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6

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5

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3

A Rural Community Learns That H.I.V. Lurked There All Along

NY Times

12-1-97

By SOMINI SENGUPTA

JAMESTOWN, N.Y., Nov. 25 — A month has passed since residents of this Chautauqua County city were jolted by the news that a 21-year-old drifter from Brooklyn, Nushawn J. Williams, had been accused of knowingly infecting several young women in the county with H.I.V., the virus that causes AIDS.

Since then, the cold weather has arrived with its usual fury and red Christmas bulbs have been strung up, as they always are, on the lamp-posts of this dim downtown. No longer are national television talk-show hosts offering perks to girls willing to talk about Mr. Williams. Nor is there a long line of teen-agers waiting to give blood for H.I.V. tests at the county health clinic. Of the more than 1,340 people tested in the last four weeks, one woman has turned up positive, joining 10 others already linked to Mr. Williams.

Still, the collision with AIDS and the brief media frenzy have left their marks on this city, once best known as the birthplace of Lucille Ball. Local college students have begun peddling condoms and safe-sex literature at nightclubs. All over the county, people have begun discussing the state's H.I.V. confidentiality laws and debating the merits of needle exchange. Workshops on AIDS and how not to spread it have become a weekly ritual: a Girl Scout official attended her first session earlier this week, and a social worker came to learn about the emotional needs of people with AIDS.

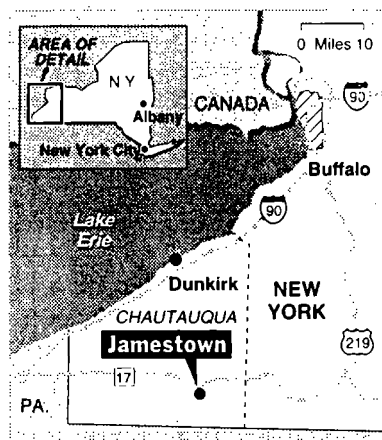
Indeed, as Cindy Chase, whose

'People are just so naïve. People don't have any awareness of the diseases.'

stepson, Cameron, died last year of complications from AIDS, observed, "A lot has changed."

Because of Mr. Williams, AIDS has surfaced on Chautauqua County's radar screen. And it has brought to light the peculiar difficulties of preventing and living with the disease in rural America, where AIDS cases have increased sharply in recent years, according to Federal health officials.

But county health officials and advocates for people with AIDS here say they are left with mixed feelings: relief, for having been spared a



AIDS in Chautauqua County has mirrored national trends.

worse public health crisis, and apprehension about the depth of the lessons learned.

The County Health Commissioner, Dr. Robert Berke, offered a somewhat gloomy prognosis. "We really have to change behavior," he said. "And you don't change behavior with one scare. There will be a lot of rationalizations."

Ms. Chase offered more personal reflections. She remembers her very visceral reaction last week when a friend casually observed that things were returning to normal. "I thought, 'Don't you dare get back to normal!'" she said. "We cannot afford to say, 'There, it's over,' close our eyes and go on. Because it will only happen again."

Things will probably never return to normal for the 14-year-old with dreamy eyes and a tough demeanor who is believed to be the youngest of those who said they contracted H.I.V. from Mr. Williams. Her life has been turned upside down; she has not been to school in a month.

Speaking only on condition of anonymity, she said she had learned quick, hard lessons since testing positive earlier this year — lessons about trust, self-protection and the peculiar perils of H.I.V. in rural communities like her own. "In a small place," she explained, "everybody does everybody."

She is also skeptical of progress. Youths in Chautauqua County, she said, now think they are safe as long as they do not sleep with a certain type of Jamestown girl — one who may have slept with Mr. Williams. "It's everywhere," she said and rolled her eyes. "They should know that by now."

Indeed, AIDS lurked in Chautauqua County long before Mr. Williams arrived. Its name was whispered in the gay bars in Jamestown. Relatives were sworn to secrecy on the

family Bible.

There were native sons like Russ Tilaro, 40, a gay man who left for New York City 20 years ago, only to return in 1995, unable to spend more than a few months at a time out of the hospital.

There was Ron Francis, 40, a gay man who never left Jamestown. He tested positive in June of last year. In a few months, his hemoglobin level plunged. He was hospitalized for lymphoma, a common AIDS-related cancer.

And there were women like Nan Nowak, a 41-year-old laid-off secretary in nearby Silver Creek, who crushes a foul-tasting 250-milligram Viracept tablet every day for her daughter, Nadia, and painfully forces it down her throat. Mother and daughter tested positive three years ago, shortly after Nadia was born. Since then, Ms. Nowak has accused her former boyfriend of knowingly infecting her. Last weekend, Sheriff's deputies arrested the man, Ernie Lockett, on an assault charge; health officials will not comment on whether he deliberately infected anyone.

Until recently, Ms. Nowak complained, "I couldn't get anyone to listen to me."

It is impossible to know just how many people in the county are H.I.V.-positive, because health officials keep records only for patients with full-blown AIDS. There were 59 confirmed AIDS cases at the end of 1996, not including those whose conditions were diagnosed outside the county, like Mr. Tilaro.

As in other rural communities, AIDS in Chautauqua County has mirrored the national epidemic. Seven years ago, when AIDS Community Services of Western New York, a nonprofit group that helps people with housing, medical and other social services, opened an office in Jamestown, case managers saw white gay men almost exclusively, followed by a few intravenous drug users.

Now, according to county statistics, gay and bisexual men make up about one-third of those with AIDS. One-fourth are women. In a 1995 county health assessment, black and Hispanic residents, who are less than 5 percent of the county's population of 141,000, made up more than one-third of those with AIDS.

Until recently, health workers say, people have been reluctant to be tested in local clinics, out of fear that word would spread. Access to services can be difficult. Mr. Francis, for instance, who required chemotherapy for his lymphoma, had to travel more than 90 minutes each way to the Roswell Park Cancer Institute in



Michelle V. Agins/The New York Times

Russ Tilaro, 40, left Falconer, N.Y., for New York City 20 years ago. He tested positive for H.I.V. in 1987 and, after several serious illnesses, returned recently to his boyhood home, where he lives with his mother.

A city where a drifter is accused of spreading the virus that causes AIDS.

Buffalo.

Moreover, the news about AIDS has been slow to reach the cornfields and battered old towns of Chautauqua County. "It's like a denial," said Patrick J. Pursky, coordinator of AIDS education for the Erie County Health Department, who offers technical assistance to health workers across western New York, including Chautauqua County. "Out in the rural areas over here, people are just so naïve. People don't have any awareness of the diseases, the opportunistic illnesses, the cancers, what have you. Now, with what happened in Jamestown, everyone wants to know. It's like, 'Where were you 15 years ago?'"

Margaret Geer, a nurse who tends to AIDS patients across the county, said she routinely answers questions like, can you get AIDS from using a public toilet? Other people have claimed they were safe because they slept only with people from their own

communities, said Ms. Geer, who works for the New York State Visiting Nurses Association. Condoms are not available in the county's high schools. And outreach workers say some schools allow them to make presentations only if they do not mention sex or condoms.

The recent spate of infections in teen-agers, Ms. Geer said, "has just been a big awakening."

Mr. Francis' awakening came on June 29, 1996, when he received the results of his first H.I.V. test. He had already lost a couple of friends to AIDS, including a former boyfriend. Still, he said, "I thought I was safer in a little town than in a city."

Besides, Mr. Francis said, he was never promiscuous. He went to the same three gay bars in town, often with the same friends with whom he had gone to Grant's lunch counter as a boy. "I didn't worry about it," he added. "I wasn't a get-around, go-around kind of person. I'm a pretty picky person."

Within months of his test, Mr. Francis was on a regimen of protease inhibitor drugs. He required several blood transfusions. Five months of chemotherapy washed away his long dusty-blond locks. Ms. Geer, his case manager, said it is likely that Mr. Francis has been infected for several years. Of her 15 patients, she said, most took the H.I.V. test only

after they became sick.

Mr. Tilaro tested positive in 1987. A few years later, he was hospitalized with a brain infection in Los Angeles, where he was living at the time. Several bouts of pneumonia and an acute case of thrush followed. He could not spend more than four months at a time out of the hospital. In May 1995, when he came home for his father's funeral, he was hospitalized again for hepatitis.

He moved back to his childhood home in Falconer, a village of 3,500 people, which he had fled as soon as he turned 18. Since returning, he has gained 20 pounds. And Mr. Tilaro, now the president of the AIDS Coalition of Chautauqua County, has not been hospitalized in two years.

But on late nights sometimes, when the wind whistling across Chautauqua Lake is the only sound he can hear from the covered porch of his mother's house, he misses the hustle and bustle of the city. He misses friends, including those who have died.

"The whole issue is a reminder of the loss I've continually suffered," Mr. Tilaro said. "And the other thing was that it happened to these children."

He has taken one of the H.I.V.-positive young women under his wing; she turned out to be a distant cousin.

Ny Times

12-1-97

AIDS Institute to Open

The University of California is to open a research institute today that will unite all the AIDS programs in the university's San Francisco branch. University officials called it the largest AIDS initiative outside the National Institutes of Health. The institute will provide financial and practical support for vaccine research, AIDS prevention, development of treatments, studies of H.I.V. transmission and policy, ethics research and community studies. (AP)



October 7, 1997

Sandy Thurman, Director
Office of National HIV/ AIDS Policy
Executive Office of the President
THE WHITE HOUSE
808 17th Street ,N.W. 8 th Floor
Washington D.C. 20006

Dear Sandy
Todd
Sarah :

I wish to express my sincere thanks to each of you for your efforts to provide me with a letter of support that met my deadline. You clearly work well together as a team even on small matters. That makes me even more interested in spending some time in your office if my sabbatical is approved and there are no problems with your review process. I'll contact you later re these matters .The University makes its decision in December.

I have enclosed some of my work on rural AIDS . A great deal more work by many more researchers is required if the needs of rural persons who are infected are to be more effectively addressed. We need better data and more information on effective service delivery models in various rural areas as well as effective rural prevention strategies.

Keep up the good work and if anyone is able to attend the Nevada Women and AIDS conference, possibly we can talk further re possible common interests.

Sincerely,

A handwritten signature in cursive script that reads "David".

David E. Berry Dr.P.H.

The Emerging Epidemiology of Rural AIDS

David E. Berry, DrPH

ABSTRACT: *The incidence of AIDS in rural areas is increasing rapidly. However, historically it has been overshadowed by AIDS in the epicenters. From 1991-1992 the increased percentage of cases was higher in nonmetropolitan areas than in any other areas of residence. The rate per 100,000 also increased at almost the same rate in rural areas as in the largest metropolitan areas, defined by the Centers for Disease Control (CDC) as having a population of more than 500,000, and in other metropolitan areas of 50,000 to 500,000 population, as designated by CDC.*

To date, the epidemiology of AIDS in rural areas has not been defined. This information is necessary to developing effective policies and programs. The research presented here reviews the literature on AIDS in specific areas and populations at risk as a basis for generating hypotheses for further study. The first wave of the epidemic, primarily affecting homosexual or bisexual men, is strongly evident in many rural locations. The second wave of the epidemic is strongly evident in the South and can be seen among high-risk groups such as black women, adolescents, migrant and seasonal farm workers, people who abuse alcohol, intravenous drug users, and users of crack cocaine, including those who trade sex for drugs. Poverty is a common characteristic of the second-wave population. Proximity to interstate highways as well as metropolitan areas may also be associated. A national study of the epidemiology of AIDS in rural America is imperative.

Acquired immune deficiency syndrome (AIDS) in rural America is a growing concern of the National Commission on AIDS, as acknowledged in its report to the president from September 1991 (National Commission on AIDS, 1991). Historically, AIDS in rural areas has been overshadowed by the number of AIDS cases in metropolitan areas. However, the epidemic continues to remain dynamic, and rural areas require immediate attention.

Table 1 illustrates the rapid rate of increase of AIDS in nonmetropolitan areas, which is even greater than the rate of increase in metropolitan areas with 50,000 to 500,000 population and almost equal to that of the largest metropolitan areas. The total number of cases is small at present. However, the concern is that

the number of AIDS cases in nonmetropolitan statistical areas (MSAs) increased 9.4 percent as compared to 3.3 percent in MSAs of 50,000 to 500,000, and 3.1 percent in MSAs with 500,000 and more (Centers for Disease Control, 1993).

The Centers for Disease Control (CDC) began reporting AIDS by nonmetropolitan area in the spring of 1991. Table 2 presents the distribution of AIDS cases by Census Divisions in rural America. Current policies prevent the CDC from making nonmetropolitan data available by state or by risk

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Table 1. AIDS Cases by Area of Residence, 1991-1992.

Areas of Residence	1991			1992			Change from 1991-1992		
	Number	Percent of Total Cases	Rate	Number	Percent of Total Cases	Rate	Number	Percent of Total Cases	Rate
Non-metropolitan area	2,734	6.03	4.8	2,992	6.38	5.3	258	+0.35	+0.5
Metropolitan areas with 500,000 or more population	37,762	83.29	25.3	38,937	82.96	25.8	1,175	-0.33	+0.5
Metropolitan areas with 50,000 to 500,000 population	4,842	10.68	10.0	5,003	10.66	10.2	161	-0.02	+0.2
Total									
Mathematical total	45,338	100	—	46,932	100	—	1,594	—	—
CDC total (includes 13 patients whose residence is unknown)	45,524	—	17.9	47,106	—	18.3	—	—	+0.4

Notes:

1. Mathematical total and CDC total do not agree because of the inclusion of cases with unknown residence by the CDC.
2. Rates are per 100,000 population and are crude rates.

