## By Daniel J. DeNoon

HE EQUATION HIV = AIDS = DEATH HAS BEEN repeated so often that it has become a vicious and self-fulfilling prophecy. It is also a killer. The surest way to acquire HIV infection, develop AIDS or die is to give up hope and to give in to denial or despair: in short, to become an AIDS victim.

"Believing that I could survive was probably the precondition necessary for my actual survival," wrote long-term AIDS survivor Michael Callen in a 1988 *Village Voice* article. "Unlike many other immune-deficient gay men, who considered themselves, in playwright Larry Kramer's famous phrase, 'ticking time bombs,' my AIDS world-view admitted from the first at least the theoretical possibility of recovery."

These are not just brave words. Experience gained over the years since AIDS burst into the national consciousness shows that people at risk of developing AIDS and people with AIDS can do much to maintain their health. This requires both hard work and courage. Making bravery especially difficult is the repetition of the seductive messages of denial ("I am not the type of person who gets HIV") and despair ("There is nothing I can do about it").

These messages keep us from learning the lessons that are being taught by the many people whose brave struggle against AIDS—a struggle to the death for more than a few—paves the way for many more people to survive

Now is the time to reject the common assumption that HIV = AIDS = Death. Over the last two years many researchers have been publicly expressing their optimism that AIDS will become a manageable illness; indeed, many of the most severe AIDS-associated diseases are already preventable and treatable. The gay community, once predicted to be a constant source of AIDS transmission, has in the last few years effected what psychologists are calling the most remarkable voluntary behavior change ever recorded, bringing homosexual AIDS transmission to a virtual halt in some areas.

Why, then, all the grim pronouncements and dire predictions?

The new frontier: The way AIDS is understood, or misunderstood, is based on the peculiar evolution of the AIDS epidemic. In 1981 the U.S. Centers for Disease Control (CDC) in Atlanta received the first reports of an uncommon form of pneumonia (pneumocystis carinii pneumonia, or PCP) or an extremely rare form of skin cancer (Kaposi's sarcoma, or KS) in young patients with unexplained immune system collapse. These and other unusual or unusually virulent infections comprised a disease syndrome first called GRID (gay-related immune deficiency). Later, when it was found to be infectious and when heterosexual men and women also acquired the syndrome, it was changed to AIDS (acquired immune deficiency syndrome).

By 1984 a new kind of virus (now called HIV, or human immunodeficiency virus) was isolated from AIDS patients' blood, and a test for antibodies to that virus was developed to identify those at risk of developing the syndrome. (While most AIDS researchers, particularly those who control funding, believe with dogmatic fervor that HIV causes AIDS, not everyone believes that the cause of AIDS has been identified. Not everyone with HIV infection has AIDS, and not

# The formula that HIV = AIDS = death kills hope and may not be true

everyone with AIDS has demonstrable HIV infection, yet the presence in the blood of antibodies to the virus is strongly associated with risk of developing AIDS.)

AIDS turned the medical world upside down. With measles and smallpox virtually eliminated, medicine was well on the way to curbing infectious diseases. The final frontiers of medicine appeared to be cancer and genetic disease. These hopes were shattered by the appearance of AIDS.

Also shattered was the conceit that the idea of disease as punishment and the consequent castigation of the afflicted were artifacts of less enlightened times. The ugly truth came as front-page news: panicked schools barring HIV-infected children, a mob burning the home of a family with AIDS, doctors refusing to treat sick patients, politicians calling for quarantine, and deep public sentiment for stigmatization of the "guilty" victims. One poll showed that 29 percent of Americans favored tattooing people exposed to HIV.

As Susan Sontag observes in her 1988

monograph AIDS and Its Metaphors, AIDS quickly surpassed cancer as the disease that symbolizes our deepest fears and prejudices.

"It seems that societies need to have one illness which becomes identified with evil, and attaches blame to its 'victims,' but it is hard to be obsessed with more than one," she writes. "For several generations now, the generic idea of death has been a death from cancer, and a cancer death is experienced as a generic defeat. Now the generic rebuke to life and to hope is AIDS."

Unlike cancer, which one either does or does not have and which proceeds by more or less clearly defined stages, "full-blown"

The AIDS epidemic has turned medicine on its head, shattering old myths and forcing new thinking.

