one could understand, the drug made him feel terrible. "I was a walking, mobile person before the study," he said. "By the end of seven weeks I could barely walk. I got so debilitated that I tried to commit suicide. I thought I was dying." He stopped the drug and started feeling better.

Besides possible side effects, there's another problem. The virus quickly develops the ability to resist new drugs, including the protease inhibitors.

The AIDS virus is a perfect example of natural selection at work. To it, a new drug represents a toxic threat. And because the virus is reproducing so rapidly, it can evolve quickly to meet that threat.

At first scientists despaired over this problem, which they have seen with every effective AIDS drug. Now, however, it looks as though some of the drugs may be useful anyway.

They may serve as temporary bridges to keep people healthy until still more drugs are developed. And different drugs that attack the virus at different points in its life cycle may pack a far more potent wallop than any single drug. Doctors have successfully treated tuberculosis and other diseases with such combinations for years. Now, they are trying to apply the idea to AIDS.

The oldest AIDS drug, AZT, has proven substantially more potent in combination with a newer drug, 3TC. Preliminary studies suggest that combination is almost as effective as the new protease drugs.

Answers to questions about how these new drugs should best be used won't arrive for years. In the interim, people will be deciding on treatment with little hard information.

Right now, four anti-HIV drugs—AZT and three of its chemical cousins—are licensed for sale in the United States. They work in a similar way, and because some of their side effects overlap, the number of possible combinations is limited.

Scientists expect 3TC, the drug that works well in combination with AZT, to be licensed fairly quickly, probably before the end of this year. With three protease inhibitors showing good results, the FDA is under intense political pressure to license them by 1996.

Some scientists think one or two other promising drugs may be licensed in that same time frame. Counting those and the interleukin-2 treatment, there might be 10 or 11 AIDS drugs on the market by the end of next year.

What will happen after that is less clear and was recently the focus of study by a federal task force. Once the current batch of AIDS drugs is licensed, people will choose among them, going off a drug once the virus shows resistance. Even though the drugs as a group are desperately needed, this means the market for any single drug could be thin.

The National Task Force on AIDS Drug Development fears that slow sales will prompt drug companies to back out of AIDS research. If that happened in the next year or two, there would be no fresh crop of drugs coming to market at the turn of the century, when many people with HIV will have exhausted their current treatments.

The task force has asked Congress to pass special tax credits for AIDS research, similar to those that apply to research on rare or orphan diseases. The Clinton administration is reviewing the issue.

In the meantime, people will be scrambling to figure out how to get the best use out of the new drugs that are about to become available.

"If we can figure out a way to use these drugs, we can have a significant impact on my life, and other people's lives," said Gregg Gonzalez of the Treatment Action Group in New York. "Hope is a powerful thing, and people want to believe we have a home run here. We have to be willing to say we're looking for a couple of singles plus a double, instead of one grand slam."

*Staff writer Don Colburn
contributed to this report.*

FOR MORE INFORMATION

Treatments for HIV and AIDS

■ **General information and referrals:** Call 1-800-342-AIDS, a U.S. government hot line staffed 24 hours. For Spanish speakers, call 1-800-344-7432 from 8 a.m. to 2 a.m. For the deaf, use a TDD to call 1-800-243-7889.

■ **Clinical trials:** 1-800-TRIALS-A is a government hot line that can provide detailed information on ongoing research studies. Open Monday to Friday, 9 a.m. to 7 p.m. For the deaf, use a TDD to call 800-243-7012. International callers use 301-217-0023.

■ **Directory:** The National AIDS Clearinghouse can answer questions about prevention and research. It can send various publications, including one free copy of a written directory of HIV and AIDS treatment options published by the American Foundation for AIDS Research. Call 1-800-458-5231, English or Spanish.

■ **Treatment information:** The Carl Vogel Center in Washington distributes information on conventional treatments, nutrition and some alternative treatments, and sponsors workshops. Call 202-638-0750 Tuesday through Saturday from noon to 6 p.m., Wednesday till 9 p.m. The Whitman-Walker Clinic in Washington, 202-797-3500, provides an extensive array of AIDS-related services; hours are 9 to 6 Monday through Friday. AIDS Action Baltimore, 410-837-2437, publishes a treatment bulletin. Project Inform of San Francisco, 1-800-822-7422, will send a packet of treatment information.

THE WASHINGTON POST

August 3, 1995

MEMORANDUM TO PATSY AND JEFF

FROM: Vanessa Potkin and Rachael Smith

Re: News for 8/3/95

"Only 4, She Has Made A Difference" (Washington Post)

With her mother's assistance, four-year-old Precious, an AIDS patient has started a campaign to raise AIDS awareness. On Friday she gave part of the keynote address at the Pathways to Freedom dinner, which honored civil rights leader Rosa Parks.

"Health Insurance Reforms" (Washington Post)

The Senate Labor and Human Resources Committee passed the Health Insurance Reform Act. The act would make it easier for millions of Americans to stay covered when they get sick or switch jobs.

"Disabled People See Budget-Cutting Fervor as Threat, New Attitude" (Washington Post)

Chai Feldblum of Georgetown Law Center states, "Representatives who voted for the ADA are the same people who are now voting to cut programs that help people with disabilities." Major issues in congress affecting disabled people are highlighted, including: Supplemental Security Income, Medicaid, Medicare, Education, Housing and the Developmental Disabilities Act.

At 4, She Has Made Her Mark on World

Precious, an AIDS Patient, Excels as Speaker

By Lonnae O'Neal Parker
Washington Post Staff Writer

Amateur photographer Deborah Bush of Southeast Washington recalled her first reaction to the 3-year-old who spoke in February at a Black History Month salute to abolitionist Frederick Douglass.

"I turned to her mom and said, 'God, she's precious, isn't she?' Her mom said, 'She really is,' and started laughing."

On Friday, Precious Thomas, who turned 4 Sunday, was posing for pictures and preparing to give part of the keynote address at the Pathways to Freedom dinner at Howard University's Blackburn Center. The dinner honored civil rights leader Rosa Parks on the Washington stop of her sixth summer bus tour tracing the Underground Railroad and the civil rights movement.

Far from practicing her lines, the

seasoned young speaker ran the hallway of the Blackburn Center. Her pink tights twisted above satin ballet slippers, and she showed off pink and white teddy-bear barrettes that secured the dozens of twists in her hair.

If you ask her, Precious will count to 10 in Swahili, Japanese, French and Spanish and name the parts of the digestive system. She'll also tell you: "I have a bad bug in my body, and it makes me sick. It attacks my immunity system."

Precious, who was adopted by Rocky and Michael Thomas, of Suitland, when she was a month old, was diagnosed as HIV-positive at age 1 after a bout with pneumonia. Her birth mother was drug-addicted. Rocky Thomas, a homemaker with three other children, said she was stunned.

"I got the news and all I wanted

See PRECIOUS, Page 2, Col. 3



BY LUCIAN PERKINS—THE WASHINGTON POST

Precious Thomas at home with her mother, Rocky Thomas, and family friends Arella Gilliam and Nathaniel Walker.

Only 4, She Has Made a Difference

PRECIOUS, From Page 1

was to be left alone, but, thank goodness, no one did," she said.

Citing support from her neighbors and from New Samaritan Baptist Church, of which she is a lifelong member, Thomas said: "It has meant so much to me to know that they are behind me. If Precious is hospitalized, sometimes the church hospital-ity club will come sit with her so I can get some rest."

Thomas said Precious was in the hospital constantly in 1992 and 1993 for upper respiratory infections. Although the last 18 months have been better and Precious has had no hospital stays, the medication is constant. So is the monitoring for fevers. "Her T-cells are at 800; that's good," Thomas said, counting white blood cells the way most parents count new teeth.

Doctors and teachers discovered that Precious had a gift for remembering facts and figures. It was then that her mother began a campaign to raise AIDS awareness and started letting Precious do motivational speaking.

Precious has appeared at dozens of functions, including being guest speaker at a World AIDS Day program at the General Services Admin-

istration. According to her mother, she is asked to give speeches at church or civil rights benefits every week, and she has shared a Howard University stage with entertainer Lola Falana. Singer Patti Labelle invited Precious backstage at a Warner Theatre concert, and she has been photographed with President Clinton and Vice President Gore, who visited her at Children's Hospital.

"I'm not keeping my mouth closed about her being HIV-positive. . . . You very seldom hear about a child like her, so strong and bright," Thomas said. "It's not about the illness; it's about all the love and affection she gives. She motivates everyone she comes into contact with. The energy is there."

Inside the Blackburn Center ballroom, Precious was carried to the microphone, where she was introduced as someone who had done more talk shows than Jesse L. Jackson. The oohs and aaahs, however, were quickly replaced by stunned silence when it was announced that Precious was HIV-positive.

As the mike was lowered to her height, Precious began speaking in a voice beyond her years: "We are here today to honor a woman who lives for peace. She changed the

world . . . by doing one peaceful act of remaining seated when those who knew not peace and had not love would have her to stand."

The charmed audience stood before she finished speaking, and flashbulbs exploded everywhere. Rosa Parks, 82, was helped to her feet, and she smiled delightedly at the child, who curtsied and blew her a kiss.

Parks was a 42-year-old seamstress on Dec. 1, 1955, when she defied a Montgomery, Ala., rule requiring blacks to yield their bus seats to whites. The incident triggered a 381-day boycott of the bus line that resulted in the desegregation of the buses and is considered one of the first acts of the modern civil rights movement.

Precious, who said she wants to be a model, a ballet dancer or a hairstylist, took her proximity to history in stride, waving and smiling for the cameras.

Ella McCall-Haygan, a co-organizer for the Pathways to Freedom program, was responsible for arranging for Precious to speak. "I heard her speak at the Frederick Douglass salute, and I was floored. I got up and gave her a standing ovation. I couldn't stop clapping for that baby."

Her eyes seemed to mist over a little. "She's just so precious," she said.

Health Insurance Reforms

■ On a unanimous vote, the Senate Labor and Human Resources Committee yesterday passed health insurance changes that would make it easier for millions of Americans to stay covered when they switch jobs or get sick.

The Health Insurance Reform Act drew broad bipartisan support, starting with its sponsors, Sens. Nancy Landon Kassebaum (R-Kan.) and Edward M. Kennedy (D-Mass.). And it stands a chance of making it to the Senate floor this fall after the battle over the Republican budget plan, including the proposed \$450 billion in savings from Medicare and Medicaid.

The labor committee united behind the insurance reforms, which would allow group health plans to impose no more than a 12-month exclusion for people with pre-existing medical conditions. If someone had kept up coverage, they could not be excluded for health reasons or subjected to a new waiting period when they switched jobs or group policies.

In a concession to objections from the insurance industry, Kassebaum agreed to stretch out from 12 to 18 months the length of time someone would have to be covered by a group plan before being able to buy an individual policy.

A person who lost group coverage would also have to exhaust the 18-months of so-called COBRA coverage that everyone is entitled to when they quit a job and agree to pay all the premiums themselves. But after three years of group and COBRA coverage, insurers could not deny an individual coverage because of health or medical history.

The bill also would allow states to certify purchasing cooperatives formed by businesses or individuals to buy insurance.

An estimated 81 million Americans have health problems that make getting insurance difficult. The General Accounting Office last month estimated the Kassebaum-Kennedy bill could help 21 million Americans, many of whom are locked into their current jobs out of fear of losing coverage. Forty-one million Americans are uninsured, or 16 percent of the population.

—Associated Press

Disabled People See Budget-Cutting Fervor as 'Threat New Attitu

MAJOR ISSUES IN CONGRESS AFFECTING DISABLED PEOPLE

In Cleveland, Fla., the parents of 14-year-old Janell Wells are anxiously tracking the congressional debates this summer, convinced that the latest tick of a pencil in Washington could dramatically alter their lives.

Janell suffers from a rare disease that keeps her body from regulating heart rate, breathing and temperature, a disorder that has pushed her annual medical bills as high as \$250,000. To help pay these bills, her family receives help from at least three federal programs—Supplemental Security Income, Medicaid and a maternal and child health fund—but all have been targeted by Congress this year for spending cuts or radical revision.

As they watch the process unfold, said Conni Wells, Janell's mother, families like mine are scared to death.

Republicans in Congress, eager to reform what they see as ineffective social policy and reduce spending, have proposed significant changes to a number of federal programs. And while almost every group that relies on social programs would be affected by those changes, people with disabilities may take a disproportionate

"Representatives who voted for the ADA... are the same people who are now voting to cut programs that help people with disabilities."

—Chai Feldblum, Georgetown Law Center

hit because they often depend on a patchwork of programs.

More disturbing than the looming budget cuts to advocates for disabled people is the fear that Washington's attitude toward disabled Americans has fundamentally changed. Last week, as disabled people marked the fifth anniversary of their greatest legislative triumph—passage of the landmark Americans With Disabilities Act (ADA)—they surveyed a vastly different political landscape. They see disabled people being lumped in with undeserving welfare recipients and viewed as overly dependent or, at the least, too expensive.

In the years since President George Bush signed the law banning discrimination against the handicapped in the workplace and in public places, "the atmosphere has changed very considerably, where people with disabilities are becoming scapegoats for the horrendous deficit and debt," said Justin Dart, a Republican and former head of the President's Committee on Employment of People with Disabilities.

"Today," said Wells, "I'm seeing a fiscally budget-driven system that looks at people according to their potential, not much on they give back, and making judgments on how much we should invest in this population."

Congressional Republicans strongly deny these charges.

"The tide has not turned against disabled people," said Rep. Jim McCrery (R-La.), who led efforts in the House to overhaul SSI. "The tide has turned against abuse of federal programs, against waste of federal dollars, but not against disabled people."

■ Supplemental Security Income: The House voted in March to reduce by more than \$20 billion over five years spending on SSI, which provides assistance to disabled and elderly people. Among the major revisions would be an end to benefits for those with alcohol or drug abuse problems and cash payments for all but the most severely disabled children.

■ Medicaid: Congress has proposed reducing projected spending by \$180 billion over seven years from Medicaid, which provides medical benefits for low-income people. The proposal would turn the funds over to the states in lump sums and reduce the rate of spending growth in the program from 10 percent to about 4 percent.

■ Medicare: Congress has said it will cut anticipated spending on Medicare, which provides health insurance to aged and disabled people, by \$270 billion over seven years. That would require reducing spending growth from 10 percent a year to 6.4 percent a year.

■ Education: A House subcommittee has proposed

eliminating several special education programs, including those providing funds for teacher training, parent training and development of innovative early childhood programs for disabled children.

■ Housing: A House appropriations bill would eliminate any new funds for rental assistance for low-income families in fiscal 1996, and a reauthorization bill eliminates the new funds contained in the 1995 appropriation. Together, these funds would have assisted about 100,000 families. Disabled Americans who are not elderly make up about 18 percent of those receiving rental assistance.

■ Developmental Disabilities Act: A House appropriations bill would eliminate funding under this law for a research and development program that tracks efforts in this area and reduce by more than 40 percent spending to train professionals to deal with people with multiple disabilities. The bill would reduce funds to set up community services for those with developmental disabilities.

—Barbara Vobejda

Among the most serious concern to advocates for disabled people is what they describe as an orchestrated campaign to gut the ADA by opponents who argue that it is too broad and places an unreasonable burden on businesses and taxpayers.

In "Restoring the Dream," a book published by the Republican National Committee to flesh out details of the House GOP's "Contract With America," Republicans take on the ADA.

"Sometimes even the best-intentioned regulations spiral out of control," the book states, citing the ADA as an example. "Under the Act, 43 million people—that's one out of every six Americans—are potentially considered 'disabled,' though they may not know they are disabled themselves. The list includes drug abusers, the obese and the 'emotionally disturbed.'"

At a town meeting outside Dallas in April, House Majority Leader Richard K. Armey (R-Tex.) said the ADA, "in its current state, is a disaster." Armey called the law an "open invitation to frivolous lawsuits" and said it had been "one of the most deeply written pieces of legislation in the history of the House of Representatives."

"Under my majority leadership, the disability act will be revisited and will be written properly so its focus and intent goes to people with genuine disabilities," he said.

Armey was one of 28 House members who voted against the ADA in 1990, a group that also included Rep. Bill Archer (R-Tex.), now chairman of the Ways and Means Committee, and Rep. Tom DeLay (R-Tex.), now majority whip.

Ed Gillespie, a spokesman for Armey, said no legislation to alter the ADA has been discussed, and he dismissed the contention that efforts on Capitol Hill to reduce spending or "tighten" the ADA reflected ill will toward people with disabilities.

"People with true disabilities have no reasonable apprehension about the programs from which they benefit," he said.

Even the philosophy underlying past victories—that disabled people as a group should be entitled to claim a set of rights—has been brought into question, Dart said.

"We've used as a prime example of the misuse of the rights argument," said Dart, who uses a wheelchair, "which is a totally wrong interpretation" of the ADA. He pointed to a written statement by House Speaker Newt Gingrich (R-Ga.) that Americans' "bewildered sense of entitlement and of victimization is exactly wrong." Gingrich did not mention disabled people, or other groups in his statement.

Chai Feldblum, a professor at

Georgetown Law Center and a major player in passage of the ADA, agrees that there is a changing philosophy about individual rights to government aid, but does not believe that threats to programs for people with disabilities are being driven by negative attitudes.

"Representatives who voted for the ADA... are the same people who are now voting to cut programs that help people with disabilities," Feldblum said. "I don't think this is a pendulum shift. It's a desire to cut the budget."

The reductions would cut far into some programs, with Congress proposing to eliminate \$180 billion in future Medicaid spending over seven years and \$270 in future Medicare spending.

Disabled people rely heavily on both of those programs for medical care, as well as SSI payments as a source of income. The House has voted to reduce SSI spending by more than \$20 billion over five years, with major changes proposed for a portion of the program that provides assistance to disabled children.

Under the House plan, only the most severely disabled children would continue to receive cash aid, some others would receive services and more than 200,000 children could lose eligibility altogether, according to an estimate from the General Accounting Office.

McCrery said his proposals to

change SSI were motivated by a desire to end what he believes is widespread fraud in the program.

"The cash acts as an incentive for some parents to not get help for their children's disabilities because they don't want them to get off the program," he said. "And... it acts as an incentive for some parents to encourage their children to act in such a way that it would lead to their qualifying for the program... thereby harming their children and their chances for success in life."

Republicans and some Democrats also have argued that the skyrocketing cost of some programs, including SSI, Medicaid and Medicare, must be brought under control. The cost of SSI benefits, for example, has more than doubled since 1985. Medicaid spending is growing at a rate of 10 percent annually and one of the Medicare trust funds is expected to run out of money by 2002.

"In the abstract, people recognize that funding to help people with disabilities gain independence is a good investment," said Leonard Rubenstein, director of the Baseline Center for Mental Health Law. "On the other hand, the obsession with budget-cutting is overwhelming that."

For Conni Wells, the fear is that Janell could be affected by several of these cuts. Because Janell's disease is not one of the medical conditions on a qualifying list for SSI, she could lose her cash benefits of about \$82 a month under the proposal approved by the House. The family has used that money to help cover the costs of medical equipment and other special needs not picked up by their private insurance or Medicaid.

"The only thing that can happen now is that it's going to get worse," Wells said.

Janell also could be affected by Med-

icaid reductions. Another program that helps cover the Maternal and Child Health Block Grant, had been slated for cut reduction, but so far, proponents have

Other parents say they could see a cut in one program but the effect of the federal cut could be devastating.

"It was just one battle," said... But it's so overwhelming. Amy Smyth, the mother of Zachary, who is severely disabled, is

Smyth, who lives in Peoria, is helping organize a letter-writing campaign to lobby Congress on a spending is reduced.

Zachary, as Medicaid for many of his medical expenses equally important to him. mother, is a Medicaid provider for daily tutoring after he can learn to live independently become employable.

His tutors work with him side a bus, personal hygiene daily living skills. Those are Smyth, "are probably going the difference between Zack job or not."

But that program, as part aid, is highly vulnerable to cut

The perception in Washington that disabled people "are just recipients," said Smyth, who her way through school and as a special education teacher earning \$26,000 a year. "I middle-class families trying to taxes. We don't want our child SSI recipients for life, or to be institutionalized."

August 4, 1995

MEMORANDUM TO PATSY AND JEFF

From: Rachel Garfield

Re: August 4 news

"AIDS Council Calls on Clinton for Leadership" (Blade 8/3/95)

The Presidential Advisory Council on HIV/AIDS held its first meeting with President Clinton on July 27. The Council stressed their recommendation that executive leadership- including action on the Council's suggestions- is essential not only to help wage a battle against the disease, but also to prove that Clinton is genuinely interested in doing something about AIDS.

"Being Under the Microscope Tough for D.C. General Clinic." (Blade 8/4/95)

The HIV/AIDS clinic at D.C. General Hospital is still getting the job done, despite the fact that there is only one full-time doctor and one full-time social worker on staff. The clinic has been under public scrutiny ever since its director and specialist in infectious diseases resigned three months ago. The D.C. General clinic treats some of the poorest and sickest patients in the city.