Source: Table was developed based on data from the Center for Disease Control, HIV/AIDS Surveillance, Year End Edition, February 1993.

Table 2. Reported Non-metropolitan AIDS Cases by Census Divisions through March 31, 1992.

Census Division	Number of Reported Cases
Mountain	564
New England	601
West North Central	633
U.S. Territories	809
Pacific	884
East North Central	1,035
East South Central	1,109
Mid-Atlantic	1,262
West South Central	1,541
South Atlantic	3,594
Total	12,062

Source: Personal communication, Centers for Disease Control, April 6, 1992.

category, although such information is collected.

Carwein and Berry (1992) provided further evidence that AIDS is a concern even in many of the most remote rural areas through their survey of frontier hospitals with fewer than 50 beds in communities with fewer than six persons per square mile. In frontier communities in the Mountain Census Division, including parts of Nevada, Arizona, New Mexico, Utah, Idaho, Wyoming, Montana, and Colorado, 16 (26%) of the 62 hospitals that responded to the survey had provided care and services to HIV-infected patients. Another 11 hospitals reported awareness of HIV-positive persons in their medical service area, providing a cumulative estimate of 44 percent of the hospitals aware of persons in their community with HIV infection.

The Problem

The epidemiology of rural AIDS must be defined to develop appropriate preventive and other health service policies and programs. This paper examines the health care literature for data on the distribution

and determinants of HIV infection in rural areas. This literature primarily may be classified as descriptive epidemiology. This article contributes to building the base for scientifically valid data through synthesis and hypothesis generation. The populations addressed are: men who have sex with men women, adolescents, migrant and seasonal farm workers, and substance abusers, as well as Native Americans and Native Alaskans.

Methods

A literature search included the following systems: MEDLINE; AIDSLINE; Expanded Academic Index—1985 to 1993; Business Index, 1982 to present; Applied Science and Technology Index, late 1983 to 1993; Education Index, late 1983 to 1993; General Science Index, 1984 to 1993; Humanities Index, 1983 to 1993; and the Social Science Index, late 1983 to 1993. Specific searches on the terms rural HIV and rural AIDS, and general searches on HIV and AIDS were performed. Sources so identified were used to locate other studies and reports.

Reporting HIV/AIDS in Rural America

Most state data on rural areas are based on public health reporting. Such data may be influenced by the state's policies on testing (anonymous or confidential), as well as approaches to partner notification and case finding. Possibly the issue of confidentiality is even more of a concern in rural than urban areas. The population using public health programs, however, clearly represents only part of the denominator.

While states commonly require private physician reporting, the reliability and validity of these processes in rural areas are unknown.

Only one HIV seroprevalence study among hospital patients in a rural area was found among the searches (Murrill, Kunch, Weeks, Whyte, Petersen, & Janssen, 1992). In a hospital-based study in rural southern Georgia, one of every 200 patients (7 patients) was found to be positive among the 15-24 year olds tested. HIV-positive persons were found on every service and among men, women, blacks, whites, and every age group tested. Some were not suspected by their physicians.

Clearly, hospitals, as well as public health departments, other public programs such as community health centers, private practitioners, and others,

cooperatively can better assess the HIV status of a community. Such studies are needed in the future.

High-risk Groups: Men Who Have Sex with Men

The number of men who have sex with men with AIDS in the combined categories of rural areas and population areas with fewer than one million residents have increased linearly from 1986 through 1991 (Karon & Berkelman, 1991) (Note 1). Incidence among the risk group of men who have sex with men is increasing less rapidly in the three major epicenters—New York City, Los Angeles, and San Francisco—as well as in many other large cities. Indications are that the incidence has plateaued, first in whites and then among all ethnic groups (Karon & Berkelman, 1991). For the United States as a whole, the first wave of the AIDS epidemic, which began with homosexual and bisexual men, is shifting to other population groups.

A popular belief is that many HIV-positive persons, primarily homosexual and bisexual men from rural areas, become infected while living in an urban area and return home as their disease progresses. HIV-infected persons who return home were a major concern of the 1990 Invitational Workshop "HIV Infection in Rural Areas: Issues in Prevention and Services," sponsored by the Health Resources Services Administration. Further research is needed to answer the question: Does a scientific base exist to substantiate that returning home characterizes a (or the) major pattern in the epidemiology of rural HIV patients?

Returning Home and AIDS in Rural Areas

Migration of HIV-positive persons to rural areas has been described in Iowa, North Carolina, West Virginia, Washington, Minnesota, and Tennessee (Davis, Cameron, & Stapleton, 1992; Rumley, Shapley, Waivers, & Esinhart, 1991; Patton, 1989; Brandt, 1992; Tucker, Pace, & Soth, 1991; Verghese, Beck, & Sarubbi, 1989). None of these reports are scientifically generalizable to all rural areas or even to all rural areas in a specific state.

Davis and colleagues (Davis, Cameron, & Stapleton, 1992) attempted to build the rural migration case based on their analysis of 262 HIV-positive

patients seen over a three-year period in the University of Iowa Virology Clinic. This number included 72 percent who were homosexual or bisexual, compared to 58 percent estimated from national risk data. Demographic data on these patients indicated that 46 percent had moved into or back to the state, whereas an estimated 8 percent moved out of the state during the study period. Comparison to state data revealed that the Iowa case figures underestimated AIDS prevalence in the state, with 23 percent of the university's patients having an AIDS diagnosis not being included in state figures.

An important methodological problem with the Iowa study is that an operational definition of rural is not presented based on any governmental or social science conventional definition. Rural was equated with low prevalence of the disease in a specific area, i.e., the state of Iowa.

Another medical center study was conducted in West Virginia (Patton, 1989). The researcher described the typical patient as homosexual, male, originally from West Virginia but infected and diagnosed in a large metropolitan area, returning to West Virginia unemployed, Medicaid dependent, younger than age 30, tertiary care dependent, i.e., high care acuity, and homeless. Like the Iowa study, low prevalence and rural were equated.

An additional medical center study was conducted by a medical school in eastern North Carolina that serves a large but not exclusively rural population (Rumley, Shappley, Waivers, & Esinhart, 1991). Their findings are interesting in that they suggest that the patterns of patients they are seeing have shifted rapidly from a population that was returning home from an urban area, especially New York to a population in which "locally infected" patients outnumber those returning home. The new rural wave is more likely to be female, non-white, and younger with heterosexual and/or intravenous drug use related transmission. Disease patterns also are shifting from diseases more common among homosexual and bisexual men such as *Pneumocystis carinii pneumonia* and Kaposi's sarcoma, to diseases such as *Cryptococcus neoformans* infections, HIV wasting, and HIV encephalitis.

All three medical center studies have limitations for estimating the epidemiological significance of migration since they included only patients using a single site for health care.

Migration to rural areas was documented in a study of 32 patients between January 1987 and January 1991 in a rural north-central Washington

community of 40,000 (Tucker, Pace, & Soth, 1991). One-half (16) of the patients were diagnosed locally, 11 elsewhere in the state, and five in other states. All were previous residents of the rural community. The patient population was not characterized by any one high-risk category.

Brandt, a nurse case manager in rural Minnesota, in a report at the Fifth Annual AIDS Update Conference (San Francisco, October 1992) estimated that 50 percent of rural persons with HIV among her case load had recently moved home due to their disease (Brandt, 1992). Most were homosexual or bisexual men.

Tatum and Schoech stress that the health services literature and the media document people both leaving and returning to rural areas. Reasons frequently cited were:

...they leave the areas to obtain services, to find physicians more knowledgeable about HIV, to participate in clinical drug trials, to escape discrimination or harassment they experience or fear, or to avoid the long travel to services in communities nearby. They return home to receive care, or in some cases to die at home. For some persons with HIV disease, this is a matter of choice. Others have depleted their resources and find themselves with virtually no place else to go (Tatum & Schoech, 1992).

Tatum and Schoech, to better understand migration, distributed a questionnaire to a sample of AIDS service providers in Dallas and to nine national experts. While the method of selecting the study group might be questioned, the work is valuable for generating hypotheses. Experts and providers agreed that diagnosis appears to be a major reason for moving. Those who moved from rural to urban areas usually were HIV positive symptomatic; those who moved from urban to rural areas often had advanced stages of HIV. Migration also occurred from urban to urban area primarily among HIV-symptomatic persons.

Providers and experts differed considerably in estimating the degree of migration, which may reflect their experience in different parts of the country. They generally agreed that approximately 20 percent of HIV-positive persons migrated in some fashion. They also agreed that rural-to-urban moves are most common. Their conclusion runs counter to most other reports on migration, which emphasize the "going home" dimension of rural AIDS, and underlines the importance of further epidemiological research.

The case of a young man from a rural coal mining area in Appalachia who was declared missing by his family for many years and returned home with HIV is documented in the office practice of Verghese, et al., in rural Tennessee (Verghese, Beck, & Sarubbi, 1989). This case suggests the possibility of yet another form of migration, runaway rural adolescents; some may have AIDS at departure while others may contract the disease in an urban setting.

States with low HIV incidence and prevalence are especially concerned if data are not adjusted for immigration, since federal and state funding may be based on case figures where initial diagnosis occurs. The results may be a higher use of local HIV services than predicted by the CDC or state data but less than a fair share of funds. Other problems also exist in providing continuity of care, such as availability of medical records and waiting periods to qualify for financial and social support services.

Locally Infected Men Who Have Sex With Men

The high-risk group of homosexual and bisexual men in rural areas is undoubtedly not limited to those returning home but includes long-term residents of rural areas.

The CDC reported for 1991 that the largest number of cases and most rapid increase of cases among homosexual/bisexual men occurred in the South, including the Census Bureau Divisions of South Atlantic, East South Central, and West South Central. They do not, however, further analyze these data in relation to metropolitan and nonmetropolitan areas (Monthly Morbidity Mortality Weekly Reports, 1992).

Homosexual and bisexual men in rural southern areas have been shown in at least one study to engage extensively in high-risk behavior, including unprotected anal intercourse and failure to use condoms during other sexual encounters. Kelly, et al., in 1990 interviewed homosexual and bisexual men who lived in Biloxi and Hattiesburg, Miss., and Monroe, La., communities of 50,000 to 70,000 residents located at least 60 miles from each other or another city of larger size (Kelly, St. Lawrence, Brasfield, Stevenson, Diaz, & Hauth, 1990). They found that 25 percent of those in the study reported participating in unprotected insertive anal intercourse and 23 percent in receptive unprotected anal intercourse during the previous two months. They express concern since this is a higher

rate than previously published and unpublished reports reviewed.

The study's strength is that it is one of the few that has focused on high-risk behavior among homosexual men other than in epicenters. However, the study population was 91 percent white. Furthermore, while labelled "rural" by the authors and possibly viewed as rural by Mississippi and Louisiana, the size of the communities would fit definitions of urban by both the Census Bureau and Office of Management and Budget. Caution seems appropriate in generalizing to all homosexual or bisexual men in the South or rural areas nationally.

Two other reports describe patterns of rural homosexual or bisexual sexual practices and HIV prevalence. Anecdotal information reported by Bell is based on unpublished interviews by Exoo, a Unitarian minister in South Carolina (Bell, 1991). He reports a significant number of married rural men who engaged in anonymous unprotected sex with other men at interstate rest stops and in adult book stores. Brandt describes her rural case load in Minnesota as approximately evenly divided between married bisexual men and homosexual/bisexual men returning home (Brandt, 1992). Whether rural married men who are bisexual or heterosexual are a significant part of rural cases is unknown.

Rural Women with AIDS: Inter-relationship with Race

AIDS is increasingly becoming a concern among women in rural areas and has earlier been recognized in urban areas. The epidemiology of women with AIDS from 1981 through 1990 shows both increases in percentages and numbers. Approximately 3 percent of all AIDS cases were women in 1981, and this has grown to 10 percent of all cases in 1990 (Ellerbrock, Bush, Chamberland, & Oxoly, 1991). Most of these women were black or Hispanic, residents of the Atlantic coast, residents of predominantly urban populations, and in the age group 15-44.

Ellerbrock, et al., (1991) found a growth from 22 percent to 28 percent of the proportion of women with AIDS reported from smaller cities and rural areas during the time period 1986-1990. For nonmetropolitan areas alone (population less than 50,000), the percentage of cases and the cumulative incidence rates were 7 percent and 12 percent per 100,000, respectively, for all women with AIDS. Local researchers, especially in the South, are beginning to

Table 3. Number of AIDS Cases¹ and Percentage of Cases Diagnosed in Intravenous Drug Users,² United States, 1989-1991.