AIDS, as a great many researchers refer to it, is a syndrome defined by the presence of a combination of constitutional symptoms and/or infectious diseases in a person with unexplained immune deficiency. This immune deficiency is, as noted above, thought to be caused by HIV—but the vast majority of those infected with HIV (in the U.S., an estimated 1.5 million people; worldwide, an estimated 5 million to 10 million people) do not have AIDS. Instead, these people are in a kind of medical limbo. They are told that they can expect to remain in limbo for an indefinite period until they develop a series of symptoms known as ARC (AIDS-related complex) and, finally, an AIDS-defining dis-

Most researchers endorse the opinion of Andrew Moss, an epidemiologist at the University of California, San Francisco (UCSF), who told a recent conference of biologists that people with HIV infection have begun "a pathological process that will give them AIDS in 10 years."

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The period between the time a person acquires HIV infection and the time that person is diagnosed with AIDS has been referred to as the incubation period for AIDS. However, as more and more individuals survive the earlier guesses, official estimates of the length of this period have increased from three years to Moss' current estimate of 9.8 years for 50 percent of those infected.

"The contention that AIDS is invariably fatal depends partly on what doctors decided to define as AIDS—and keep in reserve as distinct earlier stages of the disease," Sontag argues. "And this decision rests on a notion no less primitively metaphorical than that of a 'full-blown' (or 'full-fledged') disease.... The doctors' botanical or zoological metaphor makes development or evolution into AIDS the norm, the rule."

**Surviving AIDS:** A growing number of physicians who regularly see patients with AIDS, ARC and asymptomatic HIV infection—especially those whose practices are not limited to hospitalized patients—have begun to question whether an HIV-positive person will inevitably develop AIDS.

"My guess is that the vast majority of people who currently have ARC can be prevented from ever developing AIDS," Bernard Bihari, a physician and researcher at Downstate Medical Center in Brooklyn, told a gay and lesbian community forum last year. "And of people who currently have AIDS, a significant number will survive and recover."

At first glance this statement seems wildly optimistic in light of AIDS statistics kept by the CDC. The cold facts are these: of the 90,000 U.S. residents with AIDS reported to the CDC since 1981, 52,000—57 percent—have died. Among the 38,228 people diagnosed with AIDS before 1987, the fatality rate is 80 percent.

In understanding these statistics and the important trends concealed within them, it is important to remember that AIDS does not develop overnight and that the CDC's technical definition of AIDS is the presence

of a severe opportunistic infection secondary to severe immune dysfunction that cannot be explained—except, of course, as the result of HIV infection. Because AIDS is a syndrome that takes time to develop, almost all of the people now diagnosed as having AIDS acquired HIV infection, as UCSF researcher Moss puts it, "before we knew anything about it."

Today researchers know a lot about it. They know that the most severe of the "opportunistic" infections associated with AIDS tend to appear when a person's immune system declines to a certain, measurable point. They know that exposure to a variety of infectious agents—including repeated exposure to HIV—can activate latent HIV infection. And they know that a healthy lifestyle and enlightened medical and psychological care can prolong health.

Today it is possible to prevent many of the severe opportunistic infections (most notably PCP). And the early diagnosis and treatment of these infections and of AIDS-associated cancers is also possible. The advent of the controversial drug AZT has, at least according to some physicians and people with AIDS and ARC, also contributed to survival.

Taken together, these factors have changed the face of the AIDS epidemic. The statistics don't lie, but they show only where the epidemic has been, not where it's going. To base current predictions about whether people will survive—especially people whose HIV infection has only recently been established—entirely upon the experience of the first years of the epidemic is not only misleading, but also harmful.

Nevertheless, the news that people with AIDS and ARC are surviving and that people with asymptomatic HIV infection are maintaining their health is, while heartening, not a call for complacency. To ignore the facts that AIDS is here, that it is a killer and that the epidemic is growing is to participate in the denial upon which the spread of the epidemic depends.

A story CDC AIDS Program Director James

Curran likes to tell illustrates this point. Curran was flying to an AIDS conference and was working on his presentation when a young woman in the seat next to him, seeing his materials, began a discussion about AIDS. "What are my chances of getting AIDS?" she asked conversationally. Curran explained that he could give her a very good idea of her risk is she would answer a few very personal questoins. "Never mind," she said. "I don't think it's a problem for me."

Although AIDS is, tragically, spreading most rapidly among inner-city blacks and Hispanics (see story on page 9), HIV infection is not limited to any easily identifiable group of people. But like the young woman in Curran's story, most people cope with AIDS by denying their own risk, believing that it is something that happens to somebody else, particularly somebody who is a gay male or a black junkie. Yet these stereotypes do not hold up.

