The Minnesota Response to AIDS

by Charles Backstrom and Leonard Robins

AIDS—Acquired Immune Deficiency Syndrome—has become, in the decade it has been known, a major challenge to the health of Minnesotans. This report is an overview of how various Minnesota government and private institutions and groups have responded to HIV/AIDS and how the decisions about what to do came to be made.

The Extent of HIV/AIDS in Minnesota

As of the end of December 1990, 840 people had been diagnosed with AIDS in Minnesota. This is an increase of 186 cases in 1990, adding almost one-fourth more cases in one year. Seventy percent of these people (590) had died by the beginning of this year. The eventual mortality rate will be much higher because HIV/AIDS is a progressively worsening disease. All of those diagnosed with AIDS more than five years ago have died. AIDS is now the fifth leading cause of death among Minnesota men aged twenty to sixty-four. HIV/AIDS is an especially serious social and economic problem because most of its victims are young.

The total number of persons diagnosed with AIDS is not an adequate assessment of the extent of the disease. Many years will typically pass after infection before symptoms develop or evidence of AIDS appears. The number of AIDS cases in a given year is an indication of how widespread the infection was seven or eight years earlier. HIV/AIDS in Minnesota is actually much more widespread. As of November 1990, another 1,500 persons had been reported carrying the virus, but not yet diagnosed with AIDS. This is six times the number of people still alive with a diagnosis of AIDS (250).

Moreover, because not all people infected with HIV/AIDS have been tested, the numbers of people carrying the virus are actually substantially higher than reported.

The current estimate by Minnesota’s Department of Health is that at least 4,400 people are infected. Therefore, even if no additional persons were to become infected, the number of AIDS cases will continue to grow. The Department of Health estimates that 200 new cases will appear in 1991, and 215 in 1992. Almost 90 percent of Minnesota’s AIDS cases are in the Twin Cities metropolitan area, 54 percent in Minneapolis alone. There is a wide variation in the presence of AIDS outside the metropolitan area although the proportion of people infected with the virus is growing there as well. As of August 1991, thirty-one counties still report no cases, forty-seven report one to five, four report six to nineteen, and five report twenty or more (see map).

Minnesota ranks approximately in the middle among the states in number of AIDS cases, but a more useful measure is the rate of infection in the overall population. On this, Minnesota ranks near the bottom.

Because the number of infected people is still relatively low in Minnesota, even unsafe behavior is less likely to result in infection here. And because HIV/AIDS first turned up on both coasts, residents and government agencies in Minnesota had a

Cumulative AIDS Cases in Minnesota, August 1991

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<th>Number of Cases</th>
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<td>20 or more</td>
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Source: Minnesota Department of Health.
headstart in learning how the disease was spread, and therefore in knowing what precautions to take. Intravenous drug use is also smaller in Minnesota—an estimated 3,000-5,000 people—than in some other states. Users here are less likely to rely on "shooting galleries," where needles are commonly shared, and this too cuts down on the incidence of HIV/AIDS.

Who has HIV/AIDS in Minnesota?
Most cases of AIDS in Minnesota are found among homosexual and bisexual men. They account for four out of five of the cumulative cases. The sources of infection are classified in Figure 1. It must be emphasized that HIV/AIDS is spread by unsafe behavior by anyone, not just among certain types of people.

Intravenous drug users who are heterosexual account for 3 percent of Minnesota's cases, while homosexuals who are intravenous drug users make up 6 percent of the cases. Women constitute about one in twenty-five of the AIDS cases in Minnesota. For them, intravenous drug use is the source of one-seventh of their AIDS cases. Heterosexual contact accounts for fewer than one in thirty Minnesota AIDS cases, but half of all cases among women.

Blood transfusions, blood components for hemophiliacs, or tissue transplants accounted for one in twenty-five AIDS cases in Minnesota. This means of transmission has been rare, however, since 1985 when testing blood for the virus antibodies was begun.

Children with AIDS constitute 1 percent of Minnesota AIDS cases. There have been eight. Six acquired HIV/AIDS from their mother before birth, the others from early transfusions or transplants.

Members of minority groups have a far greater rate of AIDS than whites. African-Americans in Minnesota account for about one in ten AIDS cases, nearly five times their share of the state's population. Likewise, Hispanics (who may be of any race) make up about twice the proportion of AIDS cases as their share of the overall population. In Minnesota about one in seven African-American and one in ten Hispanic AIDS cases arose from intravenous drug use.