U.S. Geographic Region	Non-MSA		Small MSA		Large MSA	
	Total Number of AIDS Cases	Percent IDU	Total Number of AIDS Cases	Percent IDU	Total Number of AIDS Cases	Percent IDU
Northeast	1,078	45.2	2,093	53.2	35,170	46.5
North Central	1,092	16.8	1,908	19.8	9,977	18.3
South	4,340	24.3	6,154	24.0	33,218	24.5
West	942	21.7	2,357	19.8	27,008	14.9

1. Adjusted for reporting delays.

2. Includes homosexual and bisexual men who inject drugs, heterosexual men who inject drugs, and women who inject drugs.

Note: The table data exclude unknown MSAs. MSA: Metropolitan Statistical Area. IDU: Injection Drug User. Data are from Centers for Disease Control, Atlanta, GA.

Source: Steel, E., Fleming, P., & Needle, R. (1993). Letters to the editor: The HIV rates of injection drug users in less-populated areas. *American Journal of Public Health*, 83(2), 287.

more fully investigate this growth.

Three hundred and eight women with AIDS were reported in Georgia through December 1990 (Whyte & Carr, 1992). Seventy-seven (25%) were white and 228 (75%) were black. One hundred sixty-eight (54%) were from metropolitan Atlanta and 142 (46%) were from other parts of the state including a large proportion from rural areas. (The reverse is true with men, of whom 76% are from metropolitan Atlanta and the rest are from other parts of the state.) Blacks comprised 74 percent of the cases among women in urban areas and 76 percent of the cases among women in other areas. Black women account for 28 percent of the female population in Georgia and 76 percent of the total AIDS cases among women in the state.

The study also found that survival rates varied considerably among metropolitan Atlanta and other parts of the state (400 and 296 days), possibly suggesting a delay in diagnosis. The same was also true for cases of *Pneumocystis carinii* pneumonia (460 and 373 days).

Wooten (1989) described the pattern of persons with AIDS in rural California, who were also more likely to be female (Wooten, 1989). Persons with AIDS were also more frequently heterosexual and slightly more likely to be white, in contrast to the Atlanta study.

Children and Rural AIDS

Coupled with the concerns of increasing AIDS cases among women is transmission to children. The CDC estimates that 25 percent to 35 percent of the children of HIV-positive mothers become HIV positive (McCoy, Trapido, Lewis, & Khoury, 1991). No estimates have been made in relation to rural areas. Two efforts with a rural dimension may add to the understanding of these problems and have been funded by the Bureau of Health Resources Administration Pediatric/Family AIDS Service Demonstration Programs. One project is in San Antonio and includes the Rio Grande Valley; the second is a Seattle project that includes the Yakima Health District.

Substance Abuse and Rural AIDS

Concern for intravenous drug use and AIDS is noted in a recent letter to the editor of the *American Journal of Public Health*. Steel, et al., report on the number of AIDS cases and the percent diagnosed with AIDS among intravenous drug users by Census

Region for 1989-1991 (Steel, Fleming, & Needle, 1993). For nonmetropolitan statistical areas, intravenous drug use associated with AIDS is especially a concern in the Northeast Census Region and in the South and West Census Regions.

Linkage between drugs and AIDS in rural areas is also the subject of an article by Steel and Haverkos (1992). Their review indicates that substance abuse rates are approximately the same for urban and non-urban states. Historically, however, alcohol has been the most widely used drug in rural America. They also note an increased use of intravenous drugs and crack-cocaine.

The Atlanta study of women by Whyte and Carr (1992) found intravenous drugs associated with contracting AIDS among 58 percent (178) of the women in Atlanta and 42 percent (79) in rural and other areas of the state. The California study found, in contrast, that rural rather than urban women with AIDS were more likely to have a history of intravenous drug use (Wooten, 1989).

Another study in Palm Beach County, Fla., focused on rural HIV and pregnant women (Ellerbrock, et al., 1992). Among the study group, 52 of 1,011 women (5.1%) were HIV positive. Black women had the highest rate of infection, 8.3 percent. Only 0.4 percent of the women reported injecting drugs, and all of these women were seronegative for HIV. By contrast, one-third of the 43 women who reported crack-cocaine use were HIV seropositive. This study also found that HIV-positive women receiving prenatal care were three times more likely to test positive for gonorrhea, chlamydial infection, or syphilis compared to HIV-seronegative women.

A study by Forney, et al., examined patterns of exchanging sex for crack-cocaine among women in rural Georgia compared to inner-city Miami (Forney, Inciardi, & Lockwood, 1992). Despite the questions of scientifically comparing such diverse populations, the observations are of interest. Behaviors were similar, including initial and continuous drug use, as well as the practices of exchanging sex for drugs. All 60 women were selected for the study because they had exchanged sex for crack. The primary drugs used by both groups were alcohol, marijuana, and crack. Most of the women in the study had been tested for HIV, with 15 percent of the Miami women and 11 percent of the Georgia women testing positive.

McCoy, et al., studied HIV infection in the rural community of Belle Glade, Fla., which accounted for about one-third of the cases but only 4 percent of the population, many of whom are migrants, in Palm

Beach County (McCoy, Trapido, Lewis, & Khoury, 1991). A major truck route for transporting agricultural products goes through the area and both drug trafficking and prostitution are reported in the area. Nearly one half (49.5 percent) of the study population used crack more than twice daily. Alcohol was used by 84.1 percent of the subjects two to six times a week, marijuana was used less than four times a month by 57.5 percent of subjects, and other drugs (heroin and other forms of cocaine) were used rarely.

Forney and Holloway (1990) suggest that the combination of crack, syphilis, and AIDS presents a triple threat in southeast rural Georgia. While the incidence syphilis rose 68 percent nationally from 1986-1989, it increased 800 percent in southeast Georgia during this time period. They link this growth to the number of women who are supporting their crack cocaine habits through prostitution. The authors also indicate the direct linkages between these behaviors and the growth of AIDS in rural southeast Georgia.

Seavey, Berry, and Bogue (1992) also describe a rural setting in South Carolina along Interstate 1 where crack has become a major concern. Sex exchanged for drugs has become common, resulting in a growing number of HIV-positive black women. The extent to which this phenomena is more widespread along interstate highways is not well documented but substantiated by numerous anecdotal reports.

Adolescents and Rural AIDS

Nationally, the increase in HIV infection among teen-agers, especially from minority groups, is of growing concern. A study of seroprevalence among applicants for U.S. military service between 1985 and 1989 provides useful national data. The study group, however, is admittedly not representative or rural specific (Burke, Brundage, Goldenbaum, Gardner, Paterson, Visintine, & Redfield, 1990). Approximately one of every 3,000 teen-age applicants were seropositive. Cases of AIDS identified or reported nationally among teen-agers are much rarer, about 0.4 percent. Somewhat surprising was a rate similar among teen-age males and females, with an even higher prevalence among females 17 and 18 years old. Prevalence was highest among black teen-age applicants (1.06 per 1,000), next highest among Hispanics (.31 per 1,000), and lowest among whites (.18 per 1,000). HIV-positive applicants were more likely to come from urban, densely populated coun-

ties. Ten states had the highest number of HIV-positive individuals, some with a sizable rural population.

A study of disadvantaged out of school adolescents in the U.S. Jobs Corps found very high rates (1.7/1,000) among students in the Southeast from nonmetropolitan rural and small towns (St. Louis, Conway, Hayman, & Miller, 1991). For the South Census Division, this rate was 2.3/1,000. Overall, these rates are more than 10 times higher than for a cross section of military applicants of the same age. As was found in the military study, national rates for blacks and Hispanics were much higher than for whites.

Seroprevalence levels among adolescents who attended rural health department clinics for sexually transmitted diseases (STDs) in Mississippi have also been studied (Young, 1992). Young found that during a two-year period from 1988-1990 a seropositive rate for males and females was almost equal (4.1/1,000 for males and 3.8/1,000 for females) and suggests that the transmission was primarily heterosexual. Rates for blacks were 3.5 times greater than for whites. Rural and urban rates were about the same. Young concludes that the combination of high STD rates and high teen-age pregnancy rates makes Mississippi an "epicenter" of the HIV epidemic among adolescents.

Durant, et al., note that there is also growing evidence that AIDS among minority adolescents living in the rural South is of concern (Durant, Ashworth, Newman, McGill, Raubin, & Barcnowski, 1992). Their case is built on an analysis of CDC reports through 1991 indicating that the increase of AIDS in the South includes a high percentage of young rural blacks and an analysis of knowledge level and perceived chances of having HIV infection among 294 sixth-, seventh-, and eighth-grade students in a rural Southern county. These rural adolescents were found to score 10 percent or more below national comparable groups on knowledge level of HIV infection. This raised concerns among the authors as to whether the study group had sufficient knowledge to make reasonable decisions regarding HIV infection. Furthermore, they question a possible myth that rural youth are more insulated from getting AIDS.

This insulation myth is also questioned by a study comparing rural and urban adolescents in Arkansas (Boswell, Fox, Hubbard, & Coyle, 1992). These findings indicated no statistically significant differences related to knowledge when gender had been controlled for. Rural adolescents, however, were

less likely to have attitudes that protect against HIV. A concern for both populations was that, even with high levels of knowledge, adolescents continued high-risk behaviors.

Migrants and Seasonal Workers and AIDS

Other high-risk groups include seasonal farm workers and migrants with a high representation of blacks, especially in the South. Two East Coast studies of HIV prevalence among farm workers have been conducted (Jones, Rion, Hollis, Longshore, Leverette, & Ziff, 1991; CDC, 1988). A study of migrant and seasonal farm workers in North Carolina conducted in 1987 found a 2.6 percent HIV seropositivity among migrant and seasonal workers who attended a health clinic (CDC, 1988). Black males had a prevalence rate more than twice (5.9 percent) that of black females. Whites comprised only a small portion of the study group and all tested HIV negative. Persons testing positive for syphilis (16 percent) had more than twice the HIV-seropositive rate of persons who tested negative for syphilis. A large percent of the migrant study group was Hispanic (29.3 percent), but all tested negative for HIV. Fifty-two percent of those in the North Carolina study had a permanent residence in Florida; 85 percent were male and 75 percent single. Almost one-half (46 percent) reported that they never used condoms. No specific risk group was most common.

A study among migrant workers in South Carolina found about a one in eight (13 percent) HIV-seropositivity rate in rural migrant camps (Jones, Rion, Hollis, Longshore, Leverette, & Ziff, 1991). Part of the reason for the high rate may be that the investigators studied the population at risk in their work setting. Blacks represented 78.8 percent of the study group. These migrants commonly work from March to August in South Carolina and spend the rest of the year in Florida, Georgia, North Carolina, Virginia, West Virginia, and Pennsylvania, thus potentially increasing the geographic spread of the disease.

A concern associated with HIV infection is the frequent occurrence of tuberculosis among migrants. The recent outbreak of multi-drug resistant strains of tuberculosis is especially a threat (Ciesielski, Seed, Esposito, & Hunter, 1991; Sumaya, 1992).

The growing number of Hispanics with AIDS is of national concern. Hispanics primarily live in urban areas, especially inner cities. While no published reports directly address rural Hispanic AIDS, it is

generally recognized that there is a concern for AIDS among rural Hispanic migrant and seasonal farm workers, especially in states such as Florida, Texas, and California, as well as among persons of Hispanic origin who cross both directions in the Mexico-United States border states.

American Indians and Alaskans and Rural AIDS

Many American Indians and Alaskans live in rural areas. A survey administered in 24 Indian Centers on reservations in Oregon, Washington, and Idaho included 710 American Indians (Hall, Wilder, Bodenroeder, & Hess, 1990). The study was designed to assess knowledge and behavior. Based on data collected, the investigators estimated that 10.6 percent of the male population and 6.4 percent of female population were at high risk from factors such as high rates of sexually transmitted diseases and drug abuse, compared to 3 percent of the general population.

Conway, et al., of the Indian Health Service conducted a network of surveys in different types of clinics from July 1, 1989, through June 30, 1991 (Conway, Ambrose, Chase, Hooper, Helgersen, Johannes, Epstein, McRae, Keevama, Raymond, Schable, Statten, Petersen, & Dondero, 1992). A total of 37,681 serological specimens were collected from prenatal and sexually transmitted disease American Indian and Alaskan patients in 58 Indian Health Service clinics. The rate for prenatal patients was almost identical for rural (0.9/1,000) and urban (1.1/1,000) patients. These rates were four to eight times higher than similar women of all races. The rate of HIV infection among individuals seen in a sexually transmitted disease clinic was considerably higher for urban areas and for males than for rural areas and females: 4.5/1,000 for males (urban 10.8/1,000 and rural 2.0/1,000) and .7/1,000 for females (urban 0.9/1,000 and rural 0.6/1,000).

The Communicable Disease Centers indicate that the number and rate of reported AIDS cases among American Indians and Alaskans is relatively low (4.0 per 100,000 or a total of 237 cases through 1990) (Metler, Conway, & Stehr-Green, 1991). AIDS surveillance data indicate the rate of increase among this population is, however, rapid.

Compared to the total U.S. population, American Indians and Alaskans are younger, less educated, poorer, and less likely to be employed. These two

groups also have higher rates of sexually transmitted diseases and drug abuse (Metler, Conway, & Stehr-Green, 1991). These factors would seem to make the population at high risk for AIDS and especially vulnerable for rapid spread in tribes in isolated rural areas.