For example, a New York infectious disease specialist recently examined the records of his Staten Island practice and identified 35 women and four men who had heterosexual relations with persons who had HIV infection. Each of these individuals had different sexual partners. These middle-class individuals had an average age of 35 years, an average household income of \$41,200, an average of two lifetime sexual partners and a long-term relationship—averaging six years—with the person who exposed them

Doctors who see the range of cases are no longer so sure that being HIV positive means that AIDS, let alone death, is an inevitability.

to HIV.

All of the men and 31 of the women were white, 34 of the 39 individuals lived in private residences and one had a history of intravenous drug abuse. Nine of these people were unaware of their partner's risk of HIV infection (in these cases, intravenous drug use), and five others found out long after beginning sexual relations with their partner; 16 said they didn't know that HIV could be transmitted by heterosexual sex until after their partner tested positive for HIV antibodies.

Few of these individuals used condoms, and those who did used them only rarely. None of these 39 people fit any of the stereotypes. Eleven of them tested positive for HIV.

Another dangerous manifestation of denial is the refusal of many individuals whose behavior has put them at risk of acquiring HIV infection to come to terms with the possibility that they may develop AIDS. Among gay men, this has been referred to as "the second closet" by Martin Delaney, co-director of Project Inform in San Francisco. Simply put, the first and best step toward surviving the AIDS epidemic is voluntary, confidential, carefully planned HIV testing for people who may have been exposed to HIV.

As recently as two years ago there were as many reasons not to be tested for HIV infection as reasons to be tested. At that time medicine did not have much to offer the HIV-positive individual. Until recently, a widely repeated joke among health-care workers was that when a person tested negative for HIV, the doctor would shake his or her hand and say, "Good luck, and remember to have safe sex." When a person tested positive for HIV, however, the physician would put on a rubber glove, shake hands and say, "Good luck, and remember to have safe sex."

**Times have changed:** It remains true that the social consequences of HIV testing are potentially devastating—people publicly identified as HIV positive have suffered all kinds of discrimination. And a positive test

can be psychologically devastating as well.

The risks of voluntary testing must nevertheless be weighed against the benefits of early diagnosis. Testing itself doesn't offer protection. Neither does denial. But early medical and psychological intervention can.

Therefore, HIV testing, when properly prepared for, is the first step on the path to survival for everyone who has at one time or another risked exposure to the virus. This is especially important for gay men, for intravenous drug users and for the sexual partners of IV drug users because of the prevalence of HIV infection among these populations.

"If you take the test, you can get results on a day you choose, at a time you have lined up the appropriate support and have obtained any needed information when you still have the best possible medical options in front of you," Delaney wrote in a recent issue of *The Advocate*, the national gay newsmagazine. "If you learn by waiting for an opportunistic infection, you're likely to get the news by surprise, at a time when you least expect it, when you are unprepared to hear it and when your future medical options may have already been diminished."

The "appropriate support" to which Delaney refers should include both peer support and psychological counseling.

The isolation of facing a potentially fatal condition is compounded in the case of AIDS by society's fears and prejudices. Support is thus especially important for people with HIV infection, ARC and AIDS. In the best of circumstances, friends and family would form an integral part of such a support group. Whether or not this type of assistance is available, a person who finds that he or she must come to terms with a positive HIV test will enormously benefit from participation in an organized group of individuals in the same situation. Fortunately, AIDS organizations in most areas of the U.S. have either formed such groups or can refer people to them.

Psychological counseling, either in an individual or group setting, can be an important factor in survival. A qualified psychologist or counselor can be of enormous assistance in recognizing and overcoming the life-sapping effects of denial and despair. A psychologist can also help recognize the early signs of mental dysfunction that can sometimes be the first symptoms of AIDS. Several causes of this so-called "AIDS dementia" can, with early diagnosis and medical intervention, be treated.

By helping people confront and work through issues blocking their ability to function fully, psychological counseling enhances not only one's ability to think and feel, but also one's physical well-being.

An exciting new field of research, psychoimmunology, has found that psychological status directly influences immune function. In AIDS, a syndrome arising from immune dysfunction, these findings have a direct bearing on survival.

Lydia Temoshok, a clinical and social psychologist at Langley Porter Psychiatric Institute in San Francisco, has reported strong evidence that psychosocial factors exert an important effect on immunologic changes in AIDS. In a 1987 experiment she conducted with psychoimmunology founder George F. Solomon and others, Temoshok gave a battery of psychosocial and immunologic tests to 18 men with AIDS. They found that several psychosocial traits appeared to predict adaptive immune function.