"HIV/AIDS Media Campaign Tailored to Fit" (Blade 8/4/95)

Koba Associates, Inc. has launched a new HIV prevention model that seeks to reach out to D.C.'s African American, African, and Caribbean population. The campaign includes HIV prevention and testing brochures, Metro bus ads, and radio public service announcements and involved planning by members of the black community.

"Dr. John Stansell Talks Frankly About Efforts to 'Aid in Dying'" (Blade 8/4/95)

Dr. John Stansell, head of San Francisco General Hospital's AIDS Clinic, announced six months ago that he practiced physician-assisted suicide with some of his patients who were in the final stages of AIDS. Stansell says that he is simply "treating pain" in providing prescriptions for medication to relieve pain, knowing that the patient will use it to end his life. Though physician-assisted suicide is illegal in 49 states, a large proportion of doctors that treat patients with AIDS practice it.

"Helm's Arguments Gaining Wider Acceptance" (Blade 8/4/95)

Sen. Jesse Helms' (R-N.C.) argument that too much funding is going to battle AIDS- a disease he says is spread by "deliberate, disgusting, revolting conduct"- is gaining steam among those who feel more money should go towards combating other diseases (like heart disease, cancer, and alzheimer's). The idea that AIDS receives a disproportionate amount of funding, however, is false.

"Hill Update" (Blade 8/4/95)

- The House of Representatives passed a \$79.4 billion FY96 Veterans Affairs/ Housing and Urban Development bill with a provision to increase funding for the Housing Opportunities for People With AIDS. The amendment restored the loss of funding to HOPWA from the 23% decrease in the HUD budget that the House Committee on Appropriations approved on July 18.
- On July 21, the House Appropriations Committee unanimously approved report language offered by Rep. Nancy Pelosi (D-CA) that would grant authority to the National Institutes of Health's director to adjust the allocation of AIDS funding to the NIH's 24 institutes.
- On July 19 the House of Representatives approved an amendment proposed by Rep. Ron Packard (R-CA) which could limit the scope of the Clinton administration's federal AIDS training initiative. The amendment states the no federal funds may be used for "unconventional" federal employee training.

AIDS Council calls on Clinton for leadership

by José Zuniga

Members of the newly formed presidential Advisory Council on HIV/AIDS told President Bill Clinton and Vice President Al Gore in a July 27 White House meeting that presidential leadership is desperately needed to wage an effective battle against the AIDS epidemic.

"We were very specific about our concerns ... that there can be no real and significant campaign against this epidemic without some desperately-needed leadership from President Clinton," said Dr. Scott Hitt, a Los Angeles physician and the council's chairperson. "I'm optimistic ... but I guess in a few months from now we'll know if this panel was formed simply as a political ploy or if he is genuinely interested in doing something about AIDS."

The 23-member presidential advisory council, in town for its first meeting since it was formed five weeks ago, presented Clinton with a list of specific recommendations during the half-hour White House meeting. The advisory council recommended President Clinton:

- Hold a national summit before year's end that "encompasses the scientific, medical, social, and political aspects of the AIDS epidemic." The council said the summit, on the scale of the national economic summit held shortly after Clinton's inauguration, should consider the impact of race, culture, poverty, disability, region, gender, sexual orientation, and age, "on our ability to develop an effective national AIDS strategy."

- Address the nation, "declaring the battle against HIV a national health priority and laying out his vision for the end of this epidemic."

- Make HIV prevention programs at the U.S. Centers for Disease Control and Prevention (CDC) an "investment priority" in the White House's FY 97 budget. The council noted that, in past years, areas in which the president has placed investment priority — such as biomedical research and the Ryan White CARE Act — have received significant increases in funding. "HIV prevention efforts, such as specific population-based targeted pro-

grams, demand a similar level of commitment," advised the council.

- Continue to support the Ryan White CARE Act, the Housing Opportunities for People with AIDS (HOPWA) program, and other federal housing programs that serve people with AIDS. The council urged the president to make housing for people with AIDS an FY 97 budget priority.

- Continue to support a coordinated federal approach to AIDS research and show support for the Office of AIDS Research (OAR). In a move AIDS activists condemned, the House of Representatives last month stripped away the OAR's responsibility to distribute AIDS research money to the National Institutes of Health's 24 institutes, and failed to earmark any research money specifically for AIDS research.

- Should "speak out against HIV-related discrimination and condemn prejudice based on race or ethnicity and sexual orientation." In an apparent response to anti-Gay comments made last week by Sen. Jesse Helms (R-N.C.) during Senate debate on the Ryan White CARE Act's reauthorization, the council urged Clinton to oppose amendments to AIDS-related legislation "that are designed to divide the American people along lines of sexual orientation, substance abuse history, race or ethnicity, or other factors."

Advisory Council member H. Alexander Robinson, an openly Gay man living with HIV, said he knows there is some belief in the AIDS community that the council is a political ploy by the Clinton administration to save face with the Gay community.

Robinson said that council members made clear to Clinton that presidential action on their recommendations is a condition for their ongoing participation on the advisory council.

"I know there is cynicism and maybe some doubt and skepticism; but be assured, we're not here to be window dressing or to supply the White House rhetoric that sounds good," said Robinson, who is co-chair of the National Organizations Responding to AIDS (NORA) coalition. ▼



President Bill Clinton addresses members of the newly formed presidential Advisory Council on HIV/AIDS.

by Clint Stieb

Being under the microscope tough for D.C. General clinic

Staff at HIV/AIDS clinic wants to 'get on with the business of patient care'

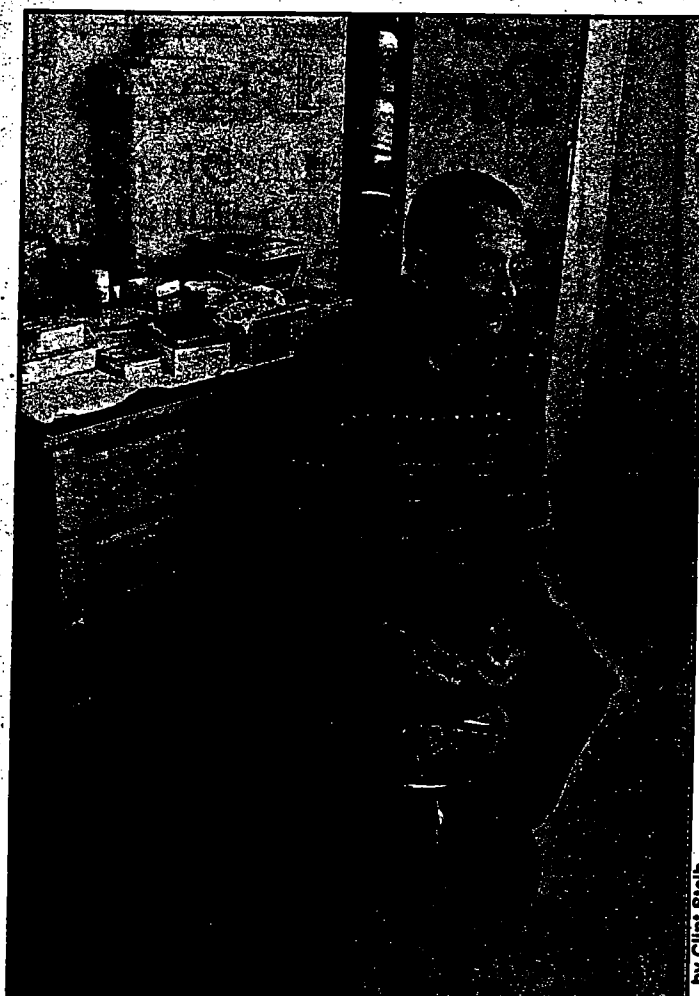
by Sue Fox

For a clinic that serves more than 800 patients with only one full-time doctor, the halls of the HIV/AIDS outpatient center of D.C. General Hospital are oddly quiet. There is no mad stampede of vexed part-time physicians scrambling through the unit, phones are not ringing off the hook, and clients do not seem to be overflowing the waiting room. In fact, hardly anyone is around.

That's because it's Friday afternoon, according to Dr. Ana Maria Espinoza, the sole full-time physician left at the AIDS center. Mondays, explained the soft-spoken doctor with a shy smile, are much livelier.

Three months after the exodus of the clinic's former director, Dr. Joseph Timpone, and another specialist in infectious diseases, Dr. Joseph Toerner, it's business as usual for the staff and patients who stayed. Patients continue to be seen by Espinoza or one of the four part-time doctors filling in until additional physicians are hired. New clients are accepted, and doctors this week said the clinic's waiting period for an appointment is generally only a couple days long. The center is still grossly understaffed, to be sure, but the unit's staff radiates the resolved serenity of those prepared to dig in for the long haul rather than the fevered disquietude of a team in crisis.

"Outside health clinics were under the impression that we were going to close, so they stopped referring patients here," Espinoza said last week. But the HIV center is now accepting same-day referrals, over-



by Clint Stelb

"They treat me real good," said James Wilson, a bisexual man who has been coming to D.C. General since another clinic began charging him.

booking to squeeze in acute cases, and even taking walk-in clients from time to time.

Continued on page 10

At D.C. General clinic, life under the microscope

Continued from page 1

"They treat me real good," said James Wilson, a bisexual man and a former intravenous drug user with AIDS who has been coming to D.C. General's clinic for two years, since another clinic began charging him for his visits. According to Espinoza, about 30 percent of her clinic's patients are Gay or bisexual men.

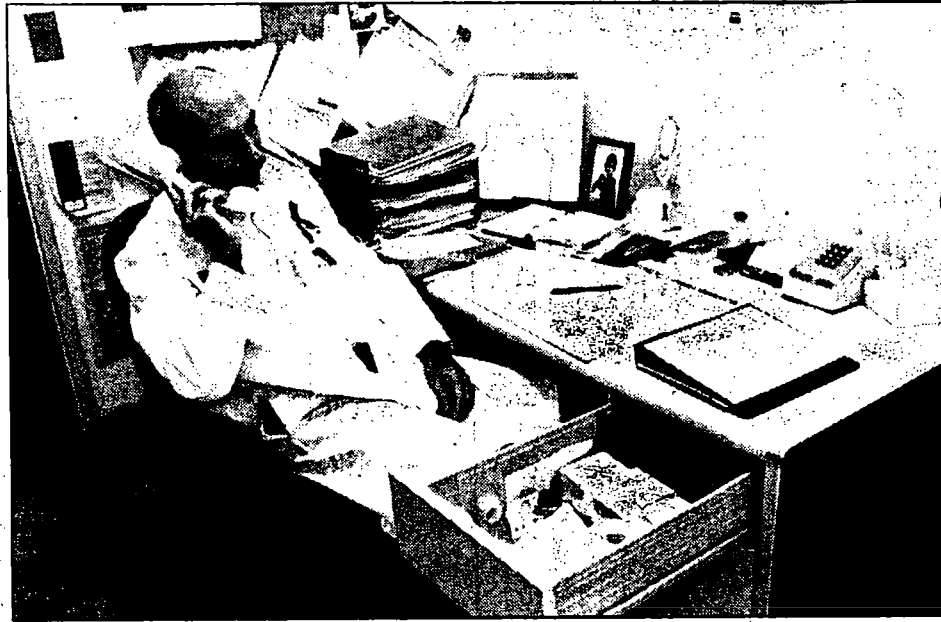
No one here appears to be ready to throw in the towel, having made it this far. Those who remain at the clinic are recovering from the hot glare of publicity surrounding the April resignations, a sudden exposure which "decimated the entire morale of the institution," according to Dr. Robin Newton, interim chair of the hospital's department of medicine.

"You really find out what you're made of in that environment," Newton said in an interview with the *Blade* last week. "You've got to ask yourself over and over again, 'Why are you here?'"

Instability persists

Though temporary measures have been taken to insure the viability of HIV outpatient services, instability continues its reign at D.C. General.

The lack of job security at the District's only public hospital reportedly initiated the current upheaval at the HIV/AIDS clinic. In a front page article in the May 10 *Washington Post*, departing doctors Timponi and Toerner cited a warning from D.C. General's medical director Lawrence Johnson that their jobs were in danger of being eliminated as part of a medical staff reduction. At the time, Johnson disputed the account, saying that although he could not provide the AIDS physicians with "an airtight guarantee," it was very unlikely they would be dismissed.



by Clint Steib

"Ultimately, the patients suffer," said Fred Pardo. "Every new patient that comes into the HIV center should be seen by a social worker for a psychosocial assessment, but I can't see everyone."

Three months later, the doctors have yet to be replaced with full-time physicians. The clinic's \$630,000 grant this year from the D.C. Agency for HIV/AIDS also calls for three social workers and other support staff, including nurses. Fred Pardo, the only social worker currently assigned to the unit, has been carrying the caseload single-handedly for almost six months now.

"Ultimately, the patients suffer," said Pardo. "Every new patient that comes into the HIV center should be seen by a social worker for a psychosocial assessment, but I can't see everyone."

Pardo now has an active caseload of 98 clients. That figure alone is enough to make most social workers quake, but several unique circumstances at D.C. General's AIDS clinic exacerbate the impact of the already cumbersome caseload.

The patients who show up at D.C. General's AIDS clinic are some of the poorest in the city. Sixty-seven percent are without any medical insurance, according to Newton. Only three to four percent are covered by private health plans, while the rest receive some type of government assistance.

The patients are also, according to Espinoza, some of the sickest. Sixty percent of the HIV clinic's clients have progressed to AIDS, requiring frequent visits and complex procedures such as intravenous blood transfusions and spinal taps not offered by other health clinics such as Whitman-Walker. Many clients also sorely need the services of a social worker to ad-

dress a melange of concerns that may be affecting their health care.

"Here people are homeless, they don't have food, they may be substance abusers, there are mothers with lots of children," explained Espinoza. "There are lots of social issues on top of the medical issues."

The optimal caseload for a social worker serving people with HIV is 30 to 40 clients, according to Pardo. With a full staff of three social workers, he believes they could each manage 75 cases.

"If I had 50," he added, "I would be in heaven."

The intense care required by people with late-stage HIV, particularly poor people who may lack access to strong home support systems, does not mix well with the hurried constraints of an overburdened system.

"One of the reasons the [AHA] grant is so important is that [caregivers can] take an hour if the patient needs an hour, since most patients have advanced disease," Newton said. "If you can pick up on more subtle signs, you can prevent hospitalization or more serious illness."

Newton, who sometimes fills in at the HIV center to make up for the shortfall in staff, said that many of her clients have no home support, making it impossible for her to prescribe treatments that demand in-home services. Instead, she keeps them in the hospital.

"They have to be self-sufficient. If they're not, they wind up back here, so there's no point in discharging them in the first place A lot I keep a full six weeks or more," she said.

A revolving door

James S. Brooks has been a patient at the hospital's HIV/AIDS clinic since 1991. He's had four different doctors during that time, but Brooks is generally positive about the care he has received there.

"There's only about one or two things I really don't like," he said. One is that the clinic sometimes reschedules his appointments without notifying him. Brooks said he is difficult to reach by telephone because he resides in the annex of a local church where his brother once served as pastor.

Another complaint Brooks has with the clinic is the long delay patients often en-

dure while waiting to be seen by a doctor.

"It's disturbing when you have a set time for an appointment and then you get here early and have to sit for an hour to be seen — and if you're 15 minutes late they won't see you," he said.

Brooks also dislikes having to explain his medical history over and over again each time he is assigned a new doctor. The irregularity of the clinic's full-time staff troubles employees as well.

"I have been here just under three years — longer than anyone else here," said Loretta Owens, a health technician at the clinic. "That in itself should raise a flag. Why is there such a revolving door here?"

Since Owens, a 23-year-veteran of D.C. General, has been stationed at the AIDS clinic, she has witnessed the comings and goings of at least a dozen staff members — half of them doctors.

"This clinic could do so much," Owens said. "It's really, really sad."

But then, it takes an exceptional sort of person to make it in the HIV/AIDS clinic of D.C. General, according to Newton and Espinoza. It takes someone who has a committed interest in taking care of people with HIV/AIDS, particularly indigent clients, someone who is "willing to push all other infectious disease [interests] to the back burner," someone undaunted by the hospital's tarnished reputation, who doesn't mind that the job pays a good 20 percent less than that offered by most hospitals. And it takes someone who is licensed to practice medicine in the District of Columbia and someone who plans to stay.

"Just because we are D.C. General, we have a black mark against us," asserted Newton. "If [a patient] has one negative experience here, the black mark grows ... [and] that word goes out into the community. We have to be very picky [about who is hired.]"

Newton said the clinic hopes to secure a second full-time doctor by Sept. 1. She and Espinoza have so far identified two strong candidates for the position, but the hiring procedure at the clinic stipulates that their recommendations be approved by officials at Georgetown University Hospital, one of D.C. General's two affiliate hospitals. The HIV clinic is affiliated with Georgetown's AIDS clinical trials. Things are already looking up; on July 17

a new part-time physician who plans to stay at D.C. General's HIV clinic, Milton Mills, began work on the unit. Newton and Espinoza have also started interviewing social workers with the intent of hiring two more.

The shortages of staff and other woes have spawned suggestions that D.C. General Hospital be converted into a private institution — or closed. The main concern hospital employees have about privatization is the potential loss of retirement benefits, according to Newton. "But there are some things about being hooked into the D.C. government that we could do without," she said, such as the inability of hospital staff to set salaries or hire in a timely manner.

"Yes, everything's in the process, but because of the bureaucracy at the D.C. government and the bureaucracy here, it takes months [to hire new doctors and social workers]," Pardo predicted wearily. "When I came on board [in April 1994], it took three and a half months to hire me, and that's when everyone was here, doing what they were supposed to be doing."

Forging ahead

Last month, James Wilson was hospitalized twice with pneumonia. Diagnosed with HIV in 1987, Wilson said his CD4-cell count is now under 100. These days, he visits the AIDS clinic at D.C. General at least once a month.

"I plan to be here for the whole day," said Wilson. "I'm not impatient like I got something to do I'm not picky and saying, 'Doctor didn't come in till 1 or 2.' She's doing her work She has a whole lot of patients and I know I'm not the only one, so why should I complain. She's a good doctor. She gives me what I need."

Christine McMurray learned she was HIV-antibody positive in September 1994 and has been a patient at the clinic ever since. Aside from a few minor complaints, she is very satisfied with the care she has received there.

"It's great," she said. "I'm still getting the proper care, but now I have to wait longer. But that's about it. I wouldn't know what to do if I didn't have my social worker [Pardo] in my life He's always there."

As the media continues to dissect D.C. General and politicians consider the hospital's future, Pardo, Espinoza, and the rest of the staff at the HIV/AIDS clinic try to keep focused on the task of caring for the people depending on them.

"The negative publicity frightens away patients," Newton said, noting that some clients have told her if they had known about the good treatment they would receive at the HIV center, they would not have waited so long to come.

Newton and Espinoza, glancing at each other with the knowing smiles of those who have spent many a trying hour side by side in the trenches, agree they are looking forward to the day that the spotlight of public interest recedes from D.C. General.

"We have a commitment to HIV patients," Newton said. "Hopefully, in 30 days we will have stopped putting out fires, the city will take us from under its microscope — and we can get on with the business of patient care." ▼

HIV/AIDS media campaign tailored to fit

by Sue Fox

It's a safe sex admonition that may not hit home with everyone — "Just be careful where you swing your ding-a-ling"—but that's the point. This message, along with an array of public service announcements, ads, and brochures, was designed to target a specific population that is often unreached by conventional HIV prevention models, many of which were developed within white Gay communities.

The "ding-a-ling" advice was delivered by David Ellis, the lead rapper of the Northeast Groovers, a local black "go-go" band recruited by the HIV/AIDS mass media campaign to get the prevention message out to the city's black youth. Judging from the number of African American teenagers who endured a press conference last week just to see the Groovers and hear Ellis's brief *cappella* riff, he seems to have struck a chord.

"The community knows exactly what it wants, what message will be effective," said Claudia Thorne, an HIV/AIDS mass media campaign organizer at Koba Associates, Inc. In September, Koba secured a \$200,000 contract with the D.C. Agency for HIV/AIDS to develop media products targeting the city's African American, African, and Caribbean populations.

According to statistics provided by the Agency for HIV/AIDS, approximately eight out of ten reported AIDS cases diagnosed in 1993 among D.C. residents were African American. Black Gay and bisexual men continue to represent the largest category of cumulative AIDS cases (32 percent), and from 1989-1994, the infection rate among black men who have sex with men increased 83 percent in the past five years in the statistical area which includes D.C. and parts of Maryland, Virginia, and West Virginia.

Last week, Koba presented the results of the yearlong campaign: two colorful HIV prevention and testing brochures, three Metro bus ads proclaiming "Get the 411 on HIV/AIDS," and two

radio public service announcements. The materials, the culmination of a unique collaboration between campaign organizers and many members of the black community, will be disseminated throughout the city.