Summary and Conclusions

This review of the existing literature on rural AIDS is primarily characterized by case studies and anecdotal information. No previous attempts have been made to link these emerging reports. This article's contribution to descriptive epidemiology is a synthesis intended to be useful in developing hypotheses for more rigorous research.

Based on the review of the literature, certain questions emerge to form a framework for conceptualizing many of the patterns that are evolving in the rural AIDS epidemic. This list is not exhaustive but would seem to be of high priority.

A first set of questions concern the validity and reliability of AIDS reporting. The differences among rural census divisions is considerable. However, it is unclear to what extent these are real differences.

1. To what extent does rural AIDS/HIV reporting reflect primarily the extent of the infection among people who participate in public health and other public programs for screening and counseling, patient care, and preventive activities? How accurately do these reports reflect the number of rural persons who are tested in private offices, receive their medical care locally through the private sector, or leave the community for testing and care?
2. To what extent is AIDS/HIV reporting in rural areas affected by policies on confidential versus anonymous reporting, practices of partner notification, and contact tracing? Do issues of confidentiality in some rural areas have a greater effect on HIV reporting than in other rural areas and urban areas?
3. To what extent is reporting better in settings where surveillance is linked to access to patient care?

As part of the process of reporting the phenomenon of rural AIDS, "returning home" has received considerable attention. The dynamics of this process as well as a broader process of rural migration are not well understood. Certain questions emerge for priority attention.

4. Is returning home to a rural area with HIV infection a similar pattern in all rural areas or is it a more common pattern in select regions, e.g., higher in the South with a tradition, especially among black families, of moving North for employment and sending children back to the South for summer vacations and high school?
5. Are returning home and migration to rural areas higher in states with large expenditures for HIV services than states with lower expenditures, e.g., New Mexico with high expenditures compared to Wyoming with low expenditures?
6. Is migration from rural areas to urban areas a common practice for HIV-positive individuals, and if so, at what stage of the illness and for what reasons?

Various factors seem to be emerging from the literature as associated with AIDS infection across rural populations. The nature and effect of these possible relationships is a major area of concern for study.

7. Are there environmental or host predictors of increased incidence and prevalence of HIV infection that can be identified in rural areas? Do these primarily account for regional rural differences or differences among select populations such as Afro-Americans and Native Americans? If so, how important are the following:
 - high rates of syphilis and other sexually transmitted diseases;
 - high teen-age pregnancy rates;
 - high levels of poverty;
 - high levels of sex exchanged for drugs;
 - high levels of substance abuse including crack cocaine, alcohol, and intravenous drug injections;
 - high levels of crime; and
 - low knowledge of AIDS transmission and negative attitudes toward protection, especially among adolescents?
8. Is a rural community's relative geographic location associated with high levels of HIV infection, e.g., close proximity to a metropolitan area, a border state with Mexico, or location on an interstate highway?
9. Do rural areas with cultural and religious traditions of low acceptance of gay and alternative lifestyles, e.g., Bible Belt and Western Mormon communities, have an

increased probability of certain risks and certain groups becoming infected by the HIV virus? For example:

- men taking risks with other men through anonymous sex, e.g., at gay bars, rest stops, and adult book stores; and
 - women becoming infected through heterosexual transmission?
10. Do rural communities that are more culturally homogenous have a higher or lower incidence and prevalence rate for HIV infection, e.g. rural Iowa versus rural Florida?

A relationship may also exist between living in a rural area and the length of time one survives with the disease following diagnosis.

11. To what extent do people from some rural areas become diagnosed at later stages of their infection than in other rural areas?
12. To what extent are there differences in life expectancy following diagnosis? How do these intrarural differences compare with urban findings?

The time has arrived to develop a more sophisticated understanding of the epidemiology of rural AIDS. Some of this understanding could be achieved by implementing existing legislation. While Public Law 101-381, Ryan White Comprehensive AIDS Resources Emergency Act of 1990, is primarily directed at emergency relief for the cities hardest hit by the AIDS epidemic, it also provides states with resources for organizing and delivering HIV services in rural areas. Section 403 also focuses specifically on the need to better understand the rural epidemiology of AIDS. It states:

- (a) ...the Secretary of Health and Human Services, after consultation with the Director of the Office of Rural Health Policy, shall:
 - (1) conduct a study for the purpose of estimating the incidence and prevalence in rural areas of cases of acquired immune deficiency syndrome and cases of infection with the etiologic agent for such syndrome; and
 - (2) in carrying out such study, determine the adequacy in rural areas of services for diagnosing such cases and providing treatment for such cases that are in the early stages of infection (PL 101-381, 1990).

A better knowledge of the epidemiological patterns of AIDS found in various parts of rural America is essential to effectively develop federal, state, and local policies as well as voluntary initiatives in response to the growing number of rural AIDS cases.

Appendix

U.S. Census Divisions and States

Census Division 1, New England

Connecticut
Maine
Massachusetts
New Hampshire
Rhode Island
Vermont

Census Division 2, Middle Atlantic

New Jersey
New York
Pennsylvania

Census Division 3, South Atlantic

Delaware
District of Columbia
Florida
Georgia
Maryland
North Carolina
South Carolina
Virginia
West Virginia

Census Division 4, East North Central

Illinois
Indiana
Michigan
Ohio
Wisconsin

Census Division 5, East South Central

Alabama
Kentucky
Mississippi
Tennessee

Census Division 6, West North Central

Iowa
Kansas
Minnesota
Missouri
Nebraska
North Dakota
South Dakota

Census Division 7, West South Central

Arkansas
Louisiana
Oklahoma
Texas

Census Division 8, Mountain

Arizona
Colorado
Idaho
Montana
Nevada
New Mexico
Utah
Wyoming

Census Division 9, Pacific

Alaska
California
Hawaii
Oregon
Washington

Notes

1. Data are not, however, available to disaggregate the proportion of rural AIDS that is accounted for by men who have sex with men.

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Rural HIV-Service Networks: Patterns of Care and Policy Issues

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INTRODUCTION

The steady progression of the AIDS epidemic from large metropolitan areas to less densely populated communities has created a need for more comprehensive information on the characteristics and needs of rural residents with HIV and the ways in which rural areas are responding to the epidemic.¹ Although residents of non-metropolitan areas accounted for only 4 percent of the newly diagnosed AIDS cases in 1986, this proportion had risen to 6 percent by June 1994.² Between 1990 and 1992, the number of new AIDS cases in non-metropolitan areas increased 21 percent, compared to an increase of 16 percent in metropolitan areas of 50,000 to 500,000 people and an increase of 8 percent in metropolitan areas with more than 500,000 people (see table 1). Both metropolitan and non-metropolitan areas reported large increases in new AIDS cases between 1992 and 1993 as a result of the expanded surveillance case definition of AIDS. The number of new AIDS cases reported in non-metropolitan areas more than doubled during this period.

In this article, we draw on case studies of rural areas in two U.S. census divisions to offer some pre-

liminary insights on how the demographic characteristics and exposure categories of people with HIV differ in areas of higher and lower AIDS prevalence and to identify the major features of the HIV-service delivery networks that are evolving in these settings. We also examine the environmental variables that have supported or inhibited the development of rural HIV-service networks and that continue to influence service utilization patterns. We use the case study findings to recommend policies and programmatic interventions that can enhance the quality, availability, and organization of services for rural residents with HIV disease.

METHODOLOGY

Because AIDS is a relatively new phenomenon in rural areas, the literature on the epidemiology of rural AIDS and the organization of HIV/AIDS care in different types of rural settings is limited.³ To build understanding of the diversity of the rural AIDS epidemic, the Bureau of Health Resources Development (BHRD) in the Health Resources and Services Administration (HRSA) commissioned four case studies.⁴ The study sites were selected from two U.S. census divisions that represent opposite ends of a rural AIDS continuum: the South Atlantic Census Division, which has the highest number of rural AIDS cases and relatively high geographic access to HIV services, and the Mountain Census Division, which has the lowest number of AIDS cases and more limited geographic access to HIV services.

In May 1993, HRSA/BHRD staff convened working groups from the eight states of the Mountain Census Division and the eight states of the South Atlantic Census Division to assist with the

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Table 1
New Cases of AIDS by Year, 1990-1993

I Metropolitan Statistical Area Population Size	Calendar Year 1990	Calendar Year 1991	Calendar Year 1992	Calendar Year 1993
MSA 500,000 and over	36,912	38,361	39,876	89,253
MSA 50,000-500,000	4,186	4,589	4,840	11,098
Non-MSA	2,184	2,449	2,647	5,763

Sources: CDC, Communication to second author, 17 June 1994;
CDC, *HIV/AIDS Surveillance Report* 6, no. 2 (1994): 9.

development of the study design. These discussions helped the authors to frame research questions and to develop a typology for classifying rural environments based on the degree of their rural nature, the prevalence of AIDS, and the epidemiological and demographic characteristics of the infected populations.⁵ Using the typological framework, the authors selected four study sites with high potential for illustrating differences in the nature and the extent of the rural AIDS epidemic and in methods of service delivery. The Mountain Census Division study sites included southeast Idaho (the Idaho Falls and Pocatello areas) and southeast New Mexico (the Roswell area). The South Atlantic Census Division study sites included the Edisto District (the Orangeburg area) of South Carolina and the Treasure Coast (the Ft. Pierce area) of Florida.

During the summer of 1993, the first author made week-long visits to the study sites. Each visit began with a half day or a full day of interviews with state government officials. The remaining time was

spent in the rural counties interviewing people living with HIV/AIDS, health and social service providers, the chairs and board members of HIV coalitions, local government officials, and community leaders. These local informants were queried about community awareness of and attitudes toward HIV/AIDS, the organization and accessibility of HIV services, HIV-service utilization patterns, unmet service needs, and mechanisms for financing HIV/AIDS care. Secondary data and documents, such as HIV/AIDS surveillance data, applications for Title II funding under the Ryan White CARE Act, and state HIV/AIDS plans, provided additional information on the epidemiology of AIDS and the organization of HIV services within the state and at the study site.

VARIATIONS IN RURAL POPULATIONS WITH HIV

Striking differences existed in the population density and rates of cumulative reported AIDS cases even within the same census division (see table 2). Population densities ranged from 8.1 persons per square mile in southeast New Mexico to 148.3 persons per square mile in the Treasure Coast area of Florida. The rates of cumulative reported AIDS cases showed a similar pattern, ranging from 13.7 per 100,000 in southeast New Mexico to 158.9 per 100,000 in the Treasure Coast area of Florida.

MOUNTAIN CENSUS DIVISION STUDY SITES

Southeast Idaho and southeast New Mexico cover geographic areas almost 12 times larger than

Table 2
Characteristics of Rural Study Sites

Study Site	Countries/ Area	Population/ Population Density	OMB Category	Cumulative Number of AIDS Cases (Dates)	Cumulative Number of AIDS Cases per 100,000
Southeast Idaho	16 counties 28,704 square miles	277,978 9.7/square mile	non-MSA	42 cases (1985-June 1993)	15.1
Southeast New Mexico	9 counties 31,601 square miles	255,816 8.1/square mile	non-MSA	35 cases (1981-June 1993)	13.7
Edisto South Carolina	3 counties 2,585 square miles	114,458 44.3/square mile	non-MSA	99 cases (1981-March 1993)	86.5
Treasure Coast Florida	4 counties 2,567 square miles	380,738 148.3/square mile	MSA and non-MSA	605 cases (1981-May 1993)	158.9

Table 3
Demographic Characteristics and Exposure Categories of Adult and Adolescent AIDS Patients at Study Sites, 1993

Site	Gender	Percent	Ethnic Group	Percent	Exposure Category	Percent
Southeast Idaho	Male	90	White	93	MSM	60
	Female	10	Hispanic	5	Blood Product	14
			Unreported	2	Unspecified	14
					Heterosexual	7
					IDU	5
Southeast New Mexico	Male	97	White	60	MSM	51
	Female	3	Hispanic	26	Unspecified	15
			Black	11	IDU	14
			Unreported	3	MSM and IDU	14
					Heterosexual	6
Edisto, South Carolina	Male	76	Black	85	IDU	31
	Female	24	White	15	MSM	23
					Heterosexual	21
					Unspecified	15
					MSM and IDU	6
Treasure Coast, Florida	Male	73	Black	59	Blood Product	4
	Female	27	White	38	Heterosexual	43
			Hispanic	3	MSM	28
					IDU	17
					Unspecified	7
					MSM and IDU	4
					Blood product	1

KEY

MSM = men who had sex with men. IDU = injection-drug user. Heterosexual = individual who had sex with an IDU, a bisexual male, a person with hemophilia, a person who contracted HIV via a blood product, or an HIV-infected person whose risk is not specified. Blood product = person who contracted HIV via receipt of blood transfusion, blood components, or tissue. Unspecified = source of infection not reported or identified.

the South Atlantic Census Division study sites, and their populations are much more dispersed. Many parts of southeast Idaho are uninhabited because of deserts, volcanic wastelands, and mountains. Of the area's 16 counties, three are reported to have fewer than two persons per square mile. The driving time from remote communities to the two largest cities—Idaho Falls and Pocatello—ranges from two to five hours, depending on the weather.