These were current involvement in a physical fitness program, generally taking care of oneself in terms of health, and less tension and anxiety

In another study, Temoshok and colleagues compared the self-report psychological measures obtained two to eight weeks after the diagnosis of PCP from 10 men with AIDS who subsequently died and from 11 men who had survived. Survival was significantly associated with avoiding a "helpless/hopeless" attitude.

Coping with AIDS: The very small number of subjects in these studies, as well as their preliminary nature, makes it impossible to draw firm conclusions. However, from these and other pilot studies and from interviews with long-term AIDS survivors, Solomon, Temoshok and colleagues hypothesize that the following traits are associated with AIDS survival:

- collaborating with one's physician and not interacting in either a passive/compliant or defiant mode;
- having a sense of personal responsibility for one's health, including a sense that one is not helpless;
- having a commitment to life in terms of unfinished business, unmet goals or as-yetunfulfilled experiences;
- having a sense of meaningfulness and purpose in life;
- finding new meaning in life as a result of HIV infection or AIDS;
- engaging in a physical fitness program to the extent that one is able;
- having the ability to be assertive and to say no;
- having the ability to withdraw from taxing situations and to nurture oneself;
- being sensitive to one's physical and psychological needs; and
- being able to communicate openly about one's concerns, especially one's illness.

The worst thing is to chase after faddish treatments. Still, it's useful to stay aware of the risks and benefits of new drugs and fresh approaches to AIDS.

In their interviews with AIDS survivors, the psychoimmunologists found three prevailing attitudes: acceptance of the reality of their diagnosis coupled with a refusal to see it as a death sentence, a personalized means of active coping with their diagnosis, and an altered lifestyle to accommodate their disease.

Temoshok says that if she were to find out tomorrow that she were HIV positive, she would take a long, hard look at her life.

"I would carefully assess my life situation and see if my life is meaningful to me," she asserts. "Perhaps this would mean doing more things for others or for myself. I'd ask myself some questions: 'Is my job causing me satisfaction? Are the people around me causing me satisfaction?' Then I would choose a physician I could work with actively, one who would tell me of important treatment options. I would look at things that would help me stay psychologically and physically well, perhaps look at biofeedback, for example—things that are powerful but not necessarily proven."

Physicians who treat AIDS patients are saying the same thing.

"The treatment of AIDS sits on a tripod," New York Hospital/Cornell Medical Center clinician Ronald Grossman said last November at a Columbia University public forum. "Leg number one is that you've got to have a doctor/patient relationship and be in the medical system. Leg number two of the tripod is how you take care of yourself, and everyone in this audience knows what that means: how you eat, how you rest, cleaning up your act from all of the bad habits that we all had. Tripod leg number three is what is often referred to as spirituality, positive thinking."

As both Temoshok and Grossman stress, the doctor/patient relationship is crucial to health maintenance. Being in the medical system, as Grossman puts it, allows a person to monitor his or her immune status and to make informed decisions about interventions such as when to begin taking medication to prevent PCP and when—or whether—to take AZT.

This medication, which is the subject of a vehement medical debate, is associated with a number of very serious toxicities. Most physicians believe that the benefits outweight the risks—and they have many patients who are doing well on the drug. Yet other physicians believe that the benefits are much less tangible—and they have many patients who are doing well without the drug. AZT is currently approved for use in patients whose immune parameters suggest that they are on the verge of developing AIDS. A huge clinical test is now being conducted to determine whether the drug can be helpful if administered to people with asymptomatic HIV infection.

Whether or not to take this drug depends on a person's particular situation; it is a decision in which one should be able to participate. Obviously, such participation requires an active partnership with one's doctor.

**Exploring options:** Although AZT is the only drug officially approved for the treatment of AIDS, other medications available either in the U.S. or in other countries have a potential, but unproven, value. Probably the worst thing to do is to participate in every faddish treatment that comes along—and in the case of AIDS, every month brings a new fad. But it is imperative that one be able to discuss the risks and benefits of experimental drugs with one's physician, and one should be willing at least to consider using innovative treatments or entering clinical trials of experimental drugs that seem appropriate.