To insure input from all groups, Koba set up a community advisory committee that represented "the entire mosaic of the African American community," according to Thorne. Evidence of the people's suggestions is everywhere, from the Northeast Groovers to pictures of Eban, an African symbol of "safety, security, and love," on the campaign brochures. HIV is referred to as "one more river to cross" for African Americans. Two of the three bus ads urging people to get tested for HIV feature mothers with children, because, according to Thorne, "women will do things for their children that they wouldn't do for themselves."

Thorne said 20,000 brochures and 450 Metro bus ads will be produced and the two radio announcements will be sent to numerous stations. Other media products such as posters targeting black men and youth and a television announcement are in the works and should be out within a month, according to campaign director Dana Olds.

AHA director Mel Wilson affirmed that the contract with Koba, which expires Aug. 31, will be renewed for another year, but declined to say at what level the campaign would be funded. Koba president Ford T. Johnson told the *Blade* he had been informed that District officials were considering cutting \$95,000 from the contract. The project is funded by D.C. appropriated, not federal, funds.

Wilson confirmed that there had been "preliminary discussions" about scaling back funds for the media campaign but he emphasized that no decision had been reached. "The case is not closed on this," Wilson said. "As it stands now, there is no commitment to cut anything." ▼

Dr. John Stanse I talks rankly about efforts to 'aid in dying'

by Sidney Brinkley

SAN FRANCISCO

— San Francisco General Hospital's Dr. John Stansell rocked the medical establishment six months ago when he publicly acknowledged putting into practice what other doctors only talked about in private: physician-assisted suicide.

"It's a very moral thing that physicians choose to provide release from pain at the end of natural life," said Stansell, 46, who calls it "aid in dying."

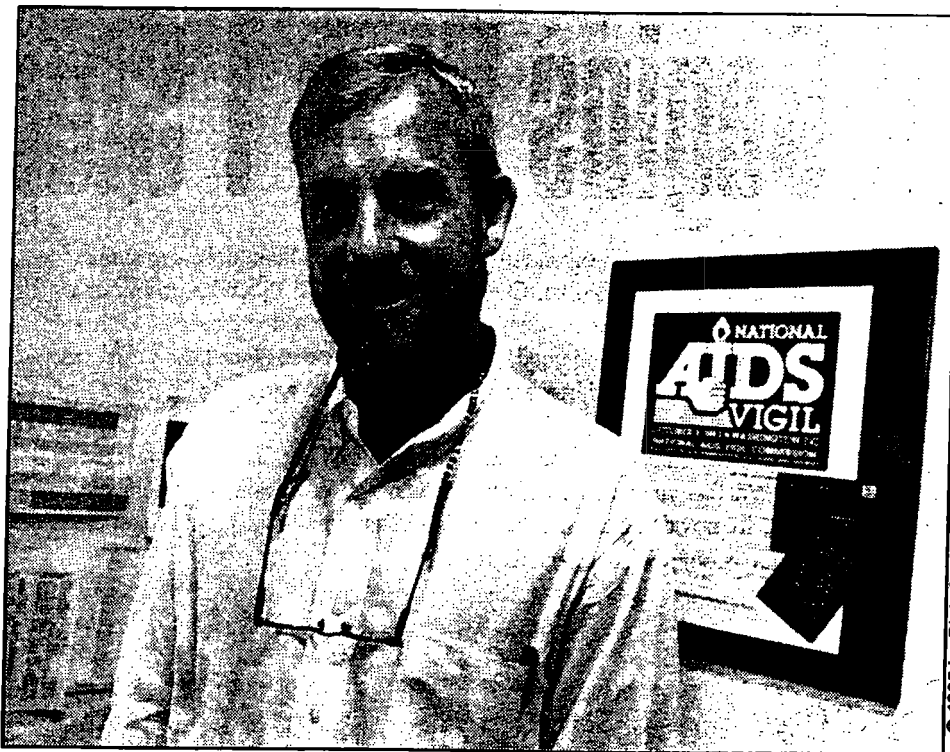
Physician-assisted suicide is illegal in 49 states. Oregon voters narrowly passed a measure last year legalizing the practice in that state, but it is currently under a temporary restraining order as a judge considers if it is constitutional. The Hippocratic oath, used for centuries to guide the moral and ethical behavior of physicians, specifically forbids physician-assisted suicide.

"To please no one will I prescribe a deadly drug, nor give advice which may cause his death," the oath states. "If I keep this oath faithfully, may I enjoy my life and practice my art, respected by all men and in all times; but if I swerve from it or violate it, may the reverse be my lot."

But Stansell firmly believes to do otherwise would not be upholding what he feels is the core principle of the physician's oath, and that is to treat the patient.

"What I am talking about is not the Dr. Jack Ker-vorkian type of suicide," Stansell told the *Blade* in a interview conducted in his office at San Francisco General Hospital. "I am talking about treating pain, whether psychic or physical pain, with medication to relieve that pain at the same time knowing that the patient is going to use that medication to abbreviate their suffering. I have absolutely no problem with that in the case of a terminal illness, with incredible suffering. We would be less than physicians, less than adherent to our oaths as physicians, if we didn't treat that kind of pain."

In his practice, Stansell see a great deal of pain and suffering. He is head of San Francisco General's renowned AIDS clinic, and the people to whom he provides aid in dying are his patients in the final stages of AIDS.



John Stansell: "I treat their pain, bearing in mind the treating of pain may entail some abbreviation of the life they have remaining to them but that is the trade-off."

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A report on pain in AIDS published in the March 1995 issue of *BETA* magazine, said a review of pain in a hospitalized population of AIDS patients reported that abdominal pain, peripheral neuropathy (destruction of the peripheral nerves), and Kaposi's sarcoma were the three most frequent pain problems. In addition, pain can occur as a result of AIDS therapy including the use of antivirals (AZT, ddI, ddC) and chemotherapy. Opiate analgesics, such as morphine, Dilaudid, and Demerol, are among the most frequently used drugs for moderate to severe pain.

"The majority of AIDS patients were in favor of physician-assisted suicide and euthanasia as options," the report concluded. "The presence of pain was highly correlated with endorsement of physician-assisted suicide or euthanasia."

Stansell, however, says he only offers aid in dying to patients he knows very well and has treated for a very long time.

"The key in any decision revolving around end of life, abbreviating suffering, has to come from a long-term physician-patient relationship," he said. "People need to get to know one another, get to know what is appropriate, how aggressive that person wants to be when faced with the inevitable demise. That absolutely is the key."

And when the demise is inevitable and the pain unendurable, Stansell will provide a prescription for pain killing opiates or barbiturates. When mixed with alcohol, the drugs become lethal. The patient falls into a deep sleep and respiratory cardiac arrest follows.

"I treat their pain, bearing in mind the treating of pain may entail some abbreviation of the life they have remaining to them but that is the trade-off. It is the double effect of treating pain."

Stansell is a pulmonary specialist—"I love the lungs"—and has always been interested in health care and enjoyed working in a hospital environment. Before becoming a doctor he was a registered nurse at George Washington University hospital in Washington, D.C. After working in the coronary unit he went to graduate school at GW to study physiology. He was close to finishing a Ph.D. when he had a revelation.

"I was walking down New Hampshire Avenue from where I lived on Dupont Circle, to the university and thinking about a life of poverty as a Ph.D. because there were no jobs available. Then it hit me at the corner of L Street and New Hampshire like a ton of bricks, 'Hey, maybe I could go to medical school!' I had never thought about it prior to that moment."

Stansell was 29 at the time and broke. With no money to interview anywhere else, he applied to GW's medical school and was accepted.

"I loved every minute of medical school," he said. "I was in my element from the start. I love learning, and they offered the environment that made my medicine a joy."

During his stay in Washington, Stansell met the man who would be his longtime companion, a law student and Gay activist named Clint Hockenberry.

They became interested in the Gay health care movement and formed the Gay Men's Venereal Dis-

Continued on page 19

Doctor 'aids in dying'

Continued from 14
ease Clinic in the basement of a church in Georgetown. Hockenberry served as president.

"When we were kicked out of the church basement, we formed a new clinic. The Whitman-Walker clinic was born on the floor of Clint's and mine's living room in D.C. I served as president for two years before Jim Graham came on board."

After medical school, Stansell and Hockenberry moved to California where he did his residency at Stanford University Hospital. He then moved on to the University of California at San Francisco as a pulmonary fellow, and then was offered the position as head of the AIDS clinic at San Francisco General which is a branch of UCSF. He has been in that position for three years.

Stansell has seen suffering in his personal life as well. Hockenberry died of AIDS in 1992. They had been together 17 years together and Stansell was devastated.

"I adored Clint," Stansell said. "Clint and I fell in love when we were children. We put each other through grad school. I worked to put him through law school and he worked to put me through medical school. Every marriage has its ups and downs, but I adored him."

The AIDS clinic at San Francisco General has been ranked the top facility for AIDS care in the country for the fourth year in a row according to a survey published by *U.S. News and World Report*. Stansell is one of the most prominent AIDS doctors in the country and it was inevitable that his acknowledgment of physician-assisted suicide would attract wide attention.



Dr. John Stansell: I got tremendous support from all over the country, from families, lovers, friends, and other professionals."

© 1995 by Rick Gerhart

Did he ever consider the consequences?

"I did consider the consequences. The only negative feedback I got was from the University of California lawyers who were worried about the liabilities of the university, and not inappropriately so, but I got tremendous support from all over the country, from families, lovers, friends, and other professionals."

According to a recent poll conducted by Dr. Donald Abrams of the San Francisco Consortium of Physicians, a group of doctors that treat primarily patients with HIV infection, over 50 percent reported giving patients medication strong enough to be lethal, knowing that the patients were going to use it in that

manner.

Despite that high figure, there have been no prosecutions in San Francisco for physician-assisted suicide. Dr. Boyd Stephens, the San Francisco medical examiner, told reporters he has never found sufficient evidence to refer such a case to the district attorney's office for possible prosecution.

Still, some physicians do have ethical issues about helping someone end their life.

"I can't say whether I'm in favor of or opposed to physician-assisted suicide," said pioneer AIDS researcher Dr. Marcus Conant.

"I have certainly come across patients who have made the decisions that they want to end their lives and I have understood why they have made that decision. However, I've seen other men who have just become depressed, withdrawn, and have inappropriately decided they wanted to end their lives. It is a very charged issue, but I don't think that we aren't capable, as a society, of dealing with something that is this important. Stansell may be telling us, from the heart, that he is anguishing over this issue and he wants to see it discussed in a public forum."

Stansell acknowledges that it is, in part, anguish — "I can't tell you the number I've watched die over the years, both patients and personal friends" — but his position is more informed by a belief that every individual has some basic human rights.

"Everyone should have some control over how they die," he said. "What could be more central to the individual than that last vestige of control. I have no difficulty at all to bringing a patient to that." ▼

He r s's arg me n s gain' ig w' der acceptance

Sen. Jesse Helms (R-N.C.) held up reauthorization of the Ryan White CARE Act because he wants the federal government to spend less money for treatment of AIDS patients. Helms wants to cut the money because HIV is spread by "deliberate, disgusting, revolting conduct." He and others — including lobbyists for some non-AIDS health groups —

Hastings Wyman Jr.

claim that more money is spent on AIDS than on other diseases that kill more people.

It doesn't take a genius to figure out, of course, that Helms's motivation is *not* more equitable distribution of health-related funds. His anti-Gay record, along with his bigoted rhetoric, strongly suggest that the right-wing senator's goal is to withhold research, treatment, and prevention dollars so that Gays will die off more quickly — sort of passive genocide.

Helms's latest volley on this issue is nothing new. It was for such as this that Texas columnist Molly Ivins recently referred to Helms as "that poisonous old hate sow, suckling all the little hate pigs." And *The New York Times*, in its article on Helms's stand on Ryan White funding, was quick to identify the senator as a lawmaker "who has vigorously fought homosexual rights."

Recently, however, and of greater concern, more respectable sources than Senator Hate Sow have begun to express similar sentiments. Some heart disease groups, according to one AIDS lobbyist, are now taking the position that AIDS is getting more than its fair share of federal funds. "This is the first time," the AIDS lobbyist told me, "that one of the other health groups has used that argument" — a trend probably inspired by the shrinking federal pie. Presumably the heart lobby doesn't care as much about

"unnatural acts" as Sen. Helms, but it smells a good argument that might increase its own coffers. Moreover, I have heard friends who are not homophobic, but who are concerned about breast cancer or other diseases, echo the Helms argument.

While no one is likely to persuade Sen. Helms that AIDS programs should be fully funded, other concerned folks out there are more open-minded, so it's important that the facts about AIDS funding get more distribution.

First, the short answer is that AIDS is *not* disproportionately funded. Figures from the U.S. Department of Health and Human Services on treatment, research, and prevention indicate that the federal government spends \$47.1 billion for heart disease, \$19.3 billion for cancer, and \$6.6 billion for AIDS.

Second, while AIDS is slightly ahead of some in the research category, the government still spends \$2.1 billion on cancer research, compared to \$1.6 billion on HIV/AIDS research. Since AIDS is relatively new, large sums have been needed to provide basic knowledge about the disease, a research base that already exists for other diseases.

Third, unlike other major diseases, HIV is infectious and continues to spread. Between 1992 and the year 2000, deaths from heart disease are projected to decline by six percent and deaths from cancer to rise by 14 percent. But deaths from HIV infection are projected to increase 100 percent, and AIDS is a heavy killer of young people. Therefore, when you look at something health statisticians call "years of potential life lost," or YPLL, you see a different dimension to the AIDS threat. While AIDS ranks eighth among diseases in total deaths, it ranks third in YPLL. In 1992, the YPLL per 100,000 people for all cancers was 836 (105 for breast cancer and eight for

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argument.

prostate cancer); for heart disease, it was 625; for HIV infection, 386.

Fourth, it makes little sense for anyone to divide the country on the basis of risk for a particular disease. Most health problems affect the entire society to some extent. I had a heart attack three years ago; I want the government to spend money on heart research, and find a cure that involves neither diet nor exercise. At age 56, my annual physical includes checking to see if I have prostate cancer, so cancer research is important to me. While breast cancer rarely strikes males, I don't want my mother, my two sisters, or my daughter to suffer from that disease because of a lack of research. (Notably, much HIV/AIDS research, because it involves the immune system, provides knowledge that is helpful in finding cures and treatments for other diseases, especially cancer.)

Fifth, much of the motivation for claiming that too much money is spent on AIDS comes, of course, from the fact that homosexual males are the highest risk group. However, critics of AIDS funding must consider that the epidemic is no longer just wiping out queers. AIDS is now the leading killer of all

Americans between 25 and 44 — that includes women and heterosexual men, as well as those of us who engage in "deliberate, disgusting, revolting conduct."

Sixth, while Helms gets exercised by the voluntary acts that transmit HIV, he doesn't advocate cutting health funds for treatment of lung cancer, which is caused by the voluntary — and some say disgusting — act of smoking. That may have something to do with the fact that he represents North Carolina, the nation's leading tobacco-growing state. Also, when syphilis — spread mainly by heterosexual activity — was incurable and eventually fatal, federal and local governments devoted enormous resources to its prevention and treatment.

Finally, Helms and company, including his fellow travelers in other disease groups, are not riding the wave of popular support they may think. A national opinion survey taken for the Human Rights Campaign Fund by the Democratic firm of Celinda Lake and the Republican firm of Lance Tarrance, found that seven out of 10 voters believe federal funding to care for people with AIDS should be maintained or increased. More than 60 percent of Republicans likely to vote in primaries — i.e., self-identified conservatives, born-again Christians, and active churchgoers — agree that AIDS treatment funds should remain steady or be increased.

So when all is said and done, what we're hearing about AIDS funding from Senator Hate Sow is so much hogwash. And the public isn't feeding at that trough.

Hastings Wyman Jr.'s column on Gay issues in American politics appears monthly in the Blade. He has published Southern Political Report, a nonpartisan newsletter, since 1978.

Hill Update

HOUSE UPS HOPWA FUNDING:

The House of Representatives Monday night passed a \$79.4 billion FY 96 Veterans Affairs/Housing and Urban Development (HUD) appropriations bill with a provision to increase funding for the Housing Opportunities for People with AIDS (HOPWA).

The House Committee on Appropriations approved July 18 an appropriations bill for VA/HUD which slashed the overall HUD budget by 23 percent, from its FY 95 level of \$26.1 billion to \$19.1 billion. The bill also consolidated Section 202 (housing for the elderly), Section 811 (housing for people with disabilities), and HOPWA, a \$186 million program that subsidizes housing for people living with AIDS who have low incomes, into a "special needs" account. Overall "special needs" funding was reduced by 47 percent to \$1 billion.

The aggregate total spent on the three "special needs" programs had been \$1.86 billion in FY 95. But an FY 95 rescissions bill, recently signed into law by President Clinton, cut spending to \$1.2 billion.

An amendment passed July 27 provides for a \$441 million increase to the "special needs" housing account in FY 96, which increases funding for the three programs by \$2 million more than the post-rescissions FY 95 level, explained AIDS Action Council's Aimee Berenson.

"It's all very confusing ... but this amendment means more than just restoring HOPWA funding," Berenson said. "If we compare this year's \$1.44 billion funding level with the post-rescission FY 95 funding level of \$1.2 billion, HOPWA fares well."

PELOSI HELPS RESEARCH:

The House Appropriations Committee July 21 unanimously approved report language offered by Rep. Nancy Pelosi (D-Calif.) that would grant authority to the National Institutes of Health's director to adjust the allocation of AIDS funding to the NIH's 24 institutes.

Although a House subcommittee on appropriations voted July 12 to increase the NIH budget by \$642 million, or 5.7 percent, it also voted to remove from the NIH's Office of AIDS Research (OAR) the responsibility to disburse AIDS research dollars to the 24 institutes conducting AIDS research. The subcommittee also did not earmark any of the NIH's research budget specifically to AIDS research, but instead left it to each individual institute to determine its own priorities for AIDS research.

Pelosi's report language, added to the FY 96 House Labor, Health and Human Services appropriations bill, allows the "[NIH] Director transfer authority to reallocate funds among appropriations accounts" and "encourages NIH to use this authority whenever it believes that an adjustment in the allocation of AIDS funding between Institutes is appropriate to

achieve scientific objectives or to facilitate promising research efforts."

Winnie Stachelberg, senior health policy advocate for the Human Rights Campaign Fund, said that Pelosi's "[v]ery short words will make such a difference for people living with AIDS."

The FY 96 House Labor, Health and Human Services appropriations bill was still before the full appropriations committee as of *Blade* deadline.

AMENDMENT PASSES: The House of Representatives approved July 19 an amendment proposed by Rep. Ron Packard (R-Calif.) which one AIDS advocate explains could significantly limit the scope of the Clinton administration's federal AIDS training initiative.

The amendment, approved 283-138 in the course of debate on a \$23 billion FY 96 Treasury/Postal Service appropriations bill, calls for no federal funds to be used for "unconventional" federal employee training, or training which "contains elements likely to induce high levels of emotional response or psychological stress in some participants." Packard explained on the House floor that unconventional training, in his eyes, includes training on the proper use of condoms.

The flap over "HIV/AIDS in the Workplace Training" began almost four months ago when the *Washington Times* reported an increasing number of complaints from federal employees who said the training was either "too graphic" or pushed people to "accept homosexuality as a viable lifestyle." The article, according to House Subcommittee on Civil Service Chairperson Rep. John Mica (R-Fla.), spurred his subcommittee to hold hearings June 23 on federal AIDS training.

Gay civil rights advocates said the hearings were more a "lynching" than fair and objective debate.

Nancy Buermeyer, policy advocate at the Human Rights Campaign Fund (HRCF), said the Packard amendment is an extension of the ignorance surrounding AIDS prevention.

"You can't teach people about AIDS without teaching them how to prevent contracting the virus. We're obviously disappointed with the passing of Packard's amendment," Buermeyer said.

She added that "at a time when White House guards feel they need to wear gloves to greet Gay elected officials, it makes no sense to have an amendment that could put up major barriers to how AIDS training is conducted in the federal workplace."

A substitute amendment proposed by Rep. David Hobson (R-Ohio) would have allowed federal employees to "opt out" of any training they deemed objectionable, but would not have prohibited such things as training on the proper use of condoms. The substitute amendment was defeated 223-201.

— José Zuniga

August 9, 1995

MEMORANDUM TO PATSY AND JEFF

From: Rachael, Rachel, and Vanessa

Re: August 9 news

"Fiscal Crisis May Hurt Health Care: Los Angeles Makes Choices It Doesn't Really Want to Face" (New York Times)

The H. Claude Hudson Comprehensive Health Center in downtown Los Angeles is one of 6 centers and 29 community clinics that are expected to be closed to help close the budget gap. Many patients who use the clinic do not have health insurance, therefore, they will be left with no where to go for services.