Southeast New Mexico also is remote and sparsely populated; residents are dispersed over an area approximately the size of Georgia. Of the total population, 80 percent is concentrated in Roswell (Chaves County) and in three surrounding counties. The population density in four other counties ranges from 1.0 to 3.7 persons per square mile. Residents must travel four to six hours to reach major medical centers in Albuquerque and Santa Fe.

The similar rates of cumulative reported AIDS cases at the two Mountain Census Division study sites obscured differences in the demographic characteristics and exposure categories of local residents who had been diagnosed with the disease (see table 3.) In both areas, white men who had sex with men account for the majority of AIDS cases. However, the proportion of AIDS patients who were white was much higher in southeast Idaho (93 percent) than in southeast New Mexico (60 percent). In the nine southeast New Mexico counties, Hispanic residents accounted for 26 percent of the AIDS cases, and African-American residents accounted for 11 percent of the cases. Southeast New Mexico also had a much higher proportion of AIDS patients who contracted the disease through injection-drug use (14 people versus 5 percent in southeast Idaho) and a lower proportion of AIDS patients who acquired the disease through homosex-

ual or bisexual contact (51 percent versus 60 percent). Men who had sex with men *and* who used injection drugs comprised an additional 14 percent of southeast New Mexico's AIDS caseload.

Interviews with HIV-positive residents and their service providers suggested that migratory patterns also differed in the two study areas. Whereas southeast Idaho residents with HIV contracted the virus elsewhere and then returned home, about half of the southeast New Mexico residents with HIV reported that they had never lived outside the area.⁶

SOUTH ATLANTIC CENSUS DIVISION STUDY SITES

Although South Carolina's Edisto District and Florida's Treasure Coast cover geographical areas of approximately the same size, the average number of persons per square mile is more than three times higher at the Florida site (148.3 versus 44.3). The Treasure Coast area includes two metropolitan statistical areas (St. Lucie and Martin Counties) and two non-metropolitan statistical areas (Okeechobee and Indian River Counties) on the east coast of Florida.⁷ Dramatic differences in their rural nature occur even within the metropolitan statistical areas; the geography ranges from rural farmland to seacoast areas with heavy concentrations of tourists and retirees. The area also is culturally diverse, as evidenced by its mix of white, African-American, Hispanic, Haitian, and Guatemalan residents. In contrast to the Mountain Census Division study sites, Treasure Coast residents can reach a major population center in one to two hours.

The heterogeneity of the Treasure Coast area's population and economy make it markedly different from the Edisto, South Carolina study site, where 58 percent of the residents are African American, and the economy is based on farming. Edisto District residents can reach the state capital of Columbia in less than one hour. Both South Atlantic Census Division study sites are characterized by low education, low income levels, and high rates of unemployment.

Although both South Atlantic study sites had rates of cumulative reported AIDS cases that exceeded the rate for their census division (32.4 per 100,000), the rate for the Treasure Coast area of Florida (158.9 per 100,000) was almost two times

greater than the rate for the Edisto District (86.5 per 100,000). About one-quarter of the AIDS cases at each site were female, and the majority of these cases were black (59 percent in the Treasure Coast area; 85 percent in the Edisto District)(see table 3). Interviews with local service providers suggested that most of the Treasure Coast and Edisto residents with HIV contracted the disease locally.

The two study sites had comparable proportions of men who had sex with men (28 percent in the Treasure Coast area; 23 percent in the Edisto District). The proportion of AIDS cases attributable to heterosexual transmission was two times higher in the Treasure Coast area than in the Edisto District (43 percent versus 21 percent). Service providers reported that the exchange of sex for crack cocaine accounted for a high proportion of the heterosexual AIDS cases in both study areas. Drug use was a more common mode of HIV transmission in the Edisto District, where more than one-third of the AIDS cases were injection-drug users (31 percent) or male injection-drug users who also had sex with men (6 percent). In the Treasure Coast area, these proportions dropped to 17 percent and 4 percent, respectively.

ENVIRONMENTAL SUPPORT FOR HIV-SERVICE NETWORK DEVELOPMENT

We defined an HIV-service network as a collectivity of interacting organizations, groups, and individuals that participate in the provision of HIV services in a specific geographic area. While all four study sites had some HIV services in place, the features of these networks were greatly influenced by their social, physical, and resource environments.

SOCIAL ENVIRONMENTS

In all four study areas, people living with HIV/AIDS cited the stigma associated with the disease and "strong community prejudices" against men who had sex with men, injection-drug users, and racial and ethnic minorities as major deterrents to service development. Health professionals and community leaders in southeast Idaho and southeast New Mexico were more likely to deny the existence of HIV/AIDS as a local problem than their counterparts at the South Atlantic study sites.

Often, they referred to AIDS as a "big-city problem" or a problem affecting "people on the margins of mainstream society." Despite the growing rates of drug misuse, sexually transmitted diseases, and teenage pregnancies at both Mountain Census Division study sites, few people had considered the implications for HIV transmission.

The higher prevalence of AIDS at the South Atlantic study sites made it more difficult for health and community leaders to deny the need for action. However, the consortia that emerged to plan and develop HIV services were almost entirely public health agencies and other government-funded service agencies. In the absence of broader community involvement, the consortium members felt powerless to address the behaviors and circumstances that put people at risk for the disease. Many expressed the opinion that poverty was the root problem, producing large numbers of disenfranchised people with limited education and few opportunities for long-term employment.

PHYSICAL ENVIRONMENTS

Service providers in southeast Idaho and southeast New Mexico cited geographic and climatic conditions as significant barriers to HIV-service development. They pointed out that the rugged topography, severe winters, and long distances between population centers made it difficult for residents to access health and social services, whether or not they had HIV. They also commented on the difficulty of developing cost-effective services when HIV-positive clients were few in number and dispersed over large geographical areas. While endorsing the concept of regional HIV/AIDS planning and development efforts, few health and social service professionals were willing or able to travel three or more hours to participate in multi-county meetings. None of these barriers existed in the South Atlantic study areas. With their more concentrated HIV populations and the shorter distances between service providers, the Edisto and Treasure Coast areas had more favorable physical environments for developing HIV-services.

RESOURCE ENVIRONMENTS

All of the study sites reported shortages of primary care physicians and dentists. However, a greater problem seemed to be finding primary care

practitioners who were trained and willing to care for patients with HIV/AIDS. Idaho ranked 50th in the nation in its supply of primary care physicians.⁸ In the 16 southeastern counties, local informants could think of only three primary care physicians and two dentists who were willing to accept HIV-positive patients. Similar access problems were reported in southeast New Mexico, despite the fact that seven of the nine counties ranked above the state median on an index of accessibility to primary healthcare.⁹ Although shortages of physicians and dentists were less acute in the South Atlantic study areas, there was general consensus that most private practitioners would prefer to leave the treatment of HIV-positive patients to public health departments and community health centers.

Of the four study sites, the Treasure Coast area appeared to have the funding environment that most supported HIV/AIDS care. Between 1986 and 1993, state appropriations for the development and provision of statewide HIV services increased more than eight-fold, from \$700,000 to almost \$5.7 million.¹⁰ Public health departments in counties with 50 or more cumulative cases of AIDS received about one-third of the state funds appropriated each year.¹¹ St. Lucie County, in the Treasure Coast area, was one of the counties that benefited from that funding arrangement. In fiscal year 1992-1993, for example, the St. Lucie County Health Department received \$99,534 to offer nursing care to patients with HIV/AIDS and to employ a health educator. In addition, the Florida Department of Health and Rehabilitative Services developed a formula for allocating Title II funds that gave priority to reported AIDS cases in the most recent years, rather than to cumulative totals, and that took the availability of other state and federal funding into account. This formula worked to the advantage of rural areas, such as the Treasure Coast, where the growth of the epidemic was more recent.

Two features of Florida's Medicaid program helped rural residents with HIV/AIDS gain access to needed services: a "medically needy" category for individuals and families whose income or resources exceeded the eligibility ceiling but who had high medical costs, and a Medicaid AIDS waiver program that covered a wide range of medical and social support services for AIDS patients who needed in-home care.

Although New Mexico and South Carolina both had a record of state appropriations for HIV prevention and care, the funds had minimal impact on HIV-service delivery at the study sites. Most of the \$14.6 million appropriated by the New Mexico State Legislature in 1993 went for HIV health and support services in the three largest cities: Albuquerque, Santa Fe, and Las Cruces. Of the \$2

services were least developed in southeast Idaho, where the variable geography and climate, negative community attitudes toward people with and at risk for HIV, shortages of primary care providers, and a lack of state funding posed significant barriers to forming networks. Although the physical and social environments were similar in southeast New Mexico, HIV services were somewhat more developed as a result of state and federally funded programs. HIV-care networks were most developed in the Edisto and Treasure Coast areas, where health and human service agencies recognized AIDS as a public health problem and had more federal and state resources with which to respond.

The relatively small number of residents known to be living with HIV reinforced public perceptions of HIV/AIDS as a "big-city problem." Rather than develop the capacity to serve people with HIV/AIDS, the response was to leave it to the private medical sector.

million appropriated by the South Carolina State Legislature in 1993, the bulk of the funds went for HIV prevention and CD4 lymphocyte monitoring programs in Columbia and Charleston. Neither state extended Medicaid eligibility to "medically needy" individuals and families, but some AIDS patients were able to qualify for Medicaid AIDS waiver programs.

The 16 southeast Idaho counties appeared to have the least supportive funding environment for HIV/AIDS care. To date, the Idaho State Legislature has not appropriated any funds for HIV services. The legislature authorized Medicaid coverage for "medically needy" residents in 1993, but no funds were appropriated. The state also lacks a Medicaid AIDS waiver program, although some patients with AIDS are able to qualify for personal care services through a home- and community-based Medicaid waiver program for the severely disabled.

PATTERNS OF DEVELOPMENT OF HIV- SERVICE NETWORKS

We found three distinct patterns of development of HIV-service networks in the case studies, which reflected the different environmental attributes and degrees of environmental support. HIV

services were least developed in southeast Idaho, where the variable geography and climate, negative community attitudes toward people with and at risk for HIV, shortages of primary care providers, and a lack of state funding posed significant barriers to forming networks. Although the physical and social environments were similar in southeast New Mexico, HIV services were somewhat more developed as a result of state and federally funded programs. HIV-care networks were most developed in the Edisto and Treasure Coast areas, where health and human service agencies recognized AIDS as a public health problem and had more federal and state resources with which to respond.

LAISSEZ-FAIRE APPROACH

The relatively small number of southeast Idaho residents known to be living with HIV (17 AIDS patients; 35 with HIV as of June 1993) reinforced public perceptions of HIV/AIDS as a "big-city problem." Rather than developing the capacity of public health departments and other government-funded agencies to serve people with HIV/AIDS, the southeast Idaho response was one of *laissez-faire*: that is, leave it to the private medical sector. HIV-positive residents reported great difficulty in finding physicians and dentists who accepted their lifestyle and were knowledgeable about HIV/AIDS care. Many were traveling two and one-half hours to Salt Lake City to obtain both primary and specialized medical care.

Locally, most of the HIV/AIDS care was provided by an infectious disease specialist in Idaho Falls. Although this physician sometimes had to provide primary medical care, her preferred method of practice was to support the patient's regular physician in planning and managing the treatment regimen. Primary care physicians were encouraged to consult with her or to refer patients when complex medical problems were encountered. Other sources of primary medical care included the University of Washington's family practice residency program at a regional medical center in Pocatello, and the University of Utah's outreach program for hemophiliac patients with HIV at the Idaho Falls Health

Department. Because the hospitals outside Idaho Falls and Pocatello were small (four to 65 beds), patients with HIV/AIDS were almost always admitted to facilities in these two cities.

With the exception of two HIV support groups, specialized social services for people with HIV/AIDS did not exist in the 16-county area. Hospital social workers and infectious disease surveillance personnel in local health departments functioned as informal case managers, providing information on entitlement programs and other available resources. Although home-health services were available to HIV/AIDS patients with public or private health insurance, very few AIDS patients had been admitted to local nursing homes. Other health and support services, such as mental health and substance-abuse counseling, transportation, housing assistance, and food banks, were offered by social service and voluntary agencies, but were difficult for infected individuals to obtain without disclosing their serostatus.

STATE-INITIATED PROGRAMS

In 1989, the University of New Mexico Hospital received an HIV Service Planning Program grant from HRSA to conduct a statewide assessment of services and programs needed for persons with HIV/AIDS, and to plan for the development of appropriate systems of care. More than 400 state residents helped to draft a New Mexico HIV/AIDS action plan that called for "mainstreaming services for people with HIV/AIDS into the entire health system rather than developing separate or specialized health services."¹² Guided by this five-year plan, the Department of Health and Rehabilitation Services (DHRS) and the Department of Human Services (DHS) established several statewide programs that benefited southeast New Mexico residents with HIV/AIDS.¹³

County health departments in southeast New Mexico participated in a state-funded, HIV early-intervention program that offered CD4 lymphocyte monitoring, screening for sexually transmitted diseases, tuberculosis screening, immunization updates, nutritional counseling, and general health maintenance to patients with HIV disease. Public health nurses provided these services in health department clinics and in clients' homes; however, the distances that they had to travel to reach clients

greatly restricted the number of clients whom they could see in a given day. The public health district's infectious disease surveillance coordinator conducted and monitored HIV-antibody testing and helped to link people who tested positive with the early intervention program.