What all these figures demonstrate is that up to now, Minnesota has recorded nearly a thousand AIDS cases, the tip of an iceberg that includes at least four times as many who already carry the virus. While relatively low compared to some other states, the number continues to grow.

What Minnesota Government has Done about HIV/AIDS
Minnesota is an activist state. Its citizens organize collectively to try to meet problems, and this often results in an expectation that government should intervene to protect them and advance their interests. A number of government entities have acted on HIV/AIDS.

- The Minnesota Legislature. The legislature has taken a proactive and effective role in the fight against HIV/AIDS. This has been true in terms of both the actions it has taken and the proposals it has rejected.
- Recognizing the potential for a few members to advocate panic, the legislature has taken action against the threat of a new, unknown disease. The leadership of the Minnesota legislature responded in a uniquely creative way.
American, Hispanic, Asian, and American Indian. The legislature also required all public schools to present a program of HIV/AIDS education.

What the legislature did not do was in many respects as important as what it did. Although some members introduced bills for massive mandatory testing or limiting AIDS education, these were either not brought to the floor, or if passed in the House of Representatives, were killed in the Senate or in conference.

But the legislature did not do everything possible against HIV/AIDS. Legislation that would speak to concerns that might encourage more widespread testing, such as specifically outlawing discrimination on sexual orientation, was not passed, nor seriously pushed. Minnesota is the only midwestern state where sodomy is still illegal.

Surprisingly, for a new, dangerous, potentially volatile issue, members reported virtually no communications about HIV/AIDS from people in their districts. This climate may well change with the revelation in June of this year that a doctor with HIV/AIDS did not refrain from performing invasive procedures on patients. It is likely that increased pressure will be brought to bear in the 1992 legislative session for mandatory testing of health care providers.

If the legislature should move to require mandatory testing of health workers, leading Minnesota physicians have made it clear that they would as a tradeoff demand mandatory testing for patients as well. It is inevitable, therefore, that mandatory testing would expand from a carefully targeted to a massive universal program. Although this may be popular, because superficially plausible, such action would negate the legislature’s record to this point of cautious, public-health oriented action.

- The Minnesota Department of Health (MDH). Among state health departments, Minnesota’s is much admired. Chief epidemiologist Michael Osterholm has gained national recognition, and Michael Moen, director of disease prevention and control, is also widely respected in the legislature. These officials provided critical support in the successful efforts to prevent passage of counterproductive HIV/AIDS legislation. Their confident professionalism led them to use an aggressive style in MDH’s efforts against HIV/AIDS, setting up a comprehensive program of testing, reporting, and contact tracing through six sites around the state. But the personal and political situations surrounding HIV/AIDS make it different from other diseases, and hence their particular approach in this area has been highly controversial.

MDH’s strong emphasis on testing as soon as tests were developed was the first controversy. Since there was then no treatment available, many people concerned with HIV/AIDS opposed this as a blatant invasion of privacy. But as medications were developed, nearly everyone came to agree with MDH’s stress on getting people to test.

A lasting controversy, however, surrounds MDH’s emphasis on reporting of names of those testing positive. Some public meetings with MDH officials speaking to gay groups degenerated into shouting matches. Gays decried the department’s name reporting and contact tracing units as “sex police,” and department members questioned the legitimacy of certain gay spokesmen. This discouraged further communication.

MDH also had a major confrontation with Hennepin County. In 1990 the department threatened not to renew its contract with Hennepin County’s Red Door Clinic as a HIV/AIDS counseling and testing site. The Red Door advertised and practiced effective anonyymity of testing, aiming to increase testing by countering fears of clients that their names might be disclosed and their contacts traced. But MDH, standing on their clear statutory authority requiring reporting of all those diagnosed with communicable diseases (which they had designated HIV/AIDS to be) and believing in the ultimate efficacy of this effort, insisted that the Red Door drop their anonymous testing option and obtain and report names of those testing positive for HIV/AIDS. The Red Door was actually getting names of
only 15 to 20 percent of those testing positive. MDH believed that Red Door’s staff subverted the names policy, citing in contrast the 75-80 percent that were named from those testing positive at St. Paul’s Room 111 Clinic.

MDH threatened to completely withdraw their support for HIV/AIDS testing at Red Door, even asking for other agencies to request designation as a counseling and testing site in place of Red Door. The managers of Red Door, which is responsible for over half of the HIV/AIDS tests conducted by public facilities throughout the state, resented what they saw as meddling from the state on delivery issues. The Hennepin County Board backed its own agency in the clinic fight, going so far as to consider the necessity of local funding for continued anonymous HIV/AIDS testing if the state cut off its support.