Fiscal Crisis May Hurt Health Care

Los Angeles Makes Choices It Doesn't Really Want to Face

By SETH MYDANS

LOS ANGELES, Aug. 8 — "Will run clinic for food" reads a small sign in the administrative office of a crowded, but doomed, county health center. The gallows humor speaks for an entire struggling county, which made the hard decision last week to sacrifice a social ideal to help plug a billion-dollar budget gap.

The clinic, the H. Claude Hudson Comprehensive Health Center, in downtown Los Angeles, has long been part of a ambitious commitment by Los Angeles County to extend medical care to more than one million indigent patients a year — a commitment that the county has now determined may have become too expensive to maintain.

Seeking to reduce the deficit last Tuesday, the county's five supervisors unanimously adopted an \$11.5 billion budget that envisioned the closing by Oct. 1 of all 6 comprehensive health centers and all but 10 of the county's 39 community clinics. The six county hospitals, including the huge Los Angeles County-University of Southern California Medical Center, would remain open but with severely reduced outpatient services.

"We don't have the ability to be the health maintenance organization for the world," said Supervisor Mike Antonovich, as he joined his colleagues in voting for cutbacks that none of them wanted.

The direction Los Angeles is taking is a sign of the times as county governments around the nation shrink under fiscal pressures, said Richard Weinstein, a professor of urban planning at the University of California at Los Angeles. The cuts were part of a downward spiral, he said, in which a disillusioned public denies tax money to the government, thereby reducing government services and contributing to further public disillusionment.

And when cuts are made, Mr. Weinstein said, they typically begin at the bottom. "Those who get squeezed first are those with the least power," he said. "There is nothing startling about that. All you've got to do is read history."

The result of the cuts in Los Angeles, said Dr. Mary Abbott, director of the Hudson center, will be "a tidal wave" of uninsured patients swamping and possibly forcing the closure of hospital emergency rooms, the only medical units required to accept the uninsured.

For many of the city's poor, clinics like the Hudson center have been the

A question of saving a major hospital or sacrificing clinics.

only places to go for detection and treatment of cancer or heart disease, tuberculosis or high blood pressure, diabetes or H.I.V. They go there to have a fever or sore throat eased or to have a broken bone set, to receive prenatal care, to immunize their children or for the physical exams that their children need for school.

"This is going to be a disaster for my family," said Luz Garcia, 59, who is married and has four children, as she waited for treatment for her swollen knees. "I don't know where we will go."

Without this sort of access to primary health care, Dr. Abbott said, there is a danger that people like Mrs. Garcia will become sicker, further burdening the health care system. And, she said, more communicable diseases are likely to go un-

treated, endangering the community.

Burt Margolin, whom the supervisors named last week to be the county's health crisis manager, said the planned cutbacks could be softened if public-private hospital partnerships could be formed before the Oct. 1 deadline and if Washington could provide a waiver to allow the broader use of Medicaid money for outpatient care.

Mr. Margolin said that although the county cuts in clinics and health centers were "horrendous," they were preferable to the closing of a large hospital because they were reversible. "The damage that is inflicted can be turned around in a matter of months, in contrast to the original plan, the closure of County-U.S.C. Hospital," he said.

Despite long-running differences with the public health care system, some private hospitals, like the California Medical Center in downtown Los Angeles, have expressed interest in helping keep clinics like the Hudson center open. The incentives include pre-empting a run on their emergency rooms, as well as expanding their business. But health care experts say such public-private partnerships face many obstacles.

And even if private hospitals were able to absorb half of the displaced patients, another 50,000 patients a month could swamp emergency rooms in the county, said David Langness, a spokesman for the Healthcare Association of Southern California.

Like other doctors and health administrators, Mr. Langness used the term "wartime conditions" to describe a scene of overburdened hospitals, of the sacrifice by triage of some patients and of desperate ambulances "shopping" from one crowded hospital to the next for help for their patients.

"I hate to say it because it sounds overly dramatic, but it's true: pa-



The H. Claude Hudson Comprehensive Health Center in downtown Los Angeles is one of 6 centers and 29 community clinics that are expected to be closed

so the county can close a billion-dollar budget gap. If that happens, it will be hard for people like Reyna Maderos to find treatment for her daughter Erica.

tients will die as a result of these closures," Mr. Langness said.

Virginia Price Hastings, director of the Los Angeles County Emergency Services Agency, noted that the rich would suffer alongside the poor from the difficulty of finding emergency care.

Still worse, Ms. Hastings said, the heightened demand could itself cause a reduction in the availability of emergency rooms. "The number of uninsured patients arriving in the emergency rooms will so overwhelm them financially that they will have to close to even have a stab at maintaining the survivability of the hospital," she said.

The urgent-care waiting room at the Hudson center the other day was a multi-ethnic cross section of the county's poor: mostly Hispanic residents, with a mix of blacks, Koreans and other Asian immigrants.

Reyna Maderos had brought in her 6-year-old daughter, Erica, for treatment of an abscess. Shin Young Lee had brought in his wife for her first prenatal checkup. Jorge Bedoya had come for treatment of cuts he said he got in a beating. Yoneida Espinosa, 18, was here for checkups for her two babies, Pablo and Cynthia. Jacqueline O'Neal, who works at a drug rehabilitation center, had brought a diabetic patient for treat-

ment.

"Where are they all going to go? What is going to happen to their health?" asked Brenda Bravatti, an administrative assistant at the health center.

Dr. Clara Gelbard, the center's service chief for internal medicine, said she had "dark thoughts" about the day when the clinic would simply close its doors on these people.

"Our instructions are that our patients must be referred elsewhere," Dr. Gelbard said. "That is normal medical practice. But unfortunately we don't have any place to refer them to."

August 10, 1995

MEMORANDUM FOR PATSY

FROM: Jeff

SUBJECT: Consultation with outside experts for adolescents report

Over the last several days, we have spent a good deal of time discussing the major themes and recommendations of the report. By Friday, we want to be able to fax out to the consultants coming to town on Monday an outline of these issues, as well as some key questions around which discussion will be focused. What follows is essentially what we want to share with them -- but want your sign off on to be sure that the issues we are raising and the direction in which we are moving is consistent with your view of what the report needs to address.

General guidance to the panel: The following outlines the basic themes, messages, and recommendations that have been gathered over the last several months. In reviewing this, our goal for the discussion on Monday is to seek your general reaction to them: are these the basic messages (remember we must be concise or we will lose our audience)? are these the basic recommendations that ought to be made? Can these be pared down so we are more focused? Can the recommendations be made much more specific -- so there is a clear implementation response against which we can be held accountable?

I. Overarching themes

In working on this report, there are a number of themes that emerged consistently throughout our discussions with adolescents, with providers of services for adolescents, and experts in the HIV and adolescent communities. These themes must be kept in mind and form our response to the specific problems and policy issues addressed later in this report.

[note to us: we need to reduce this to three or four main themes or they will get lost]

A. Adolescents are not big children or small adults. Our response to all aspects of HIV among adolescents must recognize that adolescents are psychologically and physiologically different from any other age group. We must identify, understand, and address the unique characteristics and needs of adolescents in designing our response to HIV among adolescents.

B. Adolescence is a normal developmental period during which young people must gain a sense of self (and self-worth), sort out values and views to develop personal beliefs and

Key Issues for Adolescent Report Panel/Page 2

principles. This process can lead to experimentation and risk taking -- something we often encourage among young people but which can have disastrous consequences when it comes to sexual activity and substance abuse. The level of self-worth an individual adolescent has will directly affect his or her choices regarding personal risk taking.

C. No one -- including adolescents -- faces HIV in a vacuum. The context in which HIV is confronted -- family life, homelessness, poverty, sexuality issues, racial and ethnic issues -- all play a role in how one responds to HIV. A young person who does not know where he is going to sleep tonight or get his next meal will have little ability to concentrate on issues of safer sex. A young person conflicted about her sexual orientation will not be able to address issues of HIV prevention unless that prevention program addresses conflicts associated with that identity crisis. This broader context, if not addressed, will render our HIV-related efforts far less effective.

D. The role of families in forming the response of young people to HIV cannot be underestimated. HIV prevention, an HIV diagnosis, and HIV care must target both the adolescent at risk and his/her family. Young people should not have to face this terrifying disease alone.

E. Throughout our discussions with young people about HIV, we heard two themes -- coexisting though contradictory: Adolescents have a sense of invulnerability that affects their beliefs about health, especially the relationship between personal behavior and physical and emotional health. The sense that "it can't happen to me" often leads an adolescent to ignore warnings and take serious health risks. Conversely, many adolescents -- especially many gay youth living in the epicenters of the epidemic -- view HIV infection as inevitable, as they have watched so many of their elders become infected and die. Similarly, many inner city youth, surrounded by violence and death, see shortened lifespans as normal -- and death from HIV as a far more distant threat. This sense of inevitability makes them see attempts at adopting behavior change as futile. To be successful in overcoming this epidemic, both of these attitudes must be confronted and overcome.

F. The strong link between unsafe sexual practices and the use of alcohol and other drugs cannot be overstated. Substance abuse prevention and treatment is also HIV prevention -- both directly (in terms of needle sharing transmission) and indirectly (drug induced willingness to take risks sexually).

G. Young people are no different than adults in the sense that they are deeply influenced by their peers. Their peers just happen to be young people also. Any programs addressing HIV must also address peer influences.

H. The popular culture -- media and the arts -- have a strong influence on adolescents. Both the public and the private sectors must begin to use this avenue to influence the behavior of young people.

Key Issues for Adolescent Report Panel/Page 3

I. The stigma associated with HIV in American society -- and the stigma associated with those people most often identified with HIV (homosexuals, substance abusers, people of color) -- constantly undermine our ability to address HIV among adolescents. Strong national leadership is needed to counter this stigma and to legitimize the work being done to counter HIV among young people and among Americans generally.

Questions for the panel (and we may want to do these last -- or we'll spend all day on them) --

- Are these the general themes that emerge from our discussion?
- Are some of these not sufficiently central that they can be deleted?
- Are some so central that they should get even greater focus?
- Is this the most effective way of articulating them -- not wordsmithing but how the concepts are put forward?

II. Epidemiology

The epidemiology section, placed early in the report, is designed less to give a total picture of the epidemic (we don't need to bore people with lots of data) -- but rather to paint a picture of the epidemic that makes people sit up and pay attention.

It is our intention in this section to combine both statistics on HIV/AIDS among adolescents *and* behavioral data. That will demonstrate both the current impact of the epidemic and its potential. It is probably the only way that we can convince one audience of this report -- parents -- that their kids are also at risk.

Questions for the panel:

- Does mixing stats and behavioral data make sense?
- Do you have better examples of data that make people sit up and pay attention?

A. Key data that reflect urgency of the epidemic:

1. Total # of adolescents diagnosed to date: 1,965.
2. Sixth leading cause of death in people 13-19 since 1991
3. Of the nearly 81,000 new cases diagnosed in 1994, 417 were among adolescents; 2,684 among young adults 20-24.
4. It is estimated that nearly 25% of new HIV infections between 1987-1991 were in people under 22.
5. Among adolescent cases, the proportion of females has more than doubled from 14% in 1987 to 32% by 1994.
6. According to unpublished CDC data, 90% of women with HIV/AIDS are pregnant at some time during their illness, 50% of whom have their first pregnancy before the age of 20.
7. AIDS disproportionately affects minority adolescents: 37% of the cases are among whites,

Key Issues for Adolescent Report Panel/Page 4

42% among African Americans, and 19% among Hispanics.

8. Injection drug use directly or indirectly accounted for 56% of AIDS cases among female adolescents.

B. Key data regarding behavior of young people reflecting the urgency of intervention in behaviors:

1. Over the past three decades, growing proportions of women and men have become sexually active in their teens. In the late sixties, 35% of women and 55% of males have had sex before their 18th birthday. Today, 56% of women and 73% of men have had intercourse before their 18th birthday.
2. Many studies report using alcohol or drugs when they have sex and, in the most recent survey, one in 62 young people in high school have injected drugs.
3. [Comparable numbers on what parents THINK their kids have done -- does this exist?]
4. 76% of 14-15 year olds are involved in drinking alcohol and smoking marijuana and are more likely to have intercourse.
5. An estimated three million adolescent women and men get an STD each year, accounting for 25% of all new STD cases annually.
6. [still getting data on linkage between drug and alcohol use and sex]

C. Policy Recommendations:

1. We need better data about the epidemic among adolescents. Questions for the panel:

- What specific surveillance and epidemiologic data are not now available that would improve our understanding of the epidemic?
- Are there seroprevalence studies not now under way that could be initiated? Are there important studies at risk of losing their funding that we should recognize?
- Is there value in recommending changing the definition of adolescence from 13-19 to 13-21?

2. We need to know much more about the behavior of adolescents. While we have some good data on what young people are doing, we know a lot less about *why* they do it and in *what contexts*. Questions for the panel:

- Can we define this agenda in general terms?
- Can we define this agenda in a way that will make such research politically viable?
- How do we address issues of parental consent in behavioral research (which are part of the Contract with America)?

III. Prevention

A. Messages about prevention we wish to convey:

Key Issues for Adolescent Report Panel/Page 5

1. Prevention programs need to recognize where adolescents are on the continuum of abstinence to sexually active without protection. The goal of prevention programs should be to support young people in maintaining safe behaviors and moving them away from unsafe behaviors.

abstinence.....contemplating sexual activity.....active and safe.....active and unsafe

Question for the panel: How do we make politically palatable recognizing this continuum (including that many young people are sexually active and unsafe) -- and the need to move young people in increments to the left along this continuum -- including to safe sex (rather than abstinence for those not ready to return there)?

2. It is important to recognize that messages of abstinence and condoms are not incompatible and they are not perceived as conflicting messages by young people. Young people are similarly instructed not to drink, yet they are told that if they do drink alcohol, they should not drive a car. Young people are able to view these messages as primary and secondary means of harm reduction.

3. The behavioral data show that most people engage in potentially risky behavior, including our children. We need to be honest with ourselves and with young people and provide them the emotional support they need to reduce their risk as well as the physical support, where appropriate. In other words, we need to help adolescents develop values and attitudes that support them in reducing risk; and we need to work with adolescents in developing the skills they need to protect themselves -- whether in negotiating relationships, using condoms, or bleaching needles.

4. Good prevention is neither easy nor inexpensive; but it is a high-return investment.

B. Programmatic issues:

1. One of the interesting findings in our discussions with prevention providers is that there was at least as much concern about spending existing prevention resources wisely as there was in finding additional sources of funding. Many felt existing resources could be more effectively deployed and better coordinated.

2. There is general recognition of the value and impact of peer-based programs for adolescents. Programs designed by and implemented by young people are a critical component to effective prevention.

3. Adults should be targeted so they understand the need for and value of prevention. They also need training so that adults who are role models, parents, spiritual leaders, *the medical community*, can all play a role in promoting the prevention message.

Question for the panel: Are there specific messages or recommendations that should

Key Issues for Adolescent Report Panel/Page 6

be made for each of these groups.

4. Prevention is not a one-shot short-term effort. Programs need to reflect the long-term nature of HIV prevention. There needs to be repetition and consistency -- and constant reinforcement of the message and constant reinforcement of social support for positive behavior change.

5. Prevention programs must recognize the diversity of young people for whom prevention programs are needed. Community and group-specific messages and activities are very important.

C. Policy Recommendations:

1. Funding for HIV prevention must remain a high budgetary priority.

2. Young people must have a central role in community prevention planning, program design, and program implementation.

3. The government can encourage the more effective use of scarce prevention resources by:

a. linking the targeting of prevention dollars and programs to the epidemiology of HIV -- which will give greater priority to the needs of young people and will permit better direction of those resources among young populations.

b. encouraging public-private partnerships in HIV prevention. Government alone cannot win this fight. Collaboration with the private sector will broaden the base of support for prevention and might permit more innovative experiments with private dollars, while focusing government funds on more "accepted" approaches.

c. doing better at technology transfer and technical assistance: educating those doing prevention at the community level about successful models of prevention while providing technical assistance to adapt these models to local communities and to evaluate the implementation of them.

4. There should be regional training centers for AIDS educators along the lines of the AIDS Education and Training Centers for health care providers.

5. AIDS education training should be a condition for receiving or renewing teacher credentials.

6. Comprehensive school-based health education programs should be required in all 50 states.

7. Government leaders at all levels must engage in efforts to destigmatize HIV and those affected by HIV. Without a change of national attitudes, prevention efforts will be undermined.

Key Issues for Adolescent Report Panel/Page 7

IV. Research

A. Messages:

1. Our understanding of HIV in adolescents has been hampered by a number of factors including:

a. adolescent biomedical research is not a clearly defined field; it is even less so for HIV disease.

b. our knowledge of how the virus behaves in the adolescent body is limited

c. our general knowledge of puberty is insufficient; it hampers our understanding of HIV (and potential treatments for HIV) in adolescents.

2. There are special issues associated with clinical trials and adolescents:

a. there is a disparity between the relative number of adolescents with HIV and the proportion of those in clinical trials who are adolescents.

b. there are special difficulties in recruiting and retaining HIV-infected adolescents for participation in clinical trials -- including access and the need for parental consent.

3. Prevention efforts are hampered by the lack of research on adolescent behavioral issues -- particularly research that gives us a better understanding of the motivation for adolescent behaviors.

B. Recommendations:

1. Both biomedical and behavioral research on HIV should have adolescent-specific portfolios, supporting adolescent-specific programs and research where appropriate.

Question for the panel: is there the need for a government-sponsored conference on defining this agenda? is there a need for structural changes in the Office of AIDS Research, in the planning process of OAR, or any of the NIH institutes that we could recommend that would move this issue along?

2. Access to clinical trials (as well as behavioral research) must be integrated into existing points of access to the system that are used by adolescents. In other words, research should be brought to the community level where adolescents will have better knowledge of them and access to them.

Question for the panel: is there a recommendation to be made about informed consent?

V. Treatment

A. Messages

1. Adolescents face challenges in accessing care and in finding providers that have special knowledge about HIV and about adolescents.

Question for the panel: Is the problem a lack of HIV specialty care or is it a problem of a lack of adolescent specialty care? Which is easier to fix? How?

2. Adolescents with HIV have a need for a continuum of services -- reflecting primary care needs as well as social service needs that make accessing primary care possible and adherence to a care protocol possible.
3. The continuum of care must include substance abuse treatment and mental health services.
4. Primary care and social service programs must address related issues facing young people with HIV -- ranging from homelessness to the needs of incarcerated youth to the special services and support needed by HIV-infected young women, especially pregnant women.
5. Financing health care poses special problems for young people. They are generally not financially independent, but fear of disclosure of their HIV status to parents may delay access to needed care. In addition, seeking HIV-related care may place the private insurance of their parents in jeopardy. [get numbers on uninsured adolescents] In some cases, adolescents may be uninsured even though their parents are eligible for Medicaid.
6. The challenges of integrating substance abuse treatment with HIV care are formidable; they are even more challenging when adolescents are involved.
7. Special effort is needed to have supportive parental involvement in the care of their adolescent children. Psychosocial support is needed for children to support them in telling their parents of their illness, to deal with parental reactions (especially if negative). Support is also needed for parents as they confront this devastating news.

B. Policy Recommendations

1. Financing issues:

- a. Don't cut Medicaid. This is the lifeline for young people accessing insurance. [get better age breakdown of adolescents with HIV on Medicaid]

Question to the panel: are there specific Medicaid coverage issues we need to address? (e.g., types of services covered; problems in managed care that are especially acute for adolescents?)

Key Issues for Adolescent Report Panel/Page 9

b. Address portability issues for private health insurance. Parents of adolescents with HIV may face job lock if their child's HIV status becomes a pre-existing condition in moving from one insurance plan to another.

c. The importance and potential of Ryan White CARE Act programs. Federally funded programs serving people with AIDS must recognize the need for specialized services for adolescents (and cannot and should not be lumped together in programs and planning with pediatric cases). CARE Act grantees should be required to provide funds to services for adolescents in some proportion to their presence in the local community's AIDS population.

2. Access to services:

a. The needs of adolescents will vary from community to community, depending on what underlying infrastructure is in place. Adolescents and advocates for adolescents must be part of the health planning process for HIV-related programs.

Question to the panel: Should we ask HRSA to develop a special program advisory/guidance on adolescent care and service needs for all programs seeing HIV-infected adolescents? Are there other specific steps that can be taken within existing resources that will highlight these issues?

b. Adolescents must be able to access adolescent-specific treatment programs. Recruitment, retention, and adherence to treatment, prevention, and research protocols is an overarching issue for adolescent care and services, that can be best addressed through adolescent-specific programs.

VI. Counseling and Testing

Note to the panel: We are still in a quandary as to where in the report counseling and testing should be addressed. Does it require a separate section simply because it can be so contentious? Or does it place too much focus on counseling and testing when so many other aspects of HIV and adolescents are neglected? This is both a tactical question and a substantive one -- because where counseling and testing is placed reflects a position regarding the role of counseling and testing. So for this section, at this stage, we have more questions to ask:

A. Should HIV routine counseling and voluntary testing become the standard of care for all adolescents? (If 70 percent of men and 53% of women have had intercourse by the age of 18, an argument could be made for this.)