The Public Health Division of New Mexico's DHRS provided case-management services for southeast New Mexico residents with HIV/AIDS through contracts with home-health agencies and other community-based organizations. Local informants outlined a number of problems with these contractual arrangements. Some believed that the case managers in contracting agencies were not sufficiently informed about available services. Others questioned whether there were sufficient referral options to make case management worthwhile. Still others commented on the financial infeasibility of offering case management under a per-case reimbursement system that did not adjust for the longer travel times in rural areas. Small numbers of clients dispersed over large geographic areas were cited as a major impediment to the development of cost-effective case-management services.

The DHRS attempted to develop a peer- and volunteer-support program for southeast New Mexico residents with HIV/AIDS through a contract with an AIDS-service organization in the southwestern part of the state. During our site visit, clients complained about canceled appointments, frequent staff turnover, and the lack of attention to clients' satisfaction. State officials have since reevaluated or canceled several support service contracts and initiated discussions on an urban-rural differential for service reimbursement.

In contrast to Idaho, where physicians and dentists had no monetary incentive to treat patients with HIV, the University of New Mexico received a grant under Title III(b) of the Ryan White CARE Act to reimburse primary care practitioners for providing HIV/AIDS care.¹⁴ The objective of the university's Partners in Care Program was to "supplement existing services" by identifying physicians, dentists, and pharmacists throughout the state who were willing to provide services to people with HIV. Patients whose income was 100 percent of the poverty level received these services at no cost, while those with higher incomes paid on a

sliding fee scale. Despite the financial incentives for providers to participate, the program generated little interest among southeast New Mexico healthcare practitioners. As of the summer of 1993, only one or two physicians and pharmacists were enrolled in each of four counties, and no dentists had agreed to participate.

If the state and federally funded HIV/AIDS programs did not exist in southeast New Mexico, the area's service infrastructure would be indistinguishable from southeast Idaho. Home-health agencies and nursing homes in southeast New Mexico

would have been able to sustain the HIV services that had been established.

Edisto, South Carolina. People with HIV/AIDS received most of their health and support services through an HIV clinic operated by the District Health Office. With financial support from Title II of the Ryan White CARE Act and a Centers for Disease Control and Prevention (CDC) HIV prevention grant, this clinic provided primary medical care, CD4 lymphocyte monitoring, laboratory tests, and dental referrals to more than 100 HIV-positive patients. Local physicians from the community health center and private practices saw patients at the clinic two evenings a week and cared for clinic patients who were admitted to area hospitals. The clinic staff also included three registered nurses who saw patients between their regularly scheduled physicians' appointments, a volunteer pharmacist, a health educator, a social

worker, and a clerk. Specialty consultation was available, primarily by telephone, from the University of South Carolina School of Medicine, the Medical University of South Carolina, and the State Department of Health and Environmental Control. This backup support has enabled the clinic's medical staff to manage most HIV/AIDS cases locally.

Before the clinic's formation in 1991, people with HIV typically sought medical care from the emergency room of the regional medical center. The District Health Office received frequent calls from local physicians who insisted that they could not follow the patients upon discharge. Some physicians maintained that they could not provide the counseling and support services needed by patients with HIV disease; others cited financial barriers, such as the inadequate reimbursement for HIV/AIDS care and the possible loss of patients who feared being exposed to the virus. The HIV clinic addressed these concerns by providing an alternative-care delivery site, experienced support staff, and contracts for physicians' services. Because of the clinic's strong links with HIV testing and counseling programs in county health departments, patients were able to receive care in earlier stages of

Small numbers of clients dispersed over large geographic areas were cited as a major impediment to the development of cost-effective case-management services.

had little or no experience in caring for AIDS patients. Mental health and substance-abuse counseling services were very limited, as they were in most parts of the state. The area's two HIV-support groups were small and had difficulty retaining members. Local informants pointed out that people with HIV often drove four hours to Albuquerque or Lubbock, Texas, to obtain medical and dental care. A travel reimbursement program, funded by the New Mexico DHS, helped to cover the transportation costs of patients who travelled more than 50 miles to obtain specialized HIV/AIDS care.

COMMUNITY-INITIATED PROGRAMS

Faced with growing numbers of locally infected residents, public health departments and community health centers in the South Atlantic study areas took the lead in planning and providing HIV services. Both areas had a tradition of providing health services to uninsured and underinsured residents through publicly funded agencies. While this tradition has made it easier to develop services for people with HIV, it also provided an excuse for private practitioners to limit their involvement with HIV/AIDS care. Local informants commented that without federal and state funding, neither area

the disease. Through the clinic, HIV-positive patients also had access to support groups, case-management services, and health education.

As the lead agency for a consortium of health and human service providers funded under Title II, the Edisto District Health Office made a concerted effort to integrate HIV services into its existing programs. Patients with HIV/AIDS were able to obtain in-home care from the District Health Office's home health nurses or from local hospice volunteers. Public health nurses in the HIV clinic established good referral relationships with a community mental health center and a substance-abuse counseling and treatment center. Consortium members expressed disappointment that, despite these accomplishments, they had not been able to build broad community support for HIV services or for community development activities aimed at reducing the poverty, unemployment, and illicit drug use that contributed to the spread of the virus.

Treasure Coast, Florida. Community health centers and county health departments were the major providers of HIV-related health services. An infectious disease clinic, operated by a Ft. Pierce community health center with financial support from a Title III(b) grant, served as the primary source of medical care for St. Lucie and Okeechobee County residents with HIV. An infectious disease specialist, whose private practice was devoted almost exclusively to HIV/AIDS care, attended in the clinic twice a week, and was available, on call, between regularly scheduled visits. The other clinic staff included two nurse practitioners, a social worker, laboratory personnel, and clerical workers. Although the clinic was intended to be an early intervention site, the staff indicated that many patients were coming to them in late stages of the disease.

All of the county health departments were expanding their services to people with HIV/AIDS. State appropriations for AIDS teams in counties with 50 or more cumulative cases of AIDS allowed the St. Lucie County Health Department to hire a nurse and a health educator to work with patients with HIV and those who were at risk for contracting HIV. Through a contractual arrangement with the aforementioned infectious disease specialist, the Indian River County Health Department's adult STD (sexually transmitted disease) clinic was

able to offer consultation with a physician as well as primary medical care, CD4 lymphocyte monitoring, medications, and assistance in applying for entitlement programs. The Martin County Health Department offered services to HIV-positive patients at clinics in two communities.

An AIDS-service organization known as the Treasure Coast Community AIDS Network (TCCAN) served as the lead agency for the area's consortium of health and human service providers funded under Title II. In addition to administering the Title II funds, TCCAN made frequent community presentations on HIV/AIDS and provided support services, such as case-management services, assistance with transportation, housing and utility bill subsidies, and a food bank. Over an 18-month period ending in September 1993, TCCAN's caseload increased more than seven-fold, from 70 to 515 clients.

Despite the presence of home-health agencies, hospices, mental health service providers, housing authorities, and substance-abuse counseling and treatment agencies in the Treasure Coast area, local informants pointed out that very few of these agencies had sufficient resources to respond to the growing numbers of HIV and AIDS cases. In Ft. Pierce, for example, a substance-abuse counseling and treatment center offered HIV testing and counseling, but was unable to develop specialized services for HIV-positive clients due to reductions in its core funding. Home-health nurses reported that many of their AIDS patients were living alone in cardboard shacks or in homes with poor sanitation due to the scarcity of county-subsidized housing. Numerous health and social service professionals said that they were "overwhelmed" by the large numbers of clients who sought care in late stages of the disease.

DISCUSSION

The case studies illustrate the complexity of developing policies and programmatic interventions to expand and enhance HIV services in rural settings. Because rural areas exhibit great variation with respect to the epidemiology of AIDS, population density, access to health manpower and resources, and mechanisms for financing HIV/AIDS care, the incentives for developing HIV services

and the methods of organizing and delivering services must reflect this diversity. Federal and state governmental agencies can provide funding and broad guidelines for service development, but rural communities will need considerable latitude to make these services fit with the characteristics and needs of their infected populations and service providers. Funding formulas for rural areas should

Federal and state governmental agencies can provide funding and broad guidelines for service development, but rural communities will need considerable latitude to make these services fit with the characteristics and needs of their infected populations and service providers.

consider both the prevalence of AIDS and the extent of need for development of an infrastructure for delivery of services.

Public policies on the delivery of rural HIV services must be informed by empirical research on the epidemiology of AIDS, the organization and costs of providing HIV-related services, and the ways in which patients use services in different rural settings. HRSA currently is sponsoring a longitudinal study of people who receive medical care for HIV in rural areas as part of a larger HIV cost and services utilization study. The study is being conducted by RAND Corporation through a cooperative agreement with the Agency for Health Care Policy and Research. A national probability sample of 500 rural residents with HIV will be interviewed at two or more points in time about their use of health and support services, the problems they experience in attempting to use these services, and their unmet needs. The study also will gather information on migration patterns into and out of rural areas, the social support networks of rural residents with HIV, and the costs of HIV services in rural areas.

Many rural residents still view HIV disease as an urban phenomenon. An increased emphasis on HIV education in rural areas can help to build public understanding of how the virus is (and is not) transmitted, raise awareness of HIV/AIDS as a

local concern, and stimulate community support for the development of prevention and care services. HIV disease must be discussed in the context of larger community problems, such as alcohol and drug misuse, sexually transmitted diseases, teen pregnancies, poverty, and crime. Presentations to civic and religious groups by local people who live with HIV can help other citizens to see them as co-

workers, neighbors, and the children of longstanding community residents rather than as people with "deviant lifestyles."

The steady increases in the number of rural AIDS cases underscore the need to include these areas in all federal and state grant programs that address HIV/AIDS or behaviors, such as drug misuse, that put people at risk for HIV disease.

At a minimum, rural areas need planning grants that will help them to assess the kinds of programs they will need and to plan for the development of necessary services. The current U.S. House and Senate bills to reauthorize the Ryan White CARE Act empower the Secretary of the Department of Health and Human Services to give preference to rural and underserved communities when awarding planning grants to public and nonprofit private entities for the development of HIV primary care services. Similar grants are needed for planning efforts that address both medical and social services and that involve a broad cross-section of community representatives.

The dearth of rural healthcare providers who are knowledgeable about the diagnosis, treatment, and management of patients with HIV suggests that the healthcare providers are not being effectively reached by existing HIV/AIDS training programs. In addition to providing information on the clinical and psychosocial care of patients with HIV, the training programs need to address attitudinal barriers to the provision of care, such as homophobia and the fear of being labeled as "the AIDS doctor."

To develop and assess alternative approaches to delivering HIV/AIDS care, rural areas will need public and private funding for demonstration projects. The Special Projects of National Significance (SPNS) Program of the Ryan White CARE Act offers one funding source for designing and evalu-

ating innovative service delivery models. Of the 36 demonstration projects that received SPNS funding between fiscal years 1991 and 1993, three were designed to increase rural residents' access to HIV-related services. Additional public and private funding can help rural areas to experiment with other service delivery models and to replicate models that seem appropriate to their circumstances and needs.

Because people living with HIV/AIDS require a complex mix of health and social services, the spread of the disease to rural areas highlights broader health problems that require resolution. These problems include critical shortages of physicians, dentists, and other primary care practitioners; an inadequate supply of mental health and substance-abuse counseling and treatment services; difficulties in obtaining "enabling services," such as housing, transportation, and emergency financial assistance; and a lack (or shortage) of case managers to assess service needs and link clients with necessary services. Public and private efforts to create integrated service networks that are "clinically and fiscally accountable for the outcomes and the health status of the population served" must address these issues.¹⁵

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NOTES

1. The Office of Management and Budget (OMB) defines a metropolitan statistical area (MSA) as a county or group of counties that includes a city of 50,000 residents or an urbanized area with at least 50,000 people that is part of a county or group of counties with at least 100,000 people. Rural counties are all other counties. M. Hewitt, *Defining Rural Areas: Impact on Health Care Policy and Research* (Washington, D.C.: Office of Technology Assessment, U.S. Congress, 1989).

2. Centers for Disease Control and Prevention (CDC), P.L. Fleming, Chief Reporting and Analysis Section, Surveillance Branch, Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, letter to M. McClain, 2 February 1995.

3. D.E. Berry, "The Emerging Epidemiology of Rural AIDS," *Journal of Rural Health* 9, no. 4 (1993): 293-304; R.P. Graham et al., "HIV/AIDS in the Rural United States: Epidemiology and Health Services Delivery," *Medical Care*

Research and Review 52, no. 4 (1995): 435-452.

4. The BHRD, HRSA, administers Title II of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990, which authorizes formula-based grants to the 50 states, Washington, D.C., Puerto Rico, and the U.S. Territories for the provision of outpatient medical and support services to people with HIV and AIDS. Title II funds are the major source of support for rural HIV services in many states.