As mentioned above, it is now possible to prevent PCP from developing in the great majority of AIDS and ARC cases by the aerosol administration of a drug called pentamidine. To date this has been the single greatest breakthrough in AIDS patient management, as about 60 percent of AIDS deaths have been attributable to PCP infection. However, treatment is expensive and should be undertaken only when a person's immune status reaches a certain critical stage. Currently this is thought to be when a patient's T-cell count drops to less than 200 cells per cubic millimeter. Recent research indicates that an even better indication of when to begin PCP prophylaxis is when a person has two of three indicators: a T-cell count less than 200, the presence in the blood of an HIV antigen called p24 and high levels of a blood factor known as beta-2 microglobulin.

When appropriate, various antibiotic medications can be used to prevent the

onset of other opportunistic infections. However, drug sensitivities must be taken into account. A long-lasting sulfa drug known as Fansidar is particularly dangerous to sensitive individuals; its use should be closely monitored.

The decision to take prophylactic medication must be made by the patient and the physician working as partners. Both must make efforts to keep informed about current treatments, and open discussions and exchanges of information are a crucial part of therapy. If a physician is unable or unwilling to form such a partnership, he or she is probably the wrong person for the job.

The second leg of the tripod supporting survival is taking care of oneself. This should include continuing or beginning a regular program of exercise, but not to the point of exhaustion: taking care of oneself also means recognizing one's limits, especially for the person with ARC or AIDS. "Don't overdo it," is the basic admonishment for work as well as for play.

Diet is also extremely important. AIDS is a disease of the immune system, and while the immune system is perhaps the most poorly understood aspect of human metabolism, one thing that is known is that a good diet is crucial to proper immune function

Sudhir Gupta, a clinical immunologist at the University of California, Irvine, and an AIDS practitioner, strongly emphasizes a fatfree diet supplemented with vitamins and trace elements zinc and selenium.

"People tend to neglect how important nutrition is for the immune system," Gupta says. "I tell my patients to cut down on fats—they are always wanting to eat fast food—and to eat less red meat, shrimp and lobster. Fat increases cancer risk and is associated with poor immune response."

Donald Kotler, of St. Luke's Medical Center in New York, makes similar suggestions.

"AIDS patients seem to do better on a relatively lactose-restricted and low-fat diet, as long as there is a sufficient amount of protein.... I make sure that there's a supplement of protein," he told the Columbia forum. "I often tell people to find a good multivitamin with mineral preparation, I don't care what kind it is, and to take three of them, not 20, but three, maxidose rather than megadose."

Last, but by no means least important to surviving AIDS, is one's mental and spiritual attitude.

**True grit:** Michael Callen has tracked down and interviewed more than 20 long-term survivors, all of whom have had AIDS for at least three years

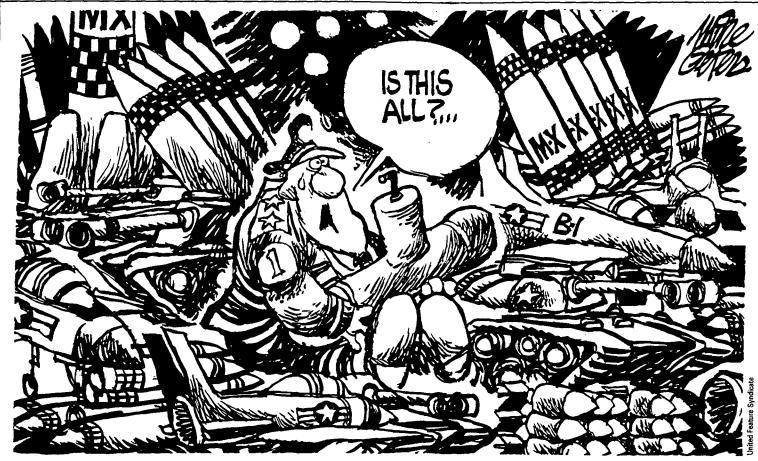
"If I had to describe in one word the common characteristic of the long-term survivors I interviewed, it would be grit," he wrote in his *Voice* article. "These people were all fighters. Opinionated, incredibly knowledgeable about AIDS, stubborn and passionately committed to living, these men and women were working hard to stay alive."

People surviving this epidemic don't have an antidote for AIDS. What they do have are the antidotes to denial and despair—the determination to be responsible for their own lives and the courage to hope. Current medical opinion confirms the validity of their struggle.