B. What settings are most appropriate for counseling and testing of adolescents? Can publicly funded counseling and testing sites successfully serve adolescents? If so, how?

Key Issues for Adolescent Report Panel/Page 10

C. What kind of outreach programs are needed to create interest and a feeling of safety for young people to be counseled and tested?

D. Are there practical solutions (that can be addressed at the federal level) to the issue of access (who pays?), consent, and confidentiality? Or are these issues we identify and urge states to address?

August 15, 1995

MEMORANDUM TO PATSY AND JEFF

From: Vanessa Potkin, Rachael Smith, Rachael Garfield

Re: News for 8/15

"GOP's Medicare Pitch Faces a Tough Crowd on the Road" (Washington Post)

Rep. Neumann announced to a group of his elderly constituents that the GOP is working on a new plan would give the elderly the option of either staying on Medicare or (for the amount spent on coverage for an average Medicare beneficiary) buying private coverage to obtain their current benefits plus eyeglasses, prescription drug and nursing home care. The plan was met with much skepticism from his constituents as well as health care analysts.

"Taking on TB" (Washington Post)

Investigators for the District Bureau of Tuberculosis Control are practicing a new strategy called directly observed therapy, whereby they go into the city and ensure that people with active cases of TB take their medicine. The therapy has been given credit for the first substantial decrease in TB cases in New York in 15 years.

"Forty Five Infected with TB by Homeless Man" (Washington Post)

A forty-eight year old homeless man with active untreated TB infected 45 people over the course of six months. Unlike other reported TB outbreaks, the high rate of infection was not caused by the pressure of HIV.

"In Italy, Rebels Without A Cure" (Washington Post)

Three HIV positive men have committed a series of bank robberies - unmasked and in broad daylight. The current law bars authorities from keeping AIDS patients in jail. They claim to be protesting the lack of care and support given to those with the disease.

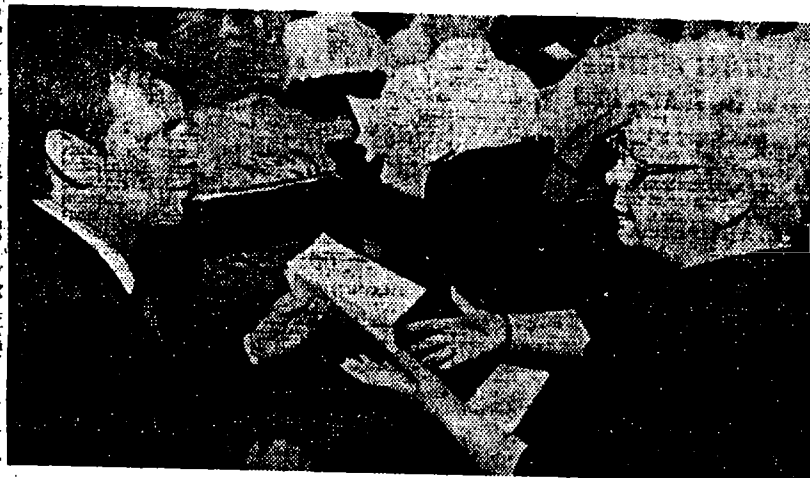
"FDA Approves Baboon Cell Test On AIDS Patient"

The FDA approved an experiment that involves injecting baboon bone marrow cells into an AIDS patient in hopes of repopulating the patients blood and other tissues with immune cells.

"Americans, Europeans are ignorant of STDs" (Washington Post)

A survey sponsored by the American Social Health Association revealed that people from 5 western European countries are no more knowledgeable about STDs than adults in the US. Of 1000 people surveyed, 30% said they knew someone with a STD. One third of people surveyed said they could not name a STD other than HIV/AIDS.

GOP's Medicare Pitch Faces a Tough Crowd on the Road



Rep. Mark W. Neumann talks with constituent Shirley Shute at a meeting in Lake Geneva, Wis., that focused on new approaches to Medicare.

By Kenneth J. Cooper
Washington Post Staff Writer

BELOIT, Wis.—Rep. Mark W. Neumann hustled like an insurance salesman last week, pitching new medical policies to elderly constituents during three long days of back-to-back meetings in southeastern Wisconsin.

The freshman Republican assured the anxious and sickly that they would be allowed to stay enrolled in Medicare, the federal health program for 37 million elderly and disabled. But, Neumann said, the GOP is working on a better option: For the amount spent on coverage for an average Medi-

care beneficiary, the bold and healthy could buy private coverage to obtain their current benefits plus eyeglasses, prescription drugs and nursing home care, too.

"You will be offered the option of staying on Medicare if you so desire," Neumann told an audience of 50 at the Beloit Senior Center. "I'm going to tell you my personal opinion, after studying this. I don't think you're going to want it."

But many who heard Neumann make his case were skeptical, especially because he offered few details, particularly about how private insurance companies could afford such generous benefits.

"You're telling me that the pri-

vate enterprise is doing things more efficiently than the single-payer system. I don't believe it," one elderly man said.

After more than a decade of frustrated government efforts to restrain the bounding costs of Medicare, Republicans who now control the House think they have discovered an approach that never occurred to their Democratic predecessors—government vouchers for private coverage. Republicans are banking that the shift from Medicare to private insurance would generate a substantial part of the \$270 billion of Medicare sav-

See MEDICARE, A4, Col. 1

Rep. Neumann 'ries To Sell GOP Medicare Ideas to Tough Crowd

MEDICARE, From A1

ings they need to balance the budget by 2002.

Party leaders dispatched Neumann and other House Republicans to sell the new GOP approach to skeptical constituents even though they have yet to agree on its details. The former businessman, armed with the same script other Republican lawmakers took to their districts for August recess performances, denounced "bureaucrats" who run Medicare as inept and professed faith in private companies' ability to deliver better benefits for the same money. But not surprisingly, Neumann didn't always seem to know what he was talking about.

"There's no way in hell a private insurance company could beat us in terms of value for the dollar," said Bruce C. Vladeck, who directs the Health Care Financing Administration (HCFA), which runs Medicare.

Vladeck said in an interview that Medicare can undercut private insurance rates for traditional coverage because the government has lower administrative costs and pays lower fees to doctors and hospitals.

Marilyn Moon, a health care analyst at the Urban Institute, said various studies have found that Medicare's administrative costs range from 2 percent to 4 percent compared to 8 percent to 25 percent for private companies, including profits. And Vladeck noted that administrative costs are highest for small companies that specialize in the kind of individual policies Republicans suggest that Medicare beneficiaries could buy.

Neumann, asked in an interview if he would be surprised to find Medicare to be more cost-effective, replied: "It would more than surprise me. I would not believe it."

Neumann cited a bar graph, extracted from HCFA data and the latest annual report of Medicare's trustees, indicating that the program's payments to hospitals went up 10.5 percent last year while health insurance costs for

large employers were going down 1.1 percent. The chart is titled, "There is hope: Private sector has made improvements that can help Medicare."

The only way private companies have demonstrated they can provide better benefits at the same cost as Medicare, Vladeck said, is "managed care," usually from health maintenance organizations (HMOs) that deliver a broad range of health services for a predetermined fee.

But Neumann did not mention managed care in his presentations unless asked about it.

"I think it scares people," he explained. "Most of our senior citizens have not had that during their careers. So if it's not something you're familiar with, it becomes fear of the unknown."

Typically, converting from traditional coverage to an HMO means a change in doctors, a frightful event for many elderly who have grown attached to their physicians.

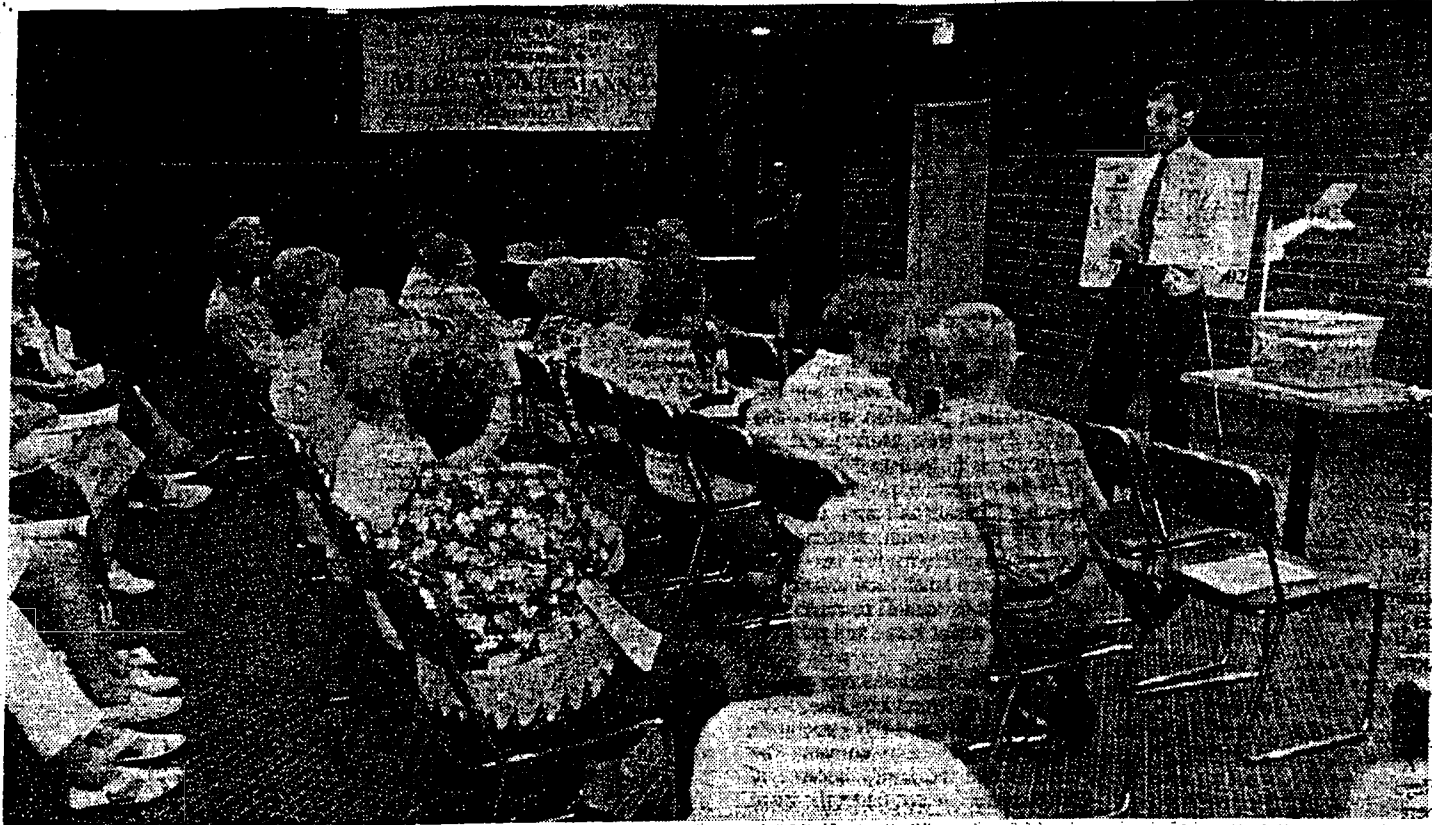
"I don't want any HMO or any of that crap," Hazel Ann Helgesen, 85, told Neumann at his Evansville meeting. Neumann vowed to oppose any plan that would not let her keep Medicare. "If you vote for it, I'll vote you out," she threatened.

Neumann predicted that Medicare vouchers and another possible option, "medical savings accounts," would appeal most to beneficiaries who are younger and healthier than Helgesen, who has had heart trouble. Through such savings accounts, Medicare beneficiaries would buy private coverage with a relatively large deductible, \$3,000 or more, and bank a similar amount each year if they escaped major illness.

"That's interesting," Freddie Stark, 76, mused out loud as she listened to Neumann's presentation in Janesville.

"I don't need any medical [care]. I'm in perfect health for an old guy," her husband, Bud Stark, also 76, explained later. "A person should be able to pay for their own medical."

An exodus of younger, healthier beneficiaries from Medicare would



BY JIM SLOSIAREK FOR THE WASHINGTON POST

Rep. Mark W. Neumann speaks to elderly constituents at a town meeting in Lake Geneva, part of three days of such gatherings in southeastern Wisconsin.

drive up the average cost for those who remain in the program, a classic insurance problem known as "adverse selection." The Republican plan being drafted by a small group of lawmakers is to address the problem, but has not decided how, Neumann said in the interview.

Neumann, who has established a reputation as one of the most aggressive budget cutters in the new Congress, told his elderly constituents that Medicare and the rest of government could cut as much as 30 percent in spending lost to fraud, waste and abuse. When he asked audiences if they believed the federal government wasted 10 percent of taxpayers' money, many snickered, and most raised their hands. A majority indicated agreement as Neumann raised the proportion wasted to 20 percent and then 30 percent.

"If the money is not filtered through all the bureaucrats that are currently involved in the system ... what was going to those bureaucrats can now go to buy you additional insurance," he said in Beloit. "The first thing that has

to be done is we have to stop waste, fraud and abuse. It's terrible."

Neumann spent most of a day talking to constituents about Medicare, scoffing at "the government dealing with all those doctors' bills" before he learned that private insurance companies play a large role in the program.

Under federal law, hospitals and doctors submit their Medicare billings to private insurance companies operating under government contracts. The companies review the bills, pay them with federal money and send notices to patients.

Neumann learned of insurers' role after holding his Evansville meeting in the regional office of Blue Cross and Blue Shield United of Wisconsin, which has processed Medicare bills since the program began in 1966. "Our outstanding review and fraud and abuse efforts ensure effective use of taxpayer dollars," the nonprofit insurer proclaims in its brochure.

HCFA employees, Neumann maintained, are still to blame. "Whose rules and regulations are these private companies working under? And who is it that's managing the private companies

to see to it that they are finding waste, fraud and abuse?"

A Janesville man told of one possible example of waste. A doctor offered to charge \$2,900 to perform gallbladder surgery on him in his outpatient clinic, but Medicare would not provide coverage unless the operation was done in a hospital, which wanted \$6,800 for keeping the man in its care about eight hours. The man persuaded the local hospital to reduce its fee to \$4,900.

Eliminating such instances of waste could finance additional benefits, Neumann said, including hearing aids, an addition made to his list at a Janesville man's suggestion.

Neumann told his elderly constituents he would give their recommendations to Republicans working on the plan to save Medicare. He told his audience that by cutting \$270 billion in projected Medicare expenditures, the program would be saved from bankruptcy. However, he did not mention that the savings were also necessary for the GOP to achieve its balanced budget goal.

"I expected to find a lot of fear amongst our senior citizens. I really

expected a stronger negative reaction," Neumann said. "The questions that came out of there were not the hostile, anti, you-can't-do-this kind of questions."

But Neumann acknowledged that his constituents did not appear to have strong feelings either way about a GOP Medicare plan that does not exist. That has not stopped Republicans and Democrats from telling uncertain beneficiaries what to make of the proposed changes.

"I'm not really understanding all I'm hearing," Helen Exstrom, 81, admitted after the Janesville meeting. "That's what I'm not understanding—which [option] would be better for me. You get one answer, and you turn it around, you get three or four answers."

FOR MORE INFORMATION

To read Post background articles about GOP plans to overhaul Medicare, see *Digital Ink*, The Post's on-line service. To learn about *Digital Ink*, call 1-800-510-5104, ext. 9000.

Taking On TB

To slow the spread of the disease, health workers visit patients three times a week to make sure they take their medicine.

■ By Paul Arnold

It's over 90 degrees in the shade when JoAnne Kelley pulls her white D.C. government sedan into an illegal parking space on a narrow street in Adams-Morgan. "That's another good thing about this job," she says as she opens the trunk to remove a small insulated cooler bag. "You can park anywhere you want." Kelley should know. Her job as a tuberculosis investigator takes her to every quadrant in the city at least three times a week.

She is one of five investigators for the District's Bureau of Tuberculosis Control. Her job is to make sure that people with active cases of tuberculosis take their medicine; it's a relatively new strategy called directly observed therapy, which officials say has helped significantly to reduce TB cases in the District.

DOT, in which TB investigators literally watch patients swallow their pills or give them injections, is for patients with active TB who have demonstrated that they can't—or won't—take medication properly on their own. The monitored treatment is usually delivered in the patient's home, although it may take place at a clinic or workplace. Since many tuberculosis patients are unemployed or homeless, food cou-

pons, shelter, transportation and other incentives are sometimes used to persuade them to complete their therapy.

People with weakened or immature immune systems—children, the elderly, alcoholics and those infected with HIV—are at greatest risk from exposure to tuberculosis.

Kelley checks the contents of her bag, making sure it contains everything she needs, especially the Mickey Mouse bandages. This afternoon, she is visiting the home of an 18-month-old girl who contracted TB from her father. The girl is too young to swallow pills, so she receives her medicine by injection.

Her disease is caused by a bacterium called *Mycobacterium tuberculosis*. Although it usually affects the lungs—it eats away lung linings—TB can also involve the spine, kidneys, brain or any other organ. Ninety percent of infected people never develop symptoms, meaning they never become infectious and cannot spread the disease. Five percent of people who have recently been infected with TB will develop the active disease within two years of infection. Another 5 percent will develop the disease later in their lives—when elderly, diabetic or otherwise physically weakened.

Infectiousness declines very rapidly after effective therapy is started, but how quickly it declines varies from patient to patient. Some patients may stop being infectious on the day they begin treatment. In general, however, a person can be considered noninfectious after two to three weeks of adequate treatment if tests show a definite positive clinical response to the medications.

TB is spread through the air when a person with active TB coughs, sneezes or speaks, expelling contaminated droplets from the lungs. A person is usually infected by TB only after prolonged, close exposure to someone with active TB in the home or the workplace.

Doctors diagnose tuberculosis using skin tests, X-rays and sputum tests. For those who have active, infectious cases, the key to treating the disease and controlling its spread is to make sure they are taking the appropriate medications, primarily isoniazid, rifampin, pyrazinamide and ethambutol—for the duration of their treatment. This can be a daunting task, because drug treatment for TB lasts anywhere from six months to a year in special cases. Untreated, about half of active TB cases become fatal within a few years.

On this early August day, Kelley enters the sweltering three-room apartment her small patient shares with seven family members and begins to prepare a syringe. The little girl is happily sitting on her mother's lap playing with her toes. Fear enters the girl's eyes the moment she sees Kelley reach into her bag. Kelley has been visiting the apartment three times a week for several weeks, and the 18-month-old knows what is coming next. She starts to scream. While the girl's parents hold her down, Kelley produces the needle from her bag and proceeds to administer a dose of medicine into the child's thigh. Neither Mickey Mouse nor Kelley's hug manage to stop her tears.

"It's hard with [the 18-month-old], because she doesn't understand what I'm doing to her. She doesn't know that I'm trying to help her get better," Kelley says later.

But that's essentially what Kelley and the District's other TB investigators try to do daily: help sick people who have been unable to help themselves get better. The District has officially recorded 83 cases of active TB this year, although that number does not reflect unreported TB carried by illegal aliens and some homeless persons. Of the 83 cases, 45

are managed by the Chest Clinic at D.C. General Hospital. The rest receive treatment from private physicians. Nearly two-thirds of the clinic's patients are enrolled in the District's directly observed therapy program.

DOT has had dramatic results in other cities that have seen a resurgence of tuberculosis. Hundreds of TB patients in New York got better when TB control officials focused their efforts on DOT, according to a recent article in the *New England Journal of Medicine*. The therapy has been given credit for the first substantial decrease in TB cases in New York in 15 years. New York, which has the highest incidence rate of any city in the country, announced a reduction from 3,811 cases in 1992 to 3,235 in 1993. In 1994, there were 2,995 cases and the downward trend appears to be continuing this year.

"What happened in New York City is one of the great medical turnarounds in history," said Lee Reichman, a tuberculosis expert who is a past president of the American Lung Association. "New York targeted unprecedented amounts of

See TUBERCULOSIS, Page 12

TUBERCULOSIS, From Page 11

resources into TB control, largely for DOT. It is a very labor-intensive therapy, but it clearly works.

"This disease is different from others such as heart disease or diabetes. If the [heart disease or diabetes] patient doesn't take or improperly takes his medicine, the only person he hurts is himself," Reichman said. "With TB, a patient who doesn't take or improperly takes his medicine can develop a resistant strain and spread it to others."

Some patients, often those who have drug or alcohol problems or those who are homeless, fail to take their medicine consistently and develop lethal drug-resistant strains of TB. They in turn may pass along potentially lethal strains of drug-resistant TB to other people.

TB control officials say watching people take their medications is the only way to ensure compliance and reduce the spread of TB.