5. D.E. Berry, M.M. McKinney, and K.M. Marconi, "A Typological Approach to the Study of Rural HIV-Service Networks," (unpublished manuscript).

6. B. Levy, District IV Health Office, Chaves County, Roswell, New Mexico, telephone conversation with M.M. McKinney, 17 November 1995.

7. Although St. Lucie and Martin Counties do not meet the OMB definition of "rural" (see note 1), many sections of these counties are classified as rural by the U.S. Bureau of the Census. The Florida Department of Health and Rehabilitative Services uses the Census Bureau definition to plan for HIV services because this definition is considered to be more sensitive to intra-county differences in population and population density.

8. Idaho Department of Health and Welfare, *A Primary Health Care Needs Assessment for the State of Idaho* (Boise, Id.: Idaho Department of Health and Welfare, Office of Health Policy and Resources Development, Division of Health, 1991).

9. New Mexico Office of Rural Health, *Statewide Primary Care Plan* (Albuquerque, N.M.: New Mexico Office of Rural Health, 1993).

10. J. Wray, Operations and Management Consultant, Florida Department of Health and Rehabilitative Services, letter to D. Berry, 15 February 1994.

11. No new counties with 50 or more AIDS cases have been added since 1989 due to a shortage of state funds.

12. University Hospital, University of New Mexico, *New Mexico's HIV/AIDS Service Action Plan* (Albuquerque, N.M.: University of New Mexico, 1990).

13. As of June 1993, 17 of the AIDS patients who reported a southeast New Mexico residence at the time of diagnosis were still alive. The District IV Health Office in Chaves County estimated that the actual number of living AIDS patients would be about 34 if patients who migrated back to the area after diagnosis were included. Because New Mexico does not require HIV reporting, no data on the number of southeast New Mexico residents living with HIV were available.

14. Title III(b) of the Ryan White CARE Act of 1990 authorizes discretionary grant funds to community-based organizations to provide outpatient HIV early intervention primary healthcare services to people who have limited access to care.

15. S. Shortell, R.R. Gillies, and D.A. Anderson, "The New World of Managed Care: Creating Organized Delivery Systems," *Health Affairs* 13, no. 5 (1994): 46-64.

A Typological Approach to the Study of Rural HIV Service Delivery Networks

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ABSTRACT: Despite the rapid growth of AIDS cases in nonmetropolitan areas, little is known about the characteristics and needs of rural residents with HIV disease or how rural areas are responding to the epidemic. This paper proposes a typology for distinguishing among rural environments and examining variations in HIV service networks. The typology identifies three dimensions that have a major impact on the development of rural HIV service networks: degree of rurality, the prevalence of AIDS, and the epidemiological and demographic characteristics of the infected populations. It assumes that residents of remote and sparsely populated areas will have greater difficulty gaining access to services; that rural areas with a higher prevalence of AIDS will need more resources to respond to service needs; and that the types of services required and the ways in which services are delivered will be influenced by the exposure categories and demographic characteristics of local residents living with the disease. Data from four case studies are used to illustrate how variations in rural environments can affect the organization and delivery of HIV/AIDS care. The typology contributes to public policy discussions by identifying key attributes of rural environments that influence program planning and implementation and the transferability of service delivery models.

A Typological Approach to the Study of Rural HIV Service Delivery Networks

As the AIDS epidemic moves beyond the large cities to less populated areas, rural communities are being challenged to meet the needs of growing and diverse populations with HIV infection. Of the 548,102 AIDS cases reported to the Centers for Disease Control and Prevention (CDC) through June 1996, 29,769 people (5%) were residing in nonmetropolitan areas of less than 50,000 population at the time of AIDS diagnosis (CDC, 1996). This proportion probably would be much higher if states collected data on the number of people who move to rural communities *after* being diagnosed with AIDS in metropolitan areas.

During the early 1990s, AIDS cases in rural areas increased at twice the rate of the largest metropolitan areas. Between 1990 and 1992, the number of new AIDS cases in nonmetropolitan areas increased 21 percent as compared to an 8 percent increase in metropolitan areas with more than 500,000 residents (Berry, McKinney, & McClain, 1996). Both metropolitan and nonmetropolitan areas reported large increases in new AIDS cases between 1992 and 1993 as a result of the expanded surveillance case definition of AIDS (Note 1). Over the next two years, the number of new AIDS cases reported in the largest metropolitan areas dropped from 89,253 (1993) to 60,912 (1995) — a 32 percent decline. However, the 1995 count of new AIDS cases from nonmetropolitan areas (4,737) was only 18 percent less than in 1993 (CDC, 1994; CDC, 1995).

Despite the rapid growth of AIDS in rural areas, little is known about the characteristics and needs of rural residents with HIV or how rural communities are

responding to the epidemic. Rural areas exhibit great variation with respect to population density, proximity to urban centers, the prevalence of AIDS, and the populations most affected by HIV. Because program outcomes often are influenced by their environmental contexts (Ricketts, Konrad, & Wagner, 1983), the different features of rural environments need to be considered when developing services for HIV-positive residents of rural areas and evaluating the transferability of service delivery models.

To build understanding of the diversity of the rural AIDS epidemic, the Bureau of Health Resources Development in the Health Resources and Services Administration (HRSA) commissioned an exploratory study. The Bureau administers Title II of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 which authorizes formula-based grants to the 50 states, Washington, D.C., Puerto Rico, and the U.S. Territories for the provision of outpatient medical and support services to people living with HIV/AIDS. In many states, Title II funds are the major source of support for rural-based HIV services (National Alliance of State and Territorial AIDS Directors, 1994). The exploratory study consisted of two activities: (1) the development of an AIDS-specific typology for categorizing and comparing rural environments and (2) the conduct of case studies in two U.S. Census Divisions that represent opposite ends of a rural AIDS continuum: the South Atlantic Census Division which has the highest number of rural AIDS cases and relatively high geographic access to HIV services, and the Mountain Census Division which has the lowest number of AIDS cases and more limited geographic access to HIV services.

This paper presents the typological framework that guided the exploratory study. Data from the case studies are used to illustrate how variations in rural environments can

affect the organization and delivery of HIV/AIDS care. While the four case study sites cannot be expected to represent all rural areas, they provide useful reference points for comparing the rural environments within which HIV services are planned and delivered. The paper concludes with a discussion of how the typology can be used for HIV-related empirical research and program planning.

Typology Development Process

To obtain background information on epidemiological and other environmental factors that influence rural HIV service networks, the first author conducted a literature search of eight abstracting and indexing services: MEDLINE/AIDSLINE, Expanded Academic Index, Business Index, Applied Science and Technology Index, Education Index, General Science Index, Humanities Index, and the Social Science Index. Identified sources were used to locate additional studies and reports. Documents produced by HRSA grantees also were reviewed. These documents included grant applications and HIV service plans submitted by cities and states, with a low prevalence of AIDS, that received HIV Services Planning Program grants in 1989 and descriptive summaries of rural HIV service delivery models that were being tested in southeast Georgia, southeastern North Carolina, and rural areas of Missouri under the "Special Projects of National Significance" grant program of the Ryan White CARE Act.

The review of the published literature and HRSA's grantee files produced a wealth of *site-specific* descriptive data but very few studies with scientifically rigorous research designs. Because the authors were trying to build a conceptual framework for grouping and

comparing rural environments, all studies were considered. An earlier article by Berry (1993) critiques the methods and findings of the studies and lists questions for future research. Together, the studies provide strong evidence that multiple rural patterns exist with respect to AIDS prevalence, risk behaviors, and infected populations (Berry, 1993; Graham et al., 1995).

Following the literature review, the authors convened working groups from the eight states of the Mountain Census Division and the eight states of the South Atlantic Census Division to assist with the development of an AIDS-specific typology. At these meetings, state coordinators of Title II CARE Act grants and rural HIV service providers compared and contrasted the rural areas of their states with respect to the characteristics and needs of people with HIV, the organization of medical and support services, and the primary mechanisms for financing HIV/AIDS care. Participants emphasized that the aggregation of all rural areas into one "rural" category misses the distinct epidemiological patterns, access barriers, and supports for care in different rural settings that affect the planning and development of HIV services.

In addition to assisting with the development of the typology, the work groups proposed possible sites for case studies of rural HIV service delivery networks. The amount of funding available from HRSA limited the case studies to four sites. These sites were selected to illustrate dramatic differences in the nature and extent of the rural AIDS epidemic and in methods of service delivery. The Mountain Census Division study sites included southeast Idaho (Idaho Falls/Pocatello area) and southeast New Mexico (Roswell area). The South Atlantic Census Division study sites included the Edisto District (Orangeburg area) of

South Carolina and the Treasure Coast (Ft. Pierce area) of southeastern Florida. These geographic areas were coterminous with public health districts in every state except Idaho where the State Health Department had combined two public health districts into one region for HIV prevention and care initiatives.

During the summer of 1993, the first author made week-long visits to the study sites. Each visit began with a half day or a full day of interviews with state government officials. The remaining time was spent in the rural counties interviewing people living with HIV/AIDS, health and social service providers, the chairs and board members of HIV coalitions, local government officials, and community leaders. When discussing the applications of the typology, the authors will use these case studies to illustrate how environmental variables support or inhibit the development of rural HIV service networks. A more detailed summary of the case study findings can be found in Berry, McKinney, and McClain (1996).

Typology of Rural HIV Service Environments

Based on the literature review and information from the regional meetings, the authors identified three environmental attributes that appear to have a major impact on the development of rural HIV service networks: degree of rurality, the prevalence of AIDS, and the epidemiological and demographic characteristics of the infected populations. Our typology assumes that residents of remote and sparsely populated areas will have greater difficulty gaining access to services; that rural areas with a higher prevalence of AIDS will need more resources to respond to service needs; and that the types of services required and

the ways in which services are delivered will be influenced by the exposure categories and demographic characteristics of people living with the disease (Note 2). Figure 1 displays the three dimensions of the environmental typology.

— Insert Figure 1 about here —

Degree of Rurality

Developing an operational definition of "rural" in the context of HIV services is complicated by the fact that no universal definition has evolved for rural and urban differences generically or for health services specifically (Cordes, 1989; Hersh & Van Hook, 1989; Miller, Farmer & Clarke, 1994; Patton, 1989). Federal agencies take two distinct approaches to defining and measuring rurality. The Office of Management and Budget (OMB) uses the county as the unit of analysis. A metropolitan statistical area (MSA) is defined as a county with a city of at least 50,000 people, or an urbanized area that is part of a county or counties with a minimum of 100,000 individuals (Miller, Farmer, & Clarke, 1994). Counties that do not meet this definition are classified as nonmetropolitan (nonMSA).

The U.S. Bureau of Census uses an urban-rural classification system. An urban area is defined as a central city of 50,000 or more residents and adjacent territories of more than 2,500 residents living outside the geopolitical boundary (Miller, Farmer, & Clarke, 1994). Any area that does not meet the Census Bureau's thresholds of settlement size and density is considered to be "rural."

Three factors make the OMB definition of nonMSA more appropriate for research on rural HIV service networks. First, the CDC requires states to use the OMB definition when

reporting their HIV/AIDS surveillance data. Second, the county is the most common unit used by states for reporting vital and health statistics and socioeconomic data. Third, county boundaries remain fairly stable over time. The one disadvantage of using the OMB definition is that it may obscure differing degrees of rurality *within* counties (Hewitt, 1989).

The rurality dimension of Figure 1 considers differences in population density. *Frontier rural* is operationally defined as a county having less than six persons per square mile (Popper, 1986). The National Rural Health Association and other groups frequently use "frontier rural" to describe Western states where the geographic areas covered by a county are much larger than in the East (Hewitt, 1989; Office of Technology Assessment, 1990). Low population density makes it difficult to develop and sustain health and support services at the local level — particularly specialized medical care. Thus, people with HIV who reside in frontier rural areas may have to travel long distances to receive services. A county classified by OMB as nonmetropolitan and having more than six persons per square mile is designated as *core rural*. These two subcategories of nonMSA can be used to develop hybrid categories, such as *mixed frontier/core rural* and *mixed MSA/nonMSA* where rural counties adjoin MSAs.

The rural classification system proposed in our typology uses population size, population density, and adjacency to MSAs as proxies for access to HIV-related services. This classification system can be refined by considering additional variables, such as number of miles to an MSA or population center, the proportion of the county's population that lives in towns of 2,500 or more, and principal economic activity. Hewitt (1989) describes the typologies that have been developed to classify nonmetropolitan counties. In her view, a

typology that includes population size, density, and proximity to large settlements is the most relevant for studies of geographic variations in access to health services.

AIDS Prevalence

The extent to which rural communities are aware of AIDS as a public health problem and motivated to plan for HIV prevention and care typically depends upon the prevalence of the disease. Although State Health Departments collect data on AIDS cases from nonmetropolitan areas, the CDC did not include nonMSAs in its *HIV/AIDS Surveillance Report* until the spring of 1991. CDC confidentiality policies do not permit the release of nonMSA data by state. However, the authors were able to obtain data on the cumulative *nonMSA* AIDS cases per 100,000 in each U.S. Census Division.