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## EDITORIAL



## American public leads the way to new politics

A growing majority of Americans see the Cold War as an anachronism. Whatever most Americans may once have thought, they now consider the threat of Communism and Soviet military power to be the least of their foreign policy and security concerns. But this truth, the logic of which *In These Times* has argued consistently for the past decade, still escapes not only the ideologues of the Republican Party and the Democratic Leadership Council, but also pragmatic political consultants like those who ran Walter Mondale's and Michael Dukakis' presidential campaigns. Like the candidates they advise, these savants remain shackled by ideology and survey results of their own making. Creatures of Cold War liberalism, they are blind to the international realities of the '80s and to the meaning of two decades of change in Europe, Japan, the Communist countries and the Third World.

Not so for the American people. While smug political consultants advise aspiring Democrats to mimic Republicans on foreign and military policy, the public looks at the world and moves in the opposite direction.

**Cold shoulder to the Cold War:** This truth has been reflected in numerous recent polls indicating that public support for the Reagan years' military buildup has been eroding. And now an indepth study by the Roosevelt Center for American Policy Studies, a non-partisan public-policy organization, confirms that a large majority of Americans desire a new set of priorities to guide public policies. The study involved more than 900 participants in forums held in 12 communities across the country. Chosen from all walks of life and from political and ideological positions corresponding closely to national averages, each assembly was representative of the community in which it was held.

Participants in the forums were asked three primary questions: What threats to national security are of greatest concern? How much money should we devote to defense spending? Given the increased risks defense cuts might pose, which specific programs, if any, should be cut, and which increased?

The most striking result was that the threats of Communist aggression in Asia, Soviet aggression in Europe and the general spread of Communism were considered to be minor or negligible by large majorities. In the list of threats considered by the participants, these three came in dead last. On the other hand, nuclear and chemical proliferation, deterioration of the global environment and domestic social concerns led the list. The proliferation of deadly weapons was a top or important concern of 86 percent of the participants, the environment was a first or second concern of 81 percent of forum members, and social needs of 77 percent.

These would be startling results if one took the pronouncements of leading political consultants seriously. But the pundits are not stupid in the ordinary sense of the word. They continue to recite received wisdom because they are by nature cautious, conservative and beholden to the elites they serve. The public has passively accepted much of this "wisdom" in the face of longtime barrages of stories about the menace posed by the Soviet Union to Europe and the Mideast and by Soviet "client states" to the Third World. A time lag for the underlying reality to become clear was only natural, especially in the absence of political leaders or popular media to challenge the Cold War shibboleths.

**New values:** But despite the propaganda to which it is constantly subjected, the public has emerged with a set of spending priorities that conforms more closely to real social needs than do those of their political "leaders" and "opinion makers." A majority, questioning the sanctity of the "strategic triad" of land-, air- and sea-based nuclear weapons, opposes further modernization of land-based ICBMs and wants to eliminate the B-2 (Stealth) bomber and the Midgetman ICBM. Only 2 percent support administration plans to modernize all three legs of the triad, while 71 percent would stop all work on the Strategic Defense Initiative (SDI) except research. Only 9 percent support the Reagan plan to test and deploy SDI.

Participants also believe that American commitments and troops in Europe and the Far East should be cut. Forty-four percent would bring home and decommission 20,000 of the 300,000 U.S. troops in Europe, while 40 percent would cut U.S. forces there by a full third. Similarly, 61 percent endorsed a plan to require Japan to assume the cost of defending its own air and sea routes and to share the costs of defending the Philippines. And a majority would withdraw all American land forces from Korea.

Yet, even though 69 percent of forum participants consider "Third-World poverty and repression" as a top or high priority threat, they are not entirely immune to prevailing neocolonial ideology. Almost half (48 percent) see "low-intensity conflicts" as problems originating in the Third World and support efforts to combat terrorism, guerrilla warfare and sabotage.

When the costs of the various programs that participants would cut or add to current military budget levels are added up, the net result would be cuts of \$111 billion over the next five years. This is a modest reduction in military spending—about \$22 billion a year, or a bit more than 10 percent. Yet considering that the proposed cuts were chosen in the absence of a rigorous public challenge to the official ideology purveyed day and night in the media and by public officals, they are highly significant.

For the left, and for the Democratic Party as a whole, the message should be clear. The problem is not that Democrats are seen as soft on defense—the public is even softer. The problem is that the party is seen as weak, without its own identity, unwilling to give leadership to the nation in a bold and committed manner. A party that took these results seriously and began to act on them by proposing a fundamentally new set of spending priorities could only increase the majorities against present policies. In the process they would also begin truly to defend our nation.

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