"There's no way anyone can predict who's going to take his medicine and who isn't," said Kurt Brandt, a physician who heads the District's Bureau of TB Control. His job requires him to evaluate each clinic patient—taking lifestyle, age and past medical history into account—in order to determine which patients should be placed on DOT. "In many cases, directly observed therapy is the only way to ensure that people are taking their medicine," he said. "Our investigators' job is to make sure they do."

The Chest Clinic operates on a \$1.6 million annual budget. Of that cost, \$725,000 is bankrolled by the federal Centers for Disease Control. Since 1990, when the District began its DOT program, cases of active TB have dropped from a high of 163 that year to 83 this year.

"The TB investigators' job is very hard," Brandt said. "They must go into shooting galleries, alleyways and other unseemly places in order to get medicine out to drug addicts, alcoholics and homeless people."

TB investigators do travel to crime-plagued housing projects, run-down neighborhoods and homeless shelters in search of their patients—but not always. In fact, some patients are middle-class people who, for various reasons, stopped taking their medicine, which can cause blurred vision, gastrointestinal problems, liver injury and other side effects. One patient told Kelley he just didn't like swallowing pills.

"Most of my patients are reasonable people," Kelley said. "I find that if I'm reasonable with them, they usually don't give me any problems. After all, they know it's all for their own good."

Kelley occasionally treats her patients with a home-baked cake or loaf of zucchini bread on visits. "Eating is good for them," she says.

"One of my greatest pleasures is watching one of my patients slowly get better and better," Kelley said. "I had one patient who was a mess when he started treatment. He had a bad cough and had lost a lot of weight. But with treatment, he got well again. That's what it's all about." ■

45 Infected With TB By Homeless Man

■ By Sandra C. Boodman

A 48-year-old homeless man with active untreated tuberculosis who spent many hours at a neighborhood bar in Minneapolis infected 45 people over the course of six months, according to a recent report in the *New England Journal of Medicine*. In all, 20 people developed active cases of tuberculosis from exposure to the homeless man.

But unlike other reported outbreaks of tuberculosis infections, the high rate of infection and of people who subsequently developed TB was not caused by the presence of the Human Immunodeficiency Virus (HIV) that causes AIDS.

HIV and AIDS have been major factors in the resurgence of TB, a disease nearly vanquished 15 years ago that has again become a major threat to public health. HIV suppresses the immune system, permitting latent tuberculosis infections to become active and allowing them to spread more quickly. Normally it takes at least three months before a person exposed to TB tests positive for the disease. Usually only a fraction of those who test positive will go on to develop TB, which is treated with months of antibiotic therapy.

A team of physicians who investigated the Minneapolis outbreak theorize that the unusually high rate of infection might be attributable to heavy alcohol use. Alcohol may play a role by weakening the immune system, permitting initial infections to progress to active TB, suggested Susan E. Kline, an infectious disease specialist with the University of Minnesota Hospitals and Clinics and lead author of the journal article.

Another possibility is that the homeless man was particularly infectious: His TB was so advanced that he could not walk when he arrived at the emergency room of Hennepin County Medical Center, a public teaching hospital in Minneapolis. During the preceding six months he had lost 68 pounds and weighed only 108 pounds upon admission. He also suffered from fever, chills and nausea and had a severe cough.

When public health investigators interviewed the homeless man about his contacts, he reported that he slept under bridges, in shelters or in a rooming house near the bar where he spent most of his days. Officials then tried to track down people with whom he had regular contact during the six-month period in 1981 and 1982; they interviewed all bar workers and regular customers, several of whom were also staying at the same rooming house.

The homeless man is believed to have infected 41 of the 97 people who were interviewed—a rate nearly double the norm—as well as four others who were not part of the initial investigation. Typically in tuberculosis outbreaks, 20 to 30 percent of the close contacts of an infected person test positive for TB, but only 1 to 2 percent develop active cases of TB. In this instance, 44 percent developed active cases.

Of the initial sample of 97 people, eight had tested positive previously for TB; seven of them had negative chest X-rays, indicating that they were exposed to TB but had not developed the disease. The remaining person, who was suffering from a chronic cough and had lost 10 pounds, appeared to be suffering from a recurrence of TB; DNA fingerprinting indicated that the disease came from the same TB strain as the homeless man's.

Of the 20 people who developed active cases of tuberculosis from exposure to the homeless man, two were secondary cases; they had not been exposed to the homeless man but to someone else he had infected. The secondary cases included a 7-month-old baby who was never in the bar.

The authors of the report said that nearly all of those who developed TB—except the baby—drank excessively. Two died, one of TB complications, shortly before or after diagnosis. All but four underwent directly observed therapy, in which they were required to take their medicine under the watchful eye of public health officers.

There were other complicating factors in this case, the authors noted; the homeless man was seriously mentally ill and suffered from chronic alcoholism both of which "effectively blocked his access to health care" even though there was a public health clinic six blocks from the bar.

FDA Approves Baboon Cell Test On AIDS Patient

Associated Press

The government has given the go-ahead for an experiment to inject baboon bone marrow cells into an AIDS patient to see whether they help rebuild his ravaged immune system.

The Food and Drug Administration confirmed yesterday that it has approved the study. Now researchers are awaiting final safety clearance from a hospital, and expect to perform the experiment in October, said Steven G. Deeks of the University of California at San Francisco, who will perform the procedure.

HIV, the AIDS virus, destroys certain cells of the body's immune system so that patients can no longer fight off infections.

Bone marrow contains stem cells that manufacture the body's blood cells, including immune cells. The theory is that baboon stem cells—which do not become infected with HIV—might help repopulate a human's blood and other tissues with immune cells.

An FDA advisory committee last month warned that the operation probably would kill the recipient and must be carefully controlled to ensure that diseases baboons carry don't spread to humans. But the committee recommended going ahead to determine whether baboons hold a key to fighting AIDS.

One candidate for the experiment is AIDS activist Jeff Getty of San Francisco, who made headlines accusing the FDA of delaying the study. Deeks said Getty "remains a leading candidate, but has not undergone the strict screening that will be required when we have an approved protocol."

AMERICANS, EUROPEANS ARE IGNORANT OF STDs

People in five Western European countries are no more knowledgeable about sexually transmitted diseases than adults in the United States, according to a survey conducted in France, Italy, Spain, Sweden, the United Kingdom and the United States in April and May of this year.

Although 30 percent of those surveyed said they knew someone with a sexually transmitted disease, one-third could not name a disease other than HIV/AIDS. The Gallup Organization interviewed about 1,000 adults in each of the countries.

Results were presented by Peggy Clarke, president of the American Social Health Association, at an international conference in Montreal earlier this summer. ASHA sponsored the survey. Clarke said that "given the global epidemic of STDs, there is an alarming lack of knowledge about these infections

across all the countries surveyed." She noted that in the United States alone an estimated 55 million people have STDs, with 12 million new infections annually.

Eight percent of the respondents said they got their information about STDs from health care providers; TV was most often cited (42 percent), followed by books and magazines (30 percent). About 57 percent said that health care providers spent "no time at all" discussing STDs with them.

Other findings: Relatively few respondents listed the STDs that have emerged during the last 20 years, Clarke said. These include genital herpes (mentioned by 17 percent), chlamydia (15 percent), and the human papillomavirus, which causes genital warts and is linked to cervical cancer (3 percent). Syphilis was mentioned most frequently (18 percent).

— Sandy Rovner

Brazen Robberies Called Protest of AIDS Policy

By Daniel Williams
Washington Post Foreign Service

ROME

It has been perhaps the most curious spate of bank robberies in Italy's history. And in a tragic way, the nickname given to the robbers by the press—"The Untouchables"—is a perfect fit.

Three men infected with HIV, the virus that causes AIDS, have repeatedly robbed banks recently in and around the industrial city of Turin. They have committed their crimes in broad daylight, unmasked. Their exploits, clearly videotaped by security cameras, have been broadcast nationally to a disbelieving public.

The three have no need for stealth, because they are protected by a loophole in a well-meaning but misguided law that bars authorities from keeping AIDS patients in jail.

So each time they have been caught, they have been quickly released. Only a small part of the \$150,000 they have stolen has been recovered.

By last week, their cause had become a national drama. Politicians expressed either wild indignation or pity. Citizens either sympathized or railed against the trio.

And then, calmly, the robbers themselves suggested a way to stop their crime wave. They did so at a press conference they staged; one of them wore a T-shirt emblazoned with the word "Wanted."

It is not the money they are after, they assured reporters, but care and support. In making their case, they repeated some of the same complaints the general public has had with the Italian health and welfare system.

"We haven't hurt anyone in any of the bank raids," said Ferdinando Atanasio, one of the gang members. "We rob because we are forced to. To eat. To keep our problem a live issue. Since 1989, when I discovered I had the disease, I have been waiting for a pension. Every time I ask, they say, 'Wait a little bit longer.'"

"When I go to rob a bank," he continued, "I do not laugh out loud. I am terrified of dying like everybody else."

See ROBBERS, D3, Col. 1

In Italy, Rebels Without A Cure

Italy's 'Untouchable' Bandits

ROBBERS, From D1

Added Sergio Magnis, another of the robbers, "I don't go around with a syringe threatening to infect people. I know the value of life. Give me a job, a place to live and treatment ... and I'll stop robbing. Otherwise, I'll continue. I have nothing to be ashamed of."

Antonio Lamarra, the third member, complained that while the government provides money and protection to Mafia informers, some of them killers, there was nothing for released prisoners with AIDS.

The three said they first met outside an AIDS treatment center. They discussed their hardships, their unemployment, their bleak prospects. Suddenly Magnis, who has the longest police record, said, "I know where the money is."

To some observers, money may have been the object, but others saw a different motivation. A columnist in the Turin newspaper *La Stampa* wrote of the gang: "They seemed to take some ultimate perverse pleasure from their impunity. It is as if knowing they are condemned by an incurable sickness, they find psychological compensation in the fact that they were humiliating and making fun of the social order that was unable to find a way to help them in their fight against death."

The 1993 law that makes the gang immune from detention was supposed to be an article of mercy. It forbids the continued jailing of anyone in the final stages of a terminal disease. AIDS patients fall into that category.

About 3,000 HIV-positive inmates, mostly

drug users, have been freed under the law. Newspapers in Turin report that in the past few months, police have arrested 25 HIV-positive thieves and released them.

Justice Ministry spokesmen claim that officials are about to close the AIDS loophole. "The dramatic events of recent days have again raised a problem that the Justice Ministry, with the Health Ministry, has for some time been working on," one said.

Officials proposed changes under which a prisoner's individual circumstances and condition would be taken into account before release would be ordered. Presumably, someone with AIDS who is still able-bodied would not be freed.

Ironically, as is often the case in Italy, money had been set aside to resolve the problem of treating AIDS in prisons before the trio began its crime spree. But nothing has actually been done.

At the time the release law was passed, a measure was passed to provide 4,600 hospital beds for AIDS patients. Money was set aside, but nothing has been built.

The government of Prime Minister Lamberto Dini is supposed to take up the issue as early as this week. "The government can and must by decree confront and solve this problem," said Raffaella Costa, a member of parliament.

Some would have the government go much further: A far right politician from the north has called for the death penalty for repeat offenders who take advantage of the law.

August 10, 1995

MEMORANDUM TO PATSY AND JEFF

From: Vanessa Potkin

Re: News for 8/10

"Gay Men's Group to Begin New H.I.V. Testing Program" (New York Times)

The Gay Men's Health Crisis will use a \$2.5 million dollar gift from the David Geffen Foundation to create its own HIV testing program. The program will offer counseling and support services for those who test HIV positive as well as those who test HIV negative. Daniel Wolf, a spokesman for the Gay Men's Health Crisis stated "We'll say, 'You're HIV negative. Now let's talk about what you can do to stay that way.'"

"Geffen's AIDS AID" (Washington Post)

David Geffen contributed \$4 million to the Gay Men's Health Crisis and God's Love We Deliver, the two leading New York based AIDS services. The Gay Men's Health Crisis plans to use the money to create a facility for HIV testing and educational and counseling services. God's Love We Deliver, who provides hot meals to homebound people with AID, will use the money to keep up with its increasing demand.

Geffen's AIDS Aid

■ Those battling the AIDS crisis got a gargantuan boost yesterday when music mogul David Geffen contributed \$4 million to the two leading New York-based AIDS service organizations—Gay Men's Health Crisis and God's Love We Deliver. The gift is the largest contribution to AIDS services in history.

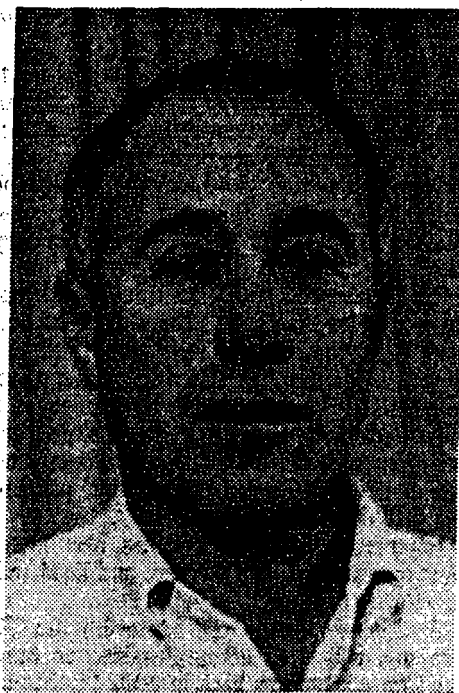
"There are just so many people infected today," said Geffen from his Los Angeles office. "People need to be conscious of what they can do—it's a great need."

This is not the first time Geffen, who is gay, has contributed money to the cause. In '92 he gave \$1 million to both GMHC and to the AIDS Project of Los Angeles.

The Gay Men's Health Crisis, the nation's oldest and largest AIDS organization, founded in 1981, will receive \$2.5 million to create a facility to provide HIV testing and educational and counseling services. It will be named the David Geffen Center for HIV Prevention and Health Education.

God's Love We Deliver, established in 1986 to provide hot meals to homebound people with AIDS, will receive \$1.5 million to keep up with its ever-increasing demand. The organization will renovate an old building in SoHo that is three times larger than its current kitchen, to be called the David Geffen Building.

"This is serious money toward a serious problem," said Andy Spahn, president of the David Geffen Foundation. "GMHC and GLWD are playing a critical role in helping to stop the spread of HIV and enhance the quality of life of those already living with AIDS."



For David Geffen, another kind of record: AIDS donation is largest ever.

Gay Men's Group to Begin New H.I.V. Testing Program

By DAVID W. DUNLAP

The Gay Men's Health Crisis plans to begin its own testing program for H.I.V., the virus that causes AIDS, offering counseling and support services not only for those who have the virus but also, in a departure from common practice, for those who do not.

The new testing center will make use of a \$2.5 million gift from the David Geffen Foundation, which is also to give \$1.5 million to God's Love We Deliver, which prepares meals for homebound people with AIDS.

The combined \$4 million donation, which was announced yesterday, is believed to be the largest single gift made to AIDS support services. Mr. Geffen, one of the most influential executives in Hollywood, is a partner in the new entertainment company Dreamworks SKG.

"This is a major step forward in reawakening people to the crisis," said Richard E. Feldman, chairman of the board of God's Love We Deliver. "The pandemic is not stopping. We're all very tired but we have to redouble our efforts because we're facing serious cuts from the government and lethargy in our community."

No location has been selected for

the testing office to be run by the Gay Men's Health Crisis, a 14-year-old AIDS organization based in the Chelsea section of Manhattan. But it already has a name, the David Geffen Center for H.I.V. Prevention and Health Education, and a distinct philosophy.

"At most other testing sites, if you're H.I.V.-negative, they say 'congratulations' and send you away," said Daniel Wolfe, a spokesman for the Gay Men's Health Crisis. "We'll say, 'You're H.I.V.-negative. Now, let's talk about what you can do to stay that way.'"

Clients will be asked to pay for tests according to their means, Mr. Wolfe said, adding that no one would be turned away. The center may be operating by early 1996.

God's Love We Deliver will use part of the Geffen Foundation gift toward building new headquarters in the former Library for the Blind and Physically Handicapped, at 166 Avenue of the Americas and Spring Street.

The 10-year-old organization long ago outgrew its kitchen at Amsterdam Avenue and 103d Street. It now prepares and delivers 1,600 meals a day and expects to handle 2,200 meals daily this winter. The purchase and renovation of the library is to cost \$5 million.



SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

CENTER FOR MENTAL HEALTH SERVICES

OFFICE OF POLICY and PLANNING

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Movies, media, music hit for teen drug use

Adolescents fault Hollywood in survey

By Rod Dreher
THE WASHINGTON TIMES

Three-quarters of adolescents and two-thirds of adults believe that movies, television, magazines and pop music encourage illegal drug use among teen-agers, according to a national survey released yesterday.

Most film, music and TV producers don't set out to encourage drug abuse, said Joseph A. Califano, chairman of Columbia University's Center on Addiction and Substance Abuse, "but that is the way our adults and young people see what they're served up in our popular culture."

"This is not, in my judgment, a problem for the American government," Mr. Califano said. "It is a problem for the American people."

The center commissioned the survey of 2,000 adults and 400 adolescents, as well as focus groups that were held around the country. Washington pollster Frank Luntz conducted the survey activities in May and June.

"This is something Hollywood can't ignore," Mr. Luntz said of the survey results. "It's not parents talking about their children. It's kids talking about themselves."

Mr. Luntz stressed that those polled do not believe the entertainment industry is a primary cause of drug abuse. But large numbers do think it is a contributing factor

by creating an environment in which drug use is not stigmatized — and is even encouraged — for the young, he said.

"Hollywood has fought back, saying it is not responsible, that it doesn't do these things," said Mr. Luntz. "Well Hollywood, you're wrong, and we've got the proof."

Mr. Califano and Mr. Luntz discussed the poll yesterday in a news conference at the National Press Club.

The findings are part of a larger survey probing Americans' attitudes about the use and abuse of a variety of substances, both illegal and legal. The complete findings will be released in mid-July.

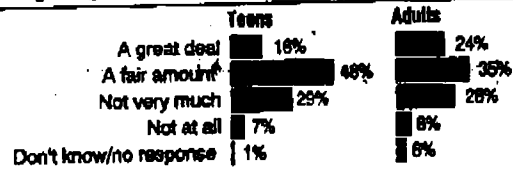
The overall survey was conducted between May 18 and June 8, as the issue of the entertainment industry's effect on the culture gained national attention: William Bennett and C. DeLores Tucker made headlines May 19 by blasting Time Warner Inc. for the filthy lyrics of some of its musical artists. And in a widely reported speech, Senate Majority Leader Bob Dole on May 31 denounced the sex and violence in Hollywood fare.

A Luntz spokesman later said most of the survey research had been done before Mr. Dole's Hollywood address. What's more, research to be released next month from Mr. Luntz's office will show that adolescents don't pay attention to the news anyway, the

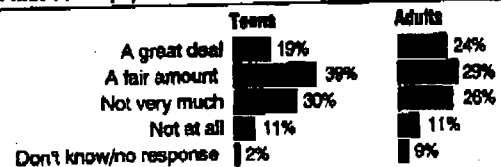
BAD INFLUENCE

A survey of 2,000 adults and 400 teen-agers asked how they feel about society and drug use. Percentages may not equal 100 due to rounding.

How much does our culture — television shows, movies, magazines — encourage illegal drug use?



How much does popular music encourage illegal drug use?



Source: Luntz Research Companies

The Washington Times

**"This is something
Hollywood can't
ignore."**

— Pollster Frank Luntz

spokesman said.

The Dole speech put the issue of moral degradation in the popular culture near the forefront of the 1996 presidential campaign: Mr. Dole is the front-runner for the Republican nomination.

Mr. Luntz, a consultant to Sen. Phil Gramm's presidential campaign, said the issue of drug abuse encouraged by the entertainment industry is too important to be capitalized on for partisan gain.

Rather, said Mr. Califano, the poll results should encourage the entertainment industry to be more mindful of how it contributes to a serious social problem by glamorizing substance abuse. He also said this should make parents more vigilant in keeping their children away from music, movies and TV shows that do.

"This is a free country, and we're going to have the kind of culture the American people want, the kind of culture the American people will pay for," he said.

The largest percentage of children aged 12 to 17 polled — 32 percent — said drugs are the biggest problem they face. Violence in schools, a problem Mr. Califano linked to drugs, was the second-worst problem, concerning 13 percent of children surveyed.

competency seemed to be of greatest concern, the issue of confidentiality between health providers and adolescents was among the top issues raised. Other factors identified in the Ginsburg et al study included whether "teens can go on their own," "visiting and testing can be anonymous," and "teens have their own medical card." These ideas were interpreted as representing youth autonomy, but may reflect concerns about the system's confidentiality. They confirm the findings of previous studies that perceived lack of confidentiality is a barrier to adolescents' obtaining care.⁹⁻¹² In one study, fewer than one third were aware of a right to confidential care for specific health issues, and 25% reported that they would forgo needed health care if their parents might find out.⁹ Recent policy efforts to require parental consent for birth control or abortion make this issue relevant. The increase in managed care has also affected adolescent access to confidential care by limiting the use of alternative sources of care by youth. Multiple entry points and a diversity of resources may be necessary to meet the needs of adolescents.