Finally, a compromise was worked out. Red Door promised to make a good faith effort to get names, and the department renewed the contract that provided funds for HIV/AIDS testing and counseling. MDH is still resentful about the situation, reporting that the percentage of names reported from Red Door has not gone up appreciably.

A new development in the testing effort transpired in June when MDH went public with the suggestion that some 339 patients of a family physician who has HIV/AIDS be tested. On these people the doctor had performed invasive procedures while he had a rash on his hands. As mentioned, the revelation that healthcare recipients could have been endangered has unleashed demands for more restrictions on healthcare practitioners.

Despite the controversies and difficulties, MDH has played a powerful proactive role regarding HIV/AIDS. It deserves special mention for the creative way it has provided money for and worked with many local public and private agencies around the state who are involved with action programs. As such, MDH has been the major underwriter and most consistent supporter of the Minnesota AIDS Project (MAP), helping the project to become far and away the largest HIV/AIDS service organization in the country in terms of the size of the people-with-AIDS population that it serves.

For educating the general population about HIV/AIDS, MDH has composed flyers and produced videos which are available to community health agencies. They also directly sponsor ads, or fund other groups to produce and run them in various media. MDH has trained county and local public health personnel, and encourages local HIV/AIDS program initiatives.

The highest priority in MDH’s educational efforts has been groups at special risk. These ventures recognize the need for very explicit statements of why and how to be safer. The materials they have produced are quite in contrast to national educational efforts, including the famed Surgeon General’s HIV/AIDS brochure, which did not recommend a category of safer sex practices. MDH has funded HIV/AIDS programs to deal with the special problems among people of color from special appropriations. Hoping to acquire a better base of knowledge for action in these communities, MDH funded a survey of African-Americans’ sexual knowledge, attitudes, and behavior conducted by CURA. A survey of Hispanics has also been completed by an out-of-state group.

In sum, despite some valid criticism, Minnesota’s Department of Health is a national leader in shaping HIV/AIDS policy.

- Minnesota’s Department of Human Services (DHS). DHS is the lead state agency in handling drug programs. Itself a challenging responsibility, drug programs have had to incorporate HIV/AIDS-reduction efforts because of the spread of HIV/AIDS through intravenous drug use and trading sex for crack. This has not been easy, because persons suitable as drug counselors, including former addicts, are not necessarily trained in HIV/AIDS counseling.

Minnesota, joked about as the “land of 10,000 treatment centers,” has been in the forefront of active intervention to help drug users stop. Unlike many high incidence states, people who want to quit in Minnesota don’t have to stand in line for months to get help.
members at the Minnesota AIDS Project. Emily Moore (left) supervises the hot line
The Minnesota AIDS Project is the largest HIV/AIDS service organization in the country

- **Minnesota's Department of Commerce.** This department regulates insurance companies and has been more vigorous in overseeing insurance companies' practices than regulators in most states. Although the state cannot tell a company they can't test for HIV/AIDS, as long as it is part of a package of tests for other risks, Minnesota has forbidden insurance companies to refuse to cover people because they live in zip codes where gay men may be concentrated or have vocations that are stereotyped as attracting gays.

- **Minnesota's Department of Human Rights (DHR).** Minnesota has a strong anti-discrimination statute and a department to enforce it. Minnesota's civil rights law does not expressly protect people from discrimination based on sexual orientation, but the Minnesota Human Rights Act has been interpreted by the Commissioner of Human Rights to cover as disabled those persons with HIV/AIDS. DHR also successfully pursued a complaint against some nursing homes who refused to admit HIV/AIDS patients.

- **Minnesota's Department of Education.** In 1988 the legislature required HIV/AIDS education in every public school. School districts were given great latitude in setting up their HIV/AIDS education programs. No specific state curriculum was prescribed, either by content or by grade level, and no deadline was set for instituting a HIV/AIDS

    instructional unit. HIV/AIDS education has encountered resistance in some communities. Several attempts to evaluate HIV/AIDS education in Minnesota are underway.

**Community Group Action on HIV/AIDS**

In Minnesota, the primary action group against HIV/AIDS is the Minnesota AIDS Project (MAP). About one-third of its $2 million budget comes from the Minnesota Department of Health. Besides its efforts at education and behavior change, MAP's unique function is to create an extensive service delivery program using volunteers, which is now being expanded statewide, with regional offices in Duluth, Rochester, Marshall, and St. Cloud. MAP is also responsible for an 800-number hot line for HIV/AIDS information which receives more than 600 calls per month.