Finally, this study has implications for the education of both adolescents and their providers. Adolescents must be educated regarding their rights to confidential health care and how to gain access to needed care. Their true risks of HIV transmission also need to be emphasized. Health care providers must be educated about consent and confidentiality guidelines. The *Guidelines for Adolescent Preventive Services* state that "physicians should establish office policies regarding confidential care for adolescents and how parents will be involved in that care."¹³ These policies must be made clear to adolescents and parents and should include mechanisms to ensure privacy in appointment scheduling, billing, record keeping, and follow-up communication.

Another area of educational need is in interpersonal communication between the provider and the adolescent. Not surprisingly, adolescents in the study by Ginsburg et al mentioned honesty, sensitivity, respect toward young people, and ability to relate to teens as important characteristics of pro-

viders. All generalist physicians require training in these interpersonal skills. Given the emphasis on prevention in primary care practice, training providers to be better communicators must become a central focus of undergraduate, graduate, and continuing medical education. Finally, physicians should be made aware of adolescents' concerns about infection and take simple steps, such as washing their hands in the adolescent's presence, to lessen these fears.

Adolescents need to take an active role in evaluating and structuring services for youth. As providers, we cannot idly wait for adolescents to approach but we must be proactive in addressing their concerns. It is only by making prevention in primary care settings more effective and more accessible to teens that we will be able to promote health and prevent disease among our nation's youth.

Tina L. Cheng, MD, MPH
Jonathan D. Klein, MD, MPH

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Recurrent Pregnancy Loss and Cytokines

Not as Simple as It Seems

Recurrent pregnancy loss is a particularly vexing problem. The patient desperately wants to achieve a successful pregnancy and is frustrated by her seeming inability to accomplish a life goal often taken for granted. The physician feels stymied because an identifiable cause can be found in only about 50% of women with recurrent pregnancy loss. Because of the unique immunologic state of pregnancy and similarities to allogeneic transplantation, putative immunologic causes have been attributed to recurrent pregnancy loss. In other words, "If we don't understand it, it must be immunologic." Consequently, a number of diagnostic tests and immunologic treatments have been tried with limited success.

Currently the most widely used immunotherapy for recurrent pregnancy loss is injecting the patient with white blood

cells obtained from the potential father. The rationale for this immunotherapy was derived from studies of kidney transplant patients, who were less likely to reject renal allografts if they had previously been immunized with the donor's leukocytes.¹ Although paternal leukocyte immunization for recurrent pregnancy loss has become widely accepted, meta-analyses of well-controlled studies have revealed only a modest beneficial effect.²

See also p 1933.

Approximately 70% of women who received paternal leukocyte immunization had live births, as did 60% of control women who received placebo. It was also estimated that 13 women would have to be immunized to achieve one additional successful pregnancy.³ Therefore, the effects of paternal leukocyte immunization appear to be modest, and there are no reliable tests to identify the small subgroup of women who may benefit from this

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Editorials

Editorials represent the opinions of the authors and THE JOURNAL and not those of the American Medical Association.

The Adolescent Viewpoint

Implications for Access and Prevention

Although most adolescents are healthy, adolescence is the age group in which mortality rates have increased most dramatically in recent decades.^{1,2} Many engage in risky behaviors that can affect their health. Unintentional injury, homicide, and suicide are the leading causes of death for teens, and as many as one in four adolescents are at risk for substance abuse, sexually transmitted diseases, early unintended pregnancy, and school failure.^{3,4} These preventable health problems make the availability of certain health services—including reproductive health services, diagnosis and treatment of sexually transmitted disease and human immunodeficiency virus (HIV), and mental health and substance abuse services—critically important for this age group. When these services are not accessible to youth, the result is missed opportunities for prevention.

See also p 1913.

Although American adolescents face major threats to their health, formidable barriers exist in seeking care. Adolescents and young adults have the lowest rate of primary care use and are more likely to be uninsured or underinsured than any age group in the United States.^{5,6} To improve adolescent health, it is necessary to determine the availability, approachability, and accessibility of services and remove the barriers to utilizing care. This is particularly important and timely in light of health system reform efforts and managed care, which may change or limit adolescents' health care options.

A critical first step is to understand the consumer's perspective. Few studies have explored adolescent attitudes and concerns in seeking health care. In this issue of JAMA, Ginsburg et al⁷ provide unique insight into the perspectives of adolescents. They asked a large sample of ninth graders about characteristics of health care providers and sites that affect their decision to seek health care. Using a five-stage study design employing focus group, nominal group, and survey methods, the authors found that infection control, provider competence, confidentiality, and provider's interpersonal skills were most important in adolescent decisions to seek health care.

The strength of the study by Ginsburg et al is its rigorous design and integration of several individual and group research methods. Their innovative step-wise use of techniques allowed adolescent interpretation of the results. Their sample of Philadelphia ninth graders was large and diverse, although, as they note, it missed many at-risk students, including drop-outs and the 35% of students who were absent from school. Most important, the study identifies the multiple character-

istics of providers and health care sites that may influence adolescent care-seeking.

Many adolescents were worried about the transmission of HIV from physician to patient in health care settings. It was not surprising that inner-city adolescents were concerned about the acquired immunodeficiency syndrome. It is ironic, however, that adolescents fear HIV transmission from health care providers. Not only is their risk from this source minimal, but health care providers are needed to counter the much greater risk of acquiring HIV elsewhere as well as to diagnose and treat HIV. Their knowledge and concern regarding the Kimberly Bergalis case of HIV transmission from a dentist appeared to have overshadowed all other HIV education efforts in Philadelphia at the time. These findings reinforce the importance of continued HIV education in clinical settings as well as through the media, schools, and other avenues.

The characteristics of providers and institutions found to be important in the study are likely to differ depending on the adolescent's reason for seeking care and his or her experience using health services. Additionally, identification of whether an issue is important may not relate to decisions to seek care. It remains unclear how many adolescents think about infection control when they choose among services and providers available to them. Given the survey methods, it is not surprising that teens would state that clean instruments and provider hand washing were important in seeking health care. Who would say that infection control was not important? The Society for Adolescent Medicine in its position paper on access to health care for adolescents discusses seven factors important in access to care—availability, visibility, quality, confidentiality, affordability, flexibility, and coordination.⁸ Perhaps adolescents only identify factors affecting access when they personally perceive a need for care.

The study by Ginsburg et al has several implications for the delivery of adolescent health care. First, it is helpful to know how teenagers evaluate their health services. Clearly, adolescents actively evaluate the care they receive and are capable of playing a role in assessing and planning services. However, if youth are to become involved in guiding the institutions that serve them, it will require empowerment by providers.

Second, adolescents' perceptions of what they want do not necessarily define all of the barriers to care, nor do they fully define goals for adolescent health services. Factors teenagers identify as important are necessary to address, but are not sufficient for structuring adolescent health services.

Third, what adolescents say they do may be different from what they actually do. This study is an important first step in defining expectations and concerns of adolescents in seeking health care. Further study of whether and how adolescents' attitudes affect behavior, health care utilization, and satisfaction is needed.

Fourth, although issues of infection control and provider

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two items for which males assigned higher ratings than females. However, all subgroups, including males, considered them among the least influential items.

Factor analysis allowed us to take observable responses and begin to understand the underlying unobserved dimensions that may lead to these responses. The first factor brings together items related both to infection control and provider competency. Perhaps teenagers view the probability of acquiring infection as being influenced by the competency of the providers. An alternative interpretation could be that teenagers tie together the use of infection control procedures with professionalism. The second factor is straightforward and reflects concern for the interpersonal relationship between teenager and health provider. The third latent factor includes both those items that offer teenagers greater autonomy and special services. Perhaps the underlying dimension pertains to teenage control. Teenagers' sense of control would be enhanced both by allowing them greater autonomy and by enabling them to choose desired services. The fourth factor encompasses the two items related to prerequisites for seeking care.

Although knowledge of adolescent perceptions allows adults to communicate more effectively with youth and to better address their concerns, an intriguing question remains: to what extent is the decision to seek care predicted by youth perceptions? Students who reported never receiving routine health care rated all items lower, suggesting there may be a correlation between perceptions and the actual decision to seek care. Nevertheless, further prospective studies are needed to explore how perceptions influence decisions.

There are several important limitations to this study. First, the results may not be generalizable to youth living in rural or suburban communities. Second, the importance of certain characteristics may vary by type of health care visit. We have no way to determine these differences since youth in this study were not asked about specific services; they were asked about health care services in general. Third, although the study was designed to include all ninth-graders in Philadelphia public schools, opinions of groups with small subsample sizes may have been diluted both in the generation of items and in the final survey results. Fourth, adolescents at highest risk for morbidity and mortality probably were underrepresented in the study sample because of high dropout rates, absenteeism, and low literacy. Fifth, although every effort was made to analyze the data objectively and quantitatively, the very nature of the study is qualitative. Interpretation of the

results draws not only on the statistical analyses, but also on the group discussions. The potential for student misinterpretation or moderator bias in the discussions must be acknowledged. Finally, this study has explored adolescent perceptions. It is not an analysis of health care utilization patterns or a controlled investigation of specific service or provider strategies.

CONCLUSIONS

This study helps clarify which variables adolescents believe influence their decision to seek health care. The results indicate that adolescents are more concerned about provider characteristics than specific site, service, or outreach characteristics. Four of the top 10 characteristics that affect the decision to seek care involve cleanliness and infection control. Qualitative analysis reveals that this is related to the fear of acquiring diseases, particularly AIDS. Adolescents must be educated about the extremely low risk of HIV transmission via preventive care. In addition, providers must be sensitive to the concerns of their adolescent patients regarding disease transmission. Routine infection control procedures, such as hand washing and use of clean instruments, should be demonstrated in the presence of adolescents.

Some of the items that adolescents state influence their decision to utilize services, particularly the fear of disease transmission, have not, to our knowledge, been published before. Many items in the adolescent-generated survey would not have been included had the investigators designed it without adolescent input. The inclusion of adolescents throughout the process yielded data that reflects the voices, concerns, and expectations of adolescents as health care consumers.

Above all, this study illustrates that adolescents are not passive recipients of care. They actively interpret interactions and evaluate services. Health care providers and planners must include adolescents in the discussions as we work together to design a system that meets the needs and ultimately improves the health status of youth.

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Table 4.—Factor Loadings in Confirmatory Factor Analysis Using the Maximum Likelihood Method*

Infection Control/Competency	
Providers and sites are clean	0.84
Providers wash hands	0.83
Providers are knowledgeable	0.83
Providers are experienced	0.81
Providers are careful not to mix things up	0.80
Providers use clean instruments	0.78
Providers are up-to-date	0.74
Providers are HIV-negative	0.69
Provider-Patient Relationship	
Providers are honest with patients	0.82
Providers and staff treat all patients equally	0.79
Providers and staff are respectful	0.78
Providers emphasize confidentiality	0.77
Providers and staff relate well to teens	0.76
Staff is happy and friendly	0.73
Provider is the same for all visits	0.70
Providers prepare teens for procedures	0.68
Autonomy/Special Services	
Out-of-pocket costs are low	0.72
Teens help design the health care system	0.70
Teens can go on their own	0.70
Appointments are made easily	0.69
Waiting room time is short	0.68
24-hr crisis centers are available	0.68
Counseling is available	0.67
Contraception is available	0.67
Teen-only sites are available	0.67
Sites provide job counseling	0.66
Sites are near home	0.61
Visits and testing can be anonymous	0.58
Teens have their own medical card	0.53
Additional Perquisites	
Sites offer incentives for health care	0.76
Sites provide entertainment while waiting	0.72

* HIV indicates human immunodeficiency virus.

While the survey contained an equal number of items describing providers and sites, 14 of the top 15 items pertained to providers. Previous studies indicate that youth view the physician as the key contact for health information,¹⁹ education about HIV,²⁰ and management of substance abuse.²¹ Adolescents who are satisfied with their providers keep appointments more consistently, and providers who are skilled in adolescent care promote better patient compliance with treatment regimens.²² Teenagers seek providers who are competent, warm, compassionate, unpretentious, nonjudgmental, and willing to respect confidentiality.^{10,12,19,22,23} This study supports these findings. However, our results suggest that provider cleanliness and demonstration of infection control procedures outrank all of these previously recognized characteristics.

Of the top 10 characteristics, four pertain to infection control: provider hand washing, use of clean instruments, provider seronegativity for HIV. These same items were consistently ranked most highly in every stage of the study, including the stage using NGT in which students directly compared items. Group discussions suggest that adolescent concern regarding the transmission of HIV explains the high ranking of all four items. When asked

what would lessen their fears, nearly all groups concurred that they wanted to witness providers washing their hands, wearing gloves, and removing instruments from sterile packaging.

The discussions indicate that there is confusion among youth about the risk of HIV transmission through routine health care visits. Some teenagers may see avoidance of health care as a positive behavior that lessens their risk of exposure to HIV. In the group discussions, youth expressed both shock and relief when informed that only six individuals are proven to have acquired HIV through routine health care.²⁴ Strehlow and Kampmann²⁵ found that HIV anxiety was most pronounced among adolescents who were poorly informed about transmission and that adolescents with less sexual experience tended to externalize their anxiety about sexual activity to a general fear of HIV and AIDS. The level of HIV fear exhibited by the adolescents in our study may be related to their relatively young age. A sample of older, more sexually experienced adolescents may have generated different results. Alternatively, our students may represent a cohort of youth who were at the highly impressionable ages of 10 to 12 years when the media focused on the Kimberly Bergalis case. Nevertheless, our findings suggest a pressing need for better public education about the near-zero risk of acquiring HIV through routine health care.

Six of the top items pertained to interpersonal characteristics of providers: honesty, respect, equal treatment of all patients, confidentiality, friendliness, and ability to relate to teenagers. Provider honesty was ranked the most important interpersonal characteristic by all subgroups. In the discussion groups, teens expressed concern that information was withheld from them but told to their parents and that private information was disclosed to parents despite provider assurance of confidentiality. Respect was said to be demonstrated by behaviors such as using understandable language, speaking directly to teens rather than to their parents, and sensitivity toward their bodies during the physical examination. Equal treatment of all patients was interpreted by the students in several different ways. Most groups addressed age first, emphasizing that adolescents should be treated as adults. All groups believed that economic or insurance status affected the quality of care. There was less agreement about the influence of race. In most groups, though, minority students shared stories of having to wait in offices, clinics, or emergency departments while others moved ahead. After medical triage was explained, the students stated that staff should explain, or post a sign explaining,

why people were being seen out of order. All groups were most confident of equal treatment if the staff was multiracial and multicultural. Finally, teenagers did not seem to want providers who spoke or dressed as they did. Rather, they looked for providers who took the time to listen and respond to their concerns.

Previous studies suggest that confidentiality is the most important characteristic to many adolescents as they decide whether to seek care.^{10,12,19,22,23} When asked why certain provider characteristics were considered even more important in this study, the discussion groups explained that adolescents would not trust providers who assured confidentiality but were considered dishonest or disrespectful. Many youth said they could protect themselves from a breach of confidentiality by withholding information but not from provider dishonesty, disrespect, or poor infection control.

The adolescents in this study believed that variables related to provider competence, such as know-how, carefulness, experience, and up-to-date knowledge and skill, influenced their decision to seek care. When asked how they judged whether providers were careful, students stated that they noticed whether providers took their time or seemed nervous. When asked how they determined whether providers were knowledgeable, up-to-date, or experienced, all groups responded, "Look at the certificates on the walls."

Students expressed greater concern about individual out-of-pocket cost than the overall cost of health care. Many students expressed confusion about why health care is so expensive. No students raised the concern that payment would inhibit their ability to seek care.

All 31 items reported in the final list are of great importance to teenagers. These items advanced from an original list of 892 ideas. Within these 31 items, provider characteristics dominated the top half of the prioritized list, and site or system characteristics dominated the lower half. Several items suggest that adolescents want to navigate the system independently: "teens can go on their own," "visits and testing can be anonymous," "teens have their own medical card," and "appointments are made easily." Several other items, such as "teen-only sites are available" and "teens help design the health care system," suggest that adolescents want services that reflect youth identity and involvement.

The outreach question generated responses regarding providers, sites, and promotional strategies. However, only two items related to promotion advanced to the final survey: sites offer incentives for health care and sites offer waiting room entertainment. These were the only

Table 3.—Rankings by Sex and Race of the Top 31 Items Influencing the Decision to Seek Health Care*

Item	Total Sample (n=621)	Sex		Race†		Parental Education‡	
		Male (n=3167)	Female (n=3442)	Black (n=3684)	White (n=1638)	High School or Less (n=3418)	Some College or More (n=2400)
Providers wash hands	1	1	1	2	1	1	1
Providers use clean instruments	1	1	1	1	1	1	1
Providers are honest with patients	1	1	1	3	1	1	1
Providers and staff are respectful	2	1	2	3	1	1	2
Providers and sites are clean	2	1	2	3	1	1	2
Providers are knowledgeable	2	1	2	3	1	1	3
Providers are careful not to mix things up	2	1	3	3	1	1	3
Providers are experienced	2	1	3	3	1	1	3
Providers are HIV-negative†	2	1	3	3	1	1	3
Providers and staff treat all patients equally	2	1	3	3	1	2	3
Providers emphasize confidentiality	3	2	4	4	1	2	4
Providers are up-to-date	4	2	5	5	2	2	4
Out-of-pocket costs are low	4	2	5	6	2	3	4
Providers and staff relate well to teens	4	3	5	6	2	3	4
Provider is the same for all visits	4	3	5	6	2	3	4
Contraception is available	4	3	6	6	2	3	4
Staff is happy and friendly	4	3	6	7	2	3	4
Waiting room time is short	4	3	6	7	2	3	4
Appointments are made easily	5	3	7	8	2	3	4
Teens can go on their own	6	3	8	8	2	3	5
Providers prepare teens for procedures	7	4	7	8	2	3	5
Visits and testing can be anonymous	7	3	7	8	2	3	5
24-hr crisis centers are available	7	4	7	8	2	3	5
Teens have their own medical card	8	5	8	8	4	4	6
Sites are near home	8	4	8	8	2	4	6
Teen-only sites are available	8	5	8	8	3	4	6
Counseling is available	8	5	8	8	3	4	6
Teens help design the health care system	8	5	8	8	3	4	6
Sites provide job counseling	9	5	9	8	4	4	7
Sites offer incentives for health care	9	5	10	9	4	5	8
Sites provide entertainment while waiting	9	5	11	9	4	5	8

*In the subgroups, significance was set at $P<.01$. Rankings are within subgroups; they are not comparable across groups.

†HIV indicates human immunodeficiency virus.

‡As subsample size decreased, rankings determined by the sign test tended to cluster. The rankings for Latino, Asian, and Native American subgroups are not given.

§Parental educational level as reported by the student.

vices promoting teen autonomy. Conversely, grouping the four latent factors into fewer dimensions resulted in a model that did not fit the data as well.

The Kruskal-Wallis test was used to test differences in Likert scale ratings between males and females, blacks and whites, parental educational levels, and time since last medical visit. Females assigned higher Likert scale ratings than males ($P<.001$) to 29 items. Males assigned higher ratings than females ($P<.001$) to only two items: sites offer incentives for health care and sites provide entertainment while waiting. Black adolescents assigned higher ratings than all other adolescents ($P<.01$) to all items except four: out-of-pocket costs are low ($P=.06$), staff is happy and friendly ($P=.02$), 24-hour crisis centers are available ($P=.2$), and sites are near home ($P=.05$). Significant differences in parental education were found on only four items. Adolescents whose parents had attended college assigned lower ratings than all other adolescents to the following: providers

wash hands ($P=.01$), providers and staff relate well to teens ($P=.008$), staff is happy and friendly ($P=.008$), and teen-only sites are available ($P=.0008$). Students who reported never receiving routine health care ($n=108$) assigned lower ratings than all other adolescents on all 31 items ($P<.001$).

The open focus groups were asked to explain why four of the top 10 items pertained to cleanliness or infection control. The immediate response in seven of the 21 groups was concern about HIV and the acquired immunodeficiency syndrome (AIDS). In the remaining 14 groups, the concern was "germs" in general. When asked what germs they were thinking about, the students in seven of these groups immediately responded, "AIDS." Facilitators asked the adolescents if they knew of anyone who became infected with HIV through a routine health visit. Youth in all 21 groups recalled the media reports of Kimberly Bergalls who reported HIV transmission via dental care.

The facilitators attempted to quantify the teenagers' perceived risk of contract-

ing HIV during a routine medical or dental visit. The students were told that an estimated 1.5 million individuals are infected with HIV. They then were asked how many of these people they thought had become infected during a health care visit. The responses ranged from 100 000 to 1 million people. While these inflated responses call into question the students' ability to estimate using large numbers, they illustrate the adolescent misperception that an alarmingly large number of HIV-positive individuals have been infected by health care providers.

COMMENT

This study explored which characteristics of the health care system urban youth believe contribute most to their utilization of services. The characteristics were generated, worded, and ranked by teenagers, not by health care experts. Many of the characteristics may have been missed entirely or obscured in a more traditional survey with items selected by adults.

Table 2.—Final Ranking and Distribution of Ratings for the Top 31 Items Influencing the Decision to Seek Health Care*

Item†	Final Ranking‡	% of Students Assigning Likert Rating	
		Rating=4	Rating=5
Providers wash hands	1	14	73
Providers use clean instruments	1	12	74
Providers are honest with patients	1	15	72
Providers and staff are respectful	2	18	68
Providers and sites are clean	2	16	69
Providers are knowledgeable	2	15	69
Providers are careful not to mix things up	2	17	67
Providers are experienced	2	18	65
Providers are HIV-negative	2	15	68
Providers and staff treat all patients equally	2	17	66
Providers emphasize confidentiality	3	20	63
Providers are up-to-date	4	20	58
Out-of-pocket costs are low	4	21	59
Providers and staff relate well to teens	4	25	56
Provider is the same for all visits	4	28	52
Contraception is available	4	23	65
Staff is happy and friendly	4	27	62
Waiting room time is short	4	26	62
Appointments are made easily	5	27	49
Teens can go on their own	6	25	51
Providers prepare teens for procedures	7	28	48
Visits and testing can be anonymous	7	25	48
24-hr crisis centers are available	7	25	47
Teens have their own medical card	8	25	45
Sites are near home	8	30	41
Teen-only sites are available	8	27	43
Counseling is available	8	30	40
Teens help design the health care system	8	30	40
Sites provide job counseling	9	29	39
Sites offer incentives for health care	9	21	41
Sites provide entertainment while waiting	9	23	37

*Students (n=6821) were asked to rate each item on a scale of 1 ("Definitely would not make me more likely to come for care") to 5 ("Definitely would make me more likely to come for care").

†Items are listed by order of their mean Likert ratings. HIV indicates human immunodeficiency virus.

‡A Bonferroni calculation was done to determine the proper significance level for the total sample. Items that did not differ by $P<.002$ by the sign test were assigned the same final ranking.

lying polychoric correlations between all variables were calculated, since they were ordinal rather than continuous. Latent factors were assumed to be continuous.²⁵

RESULTS

The results of the initial open focus groups are reflected in the selection and wording of the questions used in the NGT sessions. During these sessions, youth generated 102 responses to the provider question, 135 to the site question, and 155 to the outreach question.

The first set of surveys each contained 35 to 40 of the highest prioritized items from the NGT stage. Surveys were returned by 2619 students, approximately 88% of in-school youth. The following forms were excluded: (1) 240 (2.8%) with at least two answers recorded in inappropriate columns; (2) 45 (0.5%) with over 75% of answers left blank; and (3) 1380 (16%) with answers demonstrating no variability. An additional 258 forms (3.0%) met more than one exclusion criterion.

The data set therefore consisted of 6696 surveys, representing 68% of in-school students. Items were ordered by their mean Likert ratings (2.6 to 4.7). The 31 items with the highest mean ratings (3.5 and higher) advanced to the final survey.

Of the 7376 final surveys that were collected, the following were excluded: 460 (6.2%) with at least two answers in inappropriate columns and 96 (1.2%) with over 75% of answers left blank. Because only the highest rated items from previous stages were included, the variability exclusion criterion was not applied to this survey. The 6821 usable surveys represented approximately 45% of enrolled students and 69% of in-school students. The distribution of ages of the students follows: 12% of students were 13 years, 32% were 14 years, 44.3% were 15 years, 17.1% were 16 years, 3.8% were 17 years, and 1.7% were 18 years.

Table 2 lists the 31 items according to their mean Likert scale ratings and gives their final order by the sign test. The

first three items did not differ significantly: provider hand washing, use of clean instruments, and honesty. The next seven items did not differ significantly: provider and staff respect of patients, provider and site cleanliness, provider know-how, provider carefulness, provider experience, provider seronegativity for the human immunodeficiency virus (HIV), and equal treatment of all patients by providers and staff. One item, confidentiality, was in third place, and seven items were in fourth place.

Table 3 gives the subgroup order of the 31 items according to the sign test. The items fall into five categories for males and 11 categories for females. As the subgroup size decreased, the discriminatory power of the sign test decreased, resulting in fewer total categories. For example, there were over twice as many black than white adolescents and more than twice as many categories in the black than white subgroup. The items fell into three or fewer categories in the Latino, Asian, and Native American subgroups.

After rotation, exploratory factor analysis produced three factors with eigenvalues larger than 1.0 when using both the principal components and maximum likelihood methods. Together, these three factors explained 43% to 49% of the variability in the sample. The first factor was much stronger than the other two factors, accounting for 37% to 39% of the variability. It included heavy loadings (>0.50) on provider and infection-related variables. The second factor included nine to 10 variables and had heavy loadings on issues related to services. The third factor included six to eight variables related primarily to prerequisites and convenience.

The confirmatory factor analysis was conducted using four latent factors. The first factor included variables related to cleanliness and provider competency. The second latent factor consisted of variables pertaining to the patient-provider relationship. The third latent factor included variables related to special services, particularly those promoting teen autonomy. The final factor included variables pertaining to prerequisites.

Table 4 gives the loading estimates of each of the original variables on each of the latent factors. The overall coefficient of determination of the model was 0.997. The model shows that all loadings were higher than 0.52, indicating that the variables clearly measure part of the latent factors. Separating the infection control factor into a cleanliness component and a provider competency component created a multi-collinear situation, suggesting that there is not a clear distinction between the two. The same held true when special services were separated into direct services and ser-

Table 1.—Stages of Data Collection

Method	Stage				
	1	2	3	4	5
Objective	Open focus groups	Nominal group technique	3 surveys	1 survey	Open focus groups
	Frame questions in appropriate language	Generate responses to 3 study questions	Assess the importance of responses	Link responses with decision to seek care	Clarify the top responses
Sample size	98	341	6996*	6821*	215
Male, %	51.0	48.8	48.9	48.4	46.0
Race, %					
Black	62.2	63.0	54.4	54.0	47.0
White	19.4	22.6	23.2	24.0	27.0
Latino	12.2	12.0	9.3	9.5	21.0

*Number of participants reported is based on usable surveys.

In the first stage, 98 students participated in 10 open focus groups to help frame the study questions in age-appropriate language. The following three study questions with accompanying definitions were chosen: (1) What characteristics of a health care provider are important to you? (2) What characteristics of a health care site are important to you? (3) How could we get teenagers to come for health care? "Provider" was defined as a doctor, nurse, dentist, mental health worker, birth control counselor, or someone who treats patients with sexually transmitted diseases. "Site" was defined as any place other than an emergency department where teenagers might go for care of their bodies, teeth, minds, or emotions, including a place where they might receive birth control or treatment for sexually transmitted diseases. Characteristics of health care providers were defined as how they look, act, treat you, think about you, get information from you, and use that information. Characteristics of health care sites were defined as how they look, where they are, what services they offer, how they treat you, and how they get information from you.

In the second stage, 845 students were divided into 41 groups of eight or nine students. Each group addressed one study question using nominal group technique (NGT). This process requires no participant expertise and has been used successfully with individuals of widely varying backgrounds.¹⁴ Nominal group technique elicits each individual's ideas, allows members to build on others' ideas, and then directs the group to identify the most important ideas. It has great advantages over open focus groups in that minority opinions are more likely to be voiced, conflicting ideas are more likely to be tolerated, facilitator bias is minimized, and all participants have an equal opportunity to influence decision making.^{15,16}

In the NGT sessions, the students first generated a list of responses independently and without discussion. The facilitators then asked each student to state one response in a round-robin fashion

until all responses were recorded. Students then independently identified the five items most important to them. After completion of all groups, a mean priority score was calculated for each of the 392 generated responses.

In the third stage, in an attempt to create surveys with 35 to 40 items each, the 114 ideas with the highest priority scores were divided into three surveys. Each survey addressed one of the three study questions. The surveys were prepared in both English and Spanish. Each survey also asked about student race, age, sex, parental education (a proxy measure of socioeconomic status), guardian, last routine medical visit, and last emergency medical visit. The 39 participating schools were divided into three groups, balanced by region, racial profile, and student number. Each group received only one of the three surveys. The ninth-graders answered the surveys independently and in writing during class.

The surveys pertaining to provider and site characteristics asked students to rate each item using a Likert scale ranging from 5 ("This is extremely important to me") to 1 ("This is not at all important to me"). The survey regarding outreach strategies instructed students to rate each item using a Likert scale ranging from 5 ("Definitely would make me more likely to come for health care") to 1 ("Definitely would not make me more likely to come for health care"). Students were also able to register "No opinion" for any item.

In the fourth stage, the 30 ideas with the highest mean Likert ratings from the three surveys were combined into one survey that was distributed to all 39 schools. Before selecting the items for the final survey, the data were analyzed by sex and race to check that no item important to a subgroup was excluded. This process added one item, for a total of 31 items. All were worded in the affirmative, eg, "I would be treated with respect by people who work at the place where I get health care." The students responded to each statement using a Likert scale ranging from 5 ("Definitely would make me more likely to come for

health care") to 1 ("Definitely would not make me more likely to come for health care"). They were not asked to compare items to each other.

In the last stage, 215 students in 21 open focus groups were asked to explain the results of the final survey. These ninth-grade students were a class behind those who had completed the survey. These discussions added qualitative depth to the data and provided an opportunity to share the results with students and school personnel.

Statistical Analysis

Because of the hierarchical nature of the study, statistical analysis focused on data from the final survey. First, the survey items were ordered by their mean Likert scale ratings. The sign test then was applied to determine whether consecutive items differed in their ranking. Given the large sample size and the multiple comparisons, a Bonferroni correction was applied and statistical significance was defined as $P < .002$. Statistically equivalent items were assigned the same final rank; the first item demonstrating a significant difference was assigned the next rank.

The same analysis was applied to subgroups defined by gender, race, and parental education. Because of the smaller size of each subgroup (as low as 20% of the total sample), significance was adjusted to $P < .01$. The Kruskal-Wallis test was used to compare the ratings between subgroups. This analysis involved four multiple comparisons of the full sample (sex, race, parental education, and last medical visit).

Both exploratory and confirmatory factor analyses were performed using LISREL 7,¹⁷ a feature of SPSS for Windows, Release 6.0. Exploratory factor analysis was performed using both the principal components and maximum likelihood methods to reduce the data into only a few factors. Confirmatory factor analysis then was performed based on the results of the exploratory factor analysis as well as hypotheses generated from earlier surveys and focus groups. The under-

Original Contributions

Adolescents' Perceptions of Factors Affecting Their Decisions to Seek Health Care

Kenneth R. Ginsburg, MD, MEd; Gail B. Slap, MD, MS; Avital Cnaan, PhD;
Christine M. Forke; Catherine M. Balsley, EdD; Dionne M. Rouselle, MD

Objective.—To have adolescents, rather than adults, identify characteristics of health care providers and sites that affect their decision to seek care.

Design.—Five stages conducted over a 10-month period: (1) focus groups to frame the study questions; (2) nominal group technique to generate student responses; (3) three surveys to assess response importance; (4) one survey to link the most important responses with the decision to seek care; and (5) focus groups to explain the variables associated with the decision to seek care.

Setting.—The Philadelphia (Pa) School District.

Participants.—The study population consisted of all ninth graders from 39 of Philadelphia's 42 public high schools. The 6821 students who returned the final survey comprised the study sample (69% of in-school youth).

Results.—In the final survey, students used a Likert scale (1 to 5) to describe the impact of 31 ideas on their decision to seek care. The most important characteristics were provider hand washing, clean instruments, honesty, respect toward teens, cleanliness, know-how, carefulness, experience, seronegativity for the human immunodeficiency virus, equal treatment of all patients, and confidentiality. There was little variation in the order of the items by sex, race, or socioeconomic status. Factor analysis showed that the most important of four identified latent factors related to infection control and provider competency.

Conclusion.—Four of the top 10 characteristics that affect an adolescent's decision to seek care involve cleanliness and infection control. These findings offer providers and planners straightforward, modifiable factors that teens believe influence their decision to seek care.

(JAMA. 1996;273:1913-1918)

THE DECADE of the 1990s has witnessed a concerted effort toward improving access to health care for adolescents. The literature on barriers to care and potential solutions, however, comes from the adult perspective.¹⁻⁸ There has been little effort to gather information about needs, expectations,

or deterrents directly from adolescents.

Recognized barriers, such as inadequate health insurance, transportation, and service site, are known to affect adolescents' utilization of health care services.^{1,4,8} However, an adolescent's decision to seek care, especially preventive care, may be heavily influenced by far

For editorial comment see p 1957.

less tangible issues. Interview studies that have addressed these issues have been limited by small sample size, facilitator bias, and difficulty prioritizing ideas.⁹⁻¹¹ Larger surveys typically have been worded by adult investigators and gather data at only one time point.¹¹⁻¹⁴

The objective of this study was to ask adolescents, rather than adults, to explore how health care providers, health care sites, and outreach strategies affect an adolescent's decision to seek care. The

study focused on the adolescent perception of the decision-making process rather than the measurement of an outcome such as health care utilization. The overriding goal was to identify the perceived barriers to care confronting youth and to solicit their recommendations for creating a health care system that meets their needs and expectations.

METHODS

Study Population

The study population consisted of all ninth-grade students in the School District of Philadelphia, Pa. Of the 19411 students enrolled in September 1992, 65% were black, 20% were white, 11% were Latino, and 4% were Asian. Thirty-nine of 42 schools participated, decreasing the eligible population to 18 052. By May 1993, when the surveys were distributed, enrollment had fallen to 15 248. The daily absentee rate was 35%, leaving an estimated in-school daily census of 9846. The numbers, sex, and race of students participating in each stage of the study are shown in Table 1.

Data Collection

The study used a hierarchical series of group techniques and surveys designed to assure that ideas were generated, prioritized, and explained by adolescents. Data collection was divided into five stages (Table 1): the first four stages between January and June 1993 and the last stage in October 1993. The research protocol was approved by the Institutional Review Board of the University of Pennsylvania and the Office of Assessment of the Philadelphia School District.

In those stages involving small group meetings (stages 1, 2, and 5), each principal was asked to select students from different classrooms who represented the school's sociodemographic and academic profile. Groups were convened until students from all regions of the city had participated, all ethnic groups were represented, and the generated ideas were repetitive.

From the Craig-Dalsimer Program in Adolescent Medicine, Division of General Internal Medicine, Department of Medicine, University of Pennsylvania School of Medicine (Drs Ginsburg, Slap, Rouselle and Ms Forke), Philadelphia; Section of Adolescent Medicine, Division of General Pediatrics (Drs Ginsburg and Slap), and Division of Biostatistics and Epidemiology, Department of Pediatrics (Dr Cnaan), Children's Hospital of Philadelphia (Pa); and the Office of Student Services, School District of Philadelphia (Pa) (Dr Balsley). Dr Rouselle is now with the Department of Obstetrics and Gynecology, University of Pittsburgh (Pa).

Dr Ginsburg is the recipient of the 1994 Young Investigator Award of the Society for Adolescent Medicine.

Reprint requests to the Section of Adolescent Medicine, Children's Hospital of Philadelphia, 34th Street and Civic Center Boulevard, Philadelphia, PA 19104 (Dr Ginsburg).

MEMORANDUM

Date: August 25, 1995

To: Patsy & Jeff

From: Rachel Garfield & Vanessa Potkin

Re: today's news

"Treating STDs and Reducing AIDS Risk" (Washington Post 8/25/95)

A study by epidemiologists at the London School of Hygiene and Tropical Medicine found that treating people for sexually transmitted diseases substantially reduces their risk of contracting HIV. The study was conducted by physicians working in Tanzania and pointed out the need for STD and AIDS prevention in Africa.

Treating STDs and Reducing AIDS Risk

Doctors in Study Find Higher HIV Exposure in Untreated Villagers

Reuter

LONDON, Aug. 24—Treating people for sexually transmitted diseases like gonorrhea substantially reduces their risk of contracting the HIV virus that causes AIDS, physicians working in Tanzania report in a new study.

Villagers who were treated for sexually transmitted diseases were about 40 percent less likely to get HIV than villagers with such diseases who were not treated, according to the report, published in the Aug. 26 issue of *The Lancet*.

"This is the first such trial anywhere in the world, which amazes me," said Richard Hayes, an epidemiologist at the London School of Hygiene and Tropical Medicine, who designed the study.

The researchers chose 12 villages in the Mwanza area of Tanzania. They treated people in six of them for sexually transmitted diseases (STDs). In six other villages, they continued standard health care, which in those communities does not usually include STD treatment.

"The sexual transmission of HIV may be enhanced if either partner has a sexually transmitted disease such as syphilis, gonorrhea, or chlamydia," Hayes told a news conference.

"We were not using the most effective antibiotics. There might have been an even bigger effect if we had. In fact, we used relatively cheap drugs," said David Mabey, a professor of communicable diseases at the school.

But he said the \$7.50 to \$15 cost per treatment was beyond the means of some countries, and aid agencies would have to help. "We think this is a very cost-effective intervention," he added.

Doctors long have said that having a

sexually transmitted disease greatly increases the risk of getting AIDS.

"We believe that HIV prevention in rural Africa is an urgent priority."

— Richard Hayes, London School of Hygiene and Tropical Medicine

People with STDs usually are more sexually active than other individuals and

are unlikely to have used a condom or other barrier type of protection.

But most important, the sores, blisters and other tissue damage caused by the diseases allow the easy transmission of body fluids, which is how HIV is passed on. The virus lives in blood, semen and other fluids and is passed through an open sore or cut or in an infusion or injection of blood.

AIDS and STDs are huge problems in Africa, and the vast majority of cases are transmitted between heterosexuals. The researchers said treating STDs could save many lives.

"We believe that HIV prevention in rural Africa is an urgent priority," Hayes said.

In the treated group of 6,000 adults, 1.16 percent became infected with HIV over a two-year period, while in the untreated group of 6,000 adults 1.86 percent became infected. The risk of contracting HIV was almost 40 percent lower in the treated group than in the untreated group.

"This is a very strong result," said Heiner Grosskurth, who worked on the study.

He said this was not due to changed behavior—using condoms or avoiding sex, for instance—on the part of the villagers. Instead, it was due to the STDs actually having been cured.

All of those in the treated group recognized that they had an STD and asked for treatment. Mabey said the effects probably would have been much more significant if the population as a whole were screened and treated for STDs, but added that this was unlikely to happen because of the expense.

FYI: The Advocate, September 5, 1995

AIDS panel debuts

J. DAVID AKE/APP



President Clinton addressed the first meeting of his new AIDS commission in Washington, D.C., July 28. Clinton called for increased spending on AIDS research and chided those who would "pit one disease against another" in funding decisions. Commission members called on Clinton to show more leadership on AIDS issues.

A call to arms

Clinton and his AIDS panel in the Roosevelt Room of the White House

PATSY FLEMING: AIDS advocate

In a career spanning more than two decades in the federal government, Patricia "Patsy" Fleming has confronted her fair share, and then some, of public-policy challenges. Appointed last November as President Clinton's new director of AIDS policy, she intends to keep the burgeoning epidemic at the forefront of the national agenda and aim a steady flow of critical AIDS-prevention messages at populations expected to be most vulnerable in the coming years—particularly Black women.

"The numbers for Black women are going up, and this virus doesn't discriminate among high-, middle- or low-income sisters," the Philadelphia native explains. "Women everywhere have to take precautions and not be complacent."

A graduate of Vassar College and the mother of three sons, Fleming, 59, was legislative assistant to representatives Shirley Chisholm and Andrew Young during the seventies. From 1983 to 1992 she served as

chief of staff to Rep. Ted Weiss (D-NY), where she was instrumental in developing AIDS-related legislation for Weiss's government-operations subcommittee on human resources. At that point, her goal was to create policy in a Democrat-controlled Congress with a Republican in the White House. "I often felt myself standing on the outside of the administration looking in, banging on the doors of a bureaucracy that too often turned a deaf ear to the cries of the American people," Fleming says.

Today the characters have changed, but the scenario remains the same. Although Clinton is sympathetic to AIDS issues, Congress is now Republican-controlled and distinctly conservative. "This virus is infecting 40,000 people a year, and it does not distinguish between Democrats and



Republicans," she explains. "There is AIDS in every state and congressional district in this country. So we will have to find a way."

Still, lawmakers are in a cost-cutting mood, she claims, and less likely than in the past to support AIDS-preven-

tion and -education programs.

"I was raised to believe in fighting for the rights of the disenfranchised and against discrimination of any kind," Fleming explains. "I've attended too many funerals, I've held the hands of too many grieving friends and family members and participated in too many candlelight vigils. The utter horror of the AIDS epidemic has reinforced my need to be an activist."

—MARLENE CIMMONS >