Both in absolute terms and especially in comparison with AIDS service organizations in other states, Minnesota has been well-served by MAP.

**How Decisions Were Made In Minnesota**

A clear pattern emerges from our review of Minnesota's response to HIV/AIDS. All levels of government and most influential private sector groups have adopted a proactive, liberal approach to HIV/AIDS. In our judgment, Minnesota's response to HIV/AIDS has largely been caused by two things: Minnesota's political culture, and the conceptualization of HIV/AIDS as primarily a public health issue.

Minnesotans have a general belief in a positive and activist role for government and special willingness to spend for health programs. One can speculate that this arises from their dominant ethnic and religious backgrounds. Lutherans and Roman Catholics have historically both tended to stress collectivist values and respect for government.

But when it comes to moral issues many Minnesotans are conservative. This raises the question of why this conservatism has not resulted in a different set of HIV/AIDS policies. The answer is that policymakers in Minnesota have come generally to want to have a strong information base before launching into new ventures. When HIV/AIDS appeared, this state had a core of respected health professionals that were called upon for advice, and they were able to lay the base for action.

Studies of HIV/AIDS policymaking elsewhere have demonstrated that public health officials are the single most influential group in determining HIV/AIDS policy. Moreover, when in other states measures were passed concerning HIV/AIDS that were opposed by public health professionals, like the legislation requiring mandatory testing of marriage license
applicants for HIV/AIDS enacted in Illinois and Louisiana, the evidence of tremendous cost ineffectiveness presented by public health professionals led to their quick repeal.

What is the public health perspective on HIV/AIDS? Essentially, public health professionals stress the need for cooperation with representatives of those at high risk in developing a consensus on effective means for preventing the spread of the HIV/AIDS. Their reason for stressing a partnership rather than a regulatory approach is twofold. First, the long period of being asymptomatic coupled with the absence of a cure for HIV/AIDS means that a punitive, regulatory approach such as massive mandatory testing will be counterproductive because those at high risk will not test and will therefore become "invisible" and hence not undergo the counseling and education that might lead to behavior changes.

Second, HIV/AIDS is much more difficult to transmit than most communicable diseases, and in the vast majority of cases requires the active cooperation of the person who will receive it. Therefore public health professionals cannot find a professional reason for harsh measures such as quarantine.

Conclusions

Minnesota has mounted a very substantial, carefully thought-out government response to attacking HIV/AIDS, but major additional efforts are needed to get the other half of persons who carry HIV/AIDS to be tested. Minnesota has sufficient provider organizations and trained health care personnel to handle an increasing HIV/AIDS case load. But cost increases will put additional strains on the state budget.

Despite its best efforts, Minnesota will not be able to completely prevent new HIV/AIDS infections. Understandably this leads people to search for more dramatic ways to combat it. The great question in Minnesota concerning HIV/AIDS policy is whether the state can persevere in making decisions on the basis of public health professionalism.

The 1990 Census of Population found that the 1980s were the toughest decade in history for small towns in Minnesota. Half of the freestanding incorporated places in the state lost more than 5 percent of their population between 1980 and 1990, and only a quarter gained more than 5 percent (Figure 1)."

* We combined the numbers for contiguous incorporated places, such as Brainerd and Baxter, or the eighty-five separately incorporated places in the built-up area of the Twin Cities, and treated them as single freestanding places. We assumed that the loss or gain of less than 5 percent in ten years was not a significant change.

The percentage of Minnesota places whose population has gained 5 percent or more has declined fairly steadily at each census since World War II except for the "population turnaround" decade of the 1970s, which apparently was an aberration. The 1990 census has forced us to temper some of the optimism about small town growth that we expressed only a few years ago."


Charles Backstrom is a professor of political science at the University of Minnesota in the Twin Cities. Leonard Robins is a professor of public administration at Roosevelt University in Chicago. Robins and Backstrom are currently writing a book, *The Politics of AIDS*, to be published by Chatham House. This article is a very brief version of their full report, *The Minnesota Response to AIDS*, to be published later this year. Copies of the full report may be ordered by calling CURA at 612/625-1551.

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Tough Times for Minnesota Small Towns

by John Fraser Hart and Tanya Bendiksen Mayer

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