Figure 2 shows the rates of cumulative reported AIDS cases for nonMSAs in each U.S. Census Division as of December 31, 1992. These rates ranged from a low of 8.41 per 100,000 in the West North Central Census Division to a high of 37.02 in the Mid-Atlantic Census Division. The rates do not reflect AIDS patients who have moved to rural areas after being diagnosed in an MSA. There also is some evidence that AIDS cases in rural areas are being undercounted (Berk, McKinney, & Melichar, 1995), although CDC studies indicate that, for the nation as a whole, the reporting is 85-90 percent complete (G. Edgar, communication to M. McKinney, September 6, 1995).

— Insert Figure 2 about here —

Using the 1992 rates, the typology proposes the following scheme for classifying rates of cumulative reported AIDS cases:

<u>Low</u>	1-14 cumulative AIDS cases per 100,000
<u>Medium</u>	15-29 cumulative AIDS cases per 100,000
<u>High</u>	≥ 30 cumulative AIDS cases per 100,000

These operational definitions are based on a close to normal distribution curve for the U.S. Census Divisions. As the numbers of rural AIDS cases increase, this initial classification scheme will require refinement.

Risk Categories

Decisions on what services to offer and the manner in which the services should be delivered are greatly influenced by the risk behaviors and demographic characteristics of local populations with HIV/AIDS.

Mode of Transmission. The CDC uses seven exposure categories to classify reported AIDS cases: men who have sex with men; injecting drug use; heterosexual contact; men who have sex with men and inject drugs; hemophilia/coagulation disorder; receipt of blood transfusion, blood components, or tissue; and risk not reported or identified. Rural areas differ with respect to the proportions of AIDS cases that are attributable to each exposure category. For example, our regional work groups identified male-to-male sexual contact as being the predominant mode of transmission in the Mountain states and injecting drug use and heterosexual transmission as being more common in the South Atlantic states.

The typology assumes that the proportion of individuals in each exposure category will have a direct impact on the organization of HIV services. The literature indicates that urban residents with HIV, when classified by exposure categories, have different patterns of service use. Gay men with HIV, for example, may receive more health care services than

injecting drug users (Ettner & Weissman, 1994). HIV-positive individuals with a history of injecting drug use tend to have fewer ambulatory care visits and more inpatient admissions than HIV-positive individuals who have never used injecting drugs (Fleishman, Hsia, & Hellinger, 1994).

Because so little research has been done on the rural AIDS epidemic, it is difficult to predict how the distribution of AIDS cases among different exposure categories will affect the organization and delivery of rural HIV services. We hypothesize that rural areas in which men who have sex with men account for more than 40 percent of the adult/adolescent AIDS cases will organize HIV services differently than rural areas with smaller percentages. For example, these areas may be more likely to develop buddy programs and support groups to deal with the "deep sense of isolation" experienced by rural gay men (Rounds, 1988, 257). Rural areas in which injecting drug use and/or the exchange of sex for illicit drugs account for more than 40 percent of the AIDS cases may be more likely to develop programs that integrate primary medical care with drug treatment services.

Demographic characteristics. Within different transmission categories, people can be further distinguished by gender and race/ethnicity. Based on a multi-state study of the service needs of rural women with HIV (McKinney, 1996), we hypothesize that gender mix will affect the organization of rural HIV services when females comprise more than 20 percent of the population with AIDS. Higher proportions of women are likely to increase the demand for "enabling services," such as financial assistance, transportation, and case management (Seals et al., 1995). Further research is needed on the critical levels at which gender affects rural HIV service delivery.

The racial/ethnic composition of the rural AIDS population also affects the organization of HIV services. We hypothesize that "culturally appropriate" services will receive greater emphasis as the proportion of African Americans or Hispanics in the rural AIDS population increases. Service adaptations may be required when African Americans comprise more than 50 percent of the population with AIDS or when Hispanics account for more than 35 percent of the AIDS cases. A lower percentage is hypothesized for Hispanic residents because of the need to accommodate language and cultural differences.

Application of the Typology

By identifying key environmental attributes that affect rural HIV service delivery, the typology offers a useful framework for understanding and communicating important differences among and between rural areas. Data from our case study sites illustrate how the typology can be applied.

Table 1 shows how the four study sites vary with respect to degree of rurality. There are striking differences in population density (8.1 to 148.3 persons per square mile) and in proximity to MSAs. All of the counties in the Mountain Census Division study sites are frontier rural or core rural. All of the counties in the Edisto (South Carolina) District are core rural, while the Treasure Coast area of Florida is most appropriately classified as "mixed MSA/nonMSA." However, it is important to note that the Treasure Coast's two MSA counties include large, sparsely populated farming areas as well as seacoast areas with heavy concentrations of retirees and tourists.

— Insert Table 1 about here —

Table 2 shows that the rates of cumulative reported AIDS cases range from 13.7 per 100,000 (southeast New Mexico) to 158.9 per 100,000 (Treasure Coast, Florida). Based on our typology, the Mountain Census Division sites would be classified as "low prevalence" areas, and the South Atlantic Census Division sites would be classified as "high prevalence" areas.

— Insert Table 2 about here —

The site-specific data presented in Table 2 also reveal distinct HIV transmission patterns. In the Mountain Census Division sites, men who have sex with men account for more than half of the reported AIDS cases (51 % in southeast New Mexico; 60 % in southeast Idaho). A completely different pattern can be seen in the two South Atlantic Census Division sites. In the Edisto District of South Carolina, 58 percent of the reported AIDS cases are linked to injecting drug use and/or heterosexual transmission. These same transmission categories account for almost two-thirds of the reported AIDS cases in the Treasure Coast area of Florida.

Differences between the Mountain Census Division and South Atlantic Census Division study sites persist when race and gender are analyzed (Table 2). The vast majority of the AIDS cases in the Mountain Census Division study sites are Caucasian (60 % in southeast New Mexico; 93 % in southeast Idaho). By comparison, 59 percent of the Treasure Coast AIDS cases and 85 percent of the Edisto AIDS cases are Black (i.e., African American or Haitian). Because American Indians account for a significant proportion of the population in some sections of Idaho and New Mexico, we can assume that some of the cases

listed as "other/unreported" in Table 2 are from this ethnic group. However, national HIV/AIDS surveillance data collected by the CDC indicate that the number of reported AIDS cases among American Indians is relatively low compared to other racial/ethnic groups (Berry, 1993).

The two Mountain Census Division study sites have very few females with AIDS. Women account for only 3 percent of the AIDS cases in southeast New Mexico and 10 percent of the AIDS cases in southeast Idaho. In contrast, women account for about one-quarter of the AIDS cases in the South Atlantic Census Division study sites (24% in the Edisto District of South Carolina and 27% in the Treasure Coast area of Florida).

Table 3 shows how the case study sites are distributed with respect to the three typology dimensions: (1) AIDS prevalence, (2) degree of rurality, and (3) predominant transmission category. The case studies suggest that environmental attributes affect the organization and delivery of HIV/AIDS care in at least four ways:

— Insert Table 3 about here —

1. **If rural America is viewed as a continuum, ranging from "frontier rural" to "mixed MSA/nonMSA," HIV services will be *most difficult* to access in frontier areas and core rural areas that are distant from an MSA.**

When a rural area is located in close proximity to an MSA, many HIV services can be provided through urban outreach programs. In more remote locales, small numbers of people with HIV/AIDS, dispersed over large geographic areas, make it more difficult to offer cost-effective health and social services. For example, HIV-positive residents of

southeast Idaho and southeast New Mexico often travel 4-6 hours to obtain specialized medical care. Vast distances between population centers and inadequate public transportation systems have discouraged the development of regional HIV service networks. In-home health and support services have been particularly difficult to organize. The New Mexico Department of Health and Rehabilitation Services recently revised its per-case reimbursement system to take travel time into account.

- 2. Health professionals and community leaders are more likely to deny the existence of HIV/AIDS as a local problem when there are small numbers of cases. Denial results in minimal long-range planning for HIV service delivery.**

In the Mountain Census Division study sites, people often referred to AIDS as a "big city problem" or a problem affecting "people on the margins of mainstream society." The HIV coalitions in these areas were spending most of their time trying to raise community awareness of AIDS as a public health problem. In the South Atlantic Census Division study sites, where the prevalence of AIDS was much higher, regional HIV care consortia were much more involved in planning and developing medical and support services. For example, the HIV care consortium in the Edisto District of South Carolina had used Title II funds to establish an HIV clinic in a county health department. Between September 1991 and June 1993, this clinic provided primary medical care, CD4 lymphocyte monitoring, case management, and support groups to more than 100 patients.

3. **"High prevalence" rural areas with *incremental growth* in demand for care are more likely to be more proactive in developing HIV services than areas that are experiencing rapid growth.**

The relationship between demand for care and service development is illustrated in the Treasure Coast area of Florida and the Edisto District of South Carolina. Both areas have rates of cumulative reported AIDS cases that are substantially higher than the overall South Atlantic Census Division rate (32.4 per 100,000). However, the state appropriations for HIV prevention and care are modest when compared with other states (Leeds, 1993). Because the Edisto Health District has experienced only moderate increases in the demand for care, the staff at the HIV clinic are able to identify HIV cases early and provide these patients with ongoing medical and social support. Health department surveillance personnel report that a high proportion of HIV-positive residents are in care. In contrast, many Treasure Coast area residents are presenting at HIV clinics in advanced stages of the disease. The growing numbers of people with HIV, and the lateness with which people seek care, have left little time for the development of outreach and early intervention services. Service providers described themselves as "being on a battlefield, with the situation growing out of control."

4. **The features of rural HIV service networks are influenced by traditional methods of organizing primary medical care as well as the demographic and epidemiologic characteristics of the HIV population.**

The case studies identified two major ways of organizing primary medical care for rural residents with HIV/AIDS. At the Mountain Census Division study sites, where health care

traditionally has been provided by the private sector, there was little support for developing the capacity of public health departments or other government-funded agencies to serve people with HIV/AIDS. Rather than run the risk of having their sexual orientation or disease status disclosed, gay men frequently traveled to urban areas for primary health care. In contrast, the South Atlantic Census Division study sites had a long history of providing primary medical care through public health departments and community health centers. The injecting drug users and heterosexual clients who comprised most of their HIV population were accustomed to seeking care at these publicly-funded clinics.

At the Edisto, South Carolina study site, the growing number of pregnant women with HIV disease led to a decision to provide specialized care through the health department's prenatal clinic. The multi-cultural composition of the HIV population in the Treasure Coast area of Florida created a need for more bilingual staff. In other rural settings, where the twin epidemics of AIDS and injecting drug use are present, service providers are attempting to integrate substance abuse treatment with primary medical care (Gold et al., 1994).

Discussion and Conclusions

This typology identifies different epidemiologic and demographic attributes of rural environments that affect the organization and delivery of HIV/AIDS care. By considering different combinations of the three dimensions (degree of rurality, prevalence of AIDS, and characteristics of the infected populations), we begin to understand the diversity of rural environments and the range of approaches that are needed to address HIV service needs. Researchers can use the typology to examine how the structure and functions of HIV service

networks vary across rural environments and to assess relationships between environmental context and service outcomes. Federal, state, and local policymakers can use the typology to develop HIV-related policies and programs that allow rural areas to select service options that fit with the characteristics and needs of their HIV-positive residents.

The typology can serve as a framework for a database that contains information about HIV service delivery programs in distinct types of rural environments. A rural area desiring to initiate or adapt HIV services could use the database to learn about HIV service delivery models in rural settings with similar epidemiological and demographic characteristics. The typology also could be used to compare the relative effectiveness of HIV service delivery models in different rural environments and to identify the environments that are most suitable for program replication.

The limitation of the typology is that it does not include all of the environmental variables that may affect HIV service delivery. Even when rural areas are classified according to the three typology dimensions, the ways in which they organize medical and support services may be influenced by resource availability, financing mechanisms, community and professional attitudes, leadership patterns, and historical responses to public health problems. These factors need to be considered when analyzing and evaluating rural HIV service networks.

Overall, the typology provides a practical framework for distinguishing among rural environments and examining variations in HIV service networks. The typology also contributes to public policy discussions by identifying key attributes of rural environments that influence program implementation and the transferability of service delivery models. By

applying and testing the typology, researchers can help to refine its dimensions and assess its usefulness for epidemiological and health services research.

Notes

1. Before 1993, the AIDS surveillance case definition included only opportunistic illnesses. In 1993, CDC expanded the surveillance definition to include a laboratory measure of severe immunosuppression (CD4+ T-lymphocyte count of less than 200 cells/mm³ or a percent of total lymphocytes less than 14) and three additional clinical conditions — pulmonary tuberculosis, recurrent pneumonia, and invasive cervical cancer.
2. Stages of HIV infection can be categorized as asymptomatic, symptomatic non-AIDS, or AIDS (Fleishman, Hsia, & Hellinger, 1994). Although asymptomatic patients require certain vaccinations and screenings, the authors assume that the types of services required and the methods of service delivery will be *most influenced* by the number of local residents with HIV-related symptoms or AIDS-defining diagnoses. Readers should interpret the term "HIV/AIDS" to mean people who have AIDS or who have HIV-related symptoms.

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FIGURE 1

AN ENVIRONMENTAL TYPOLOGY FOR DIFFERENTIATING AMONG HIV SERVICE NETWORKS

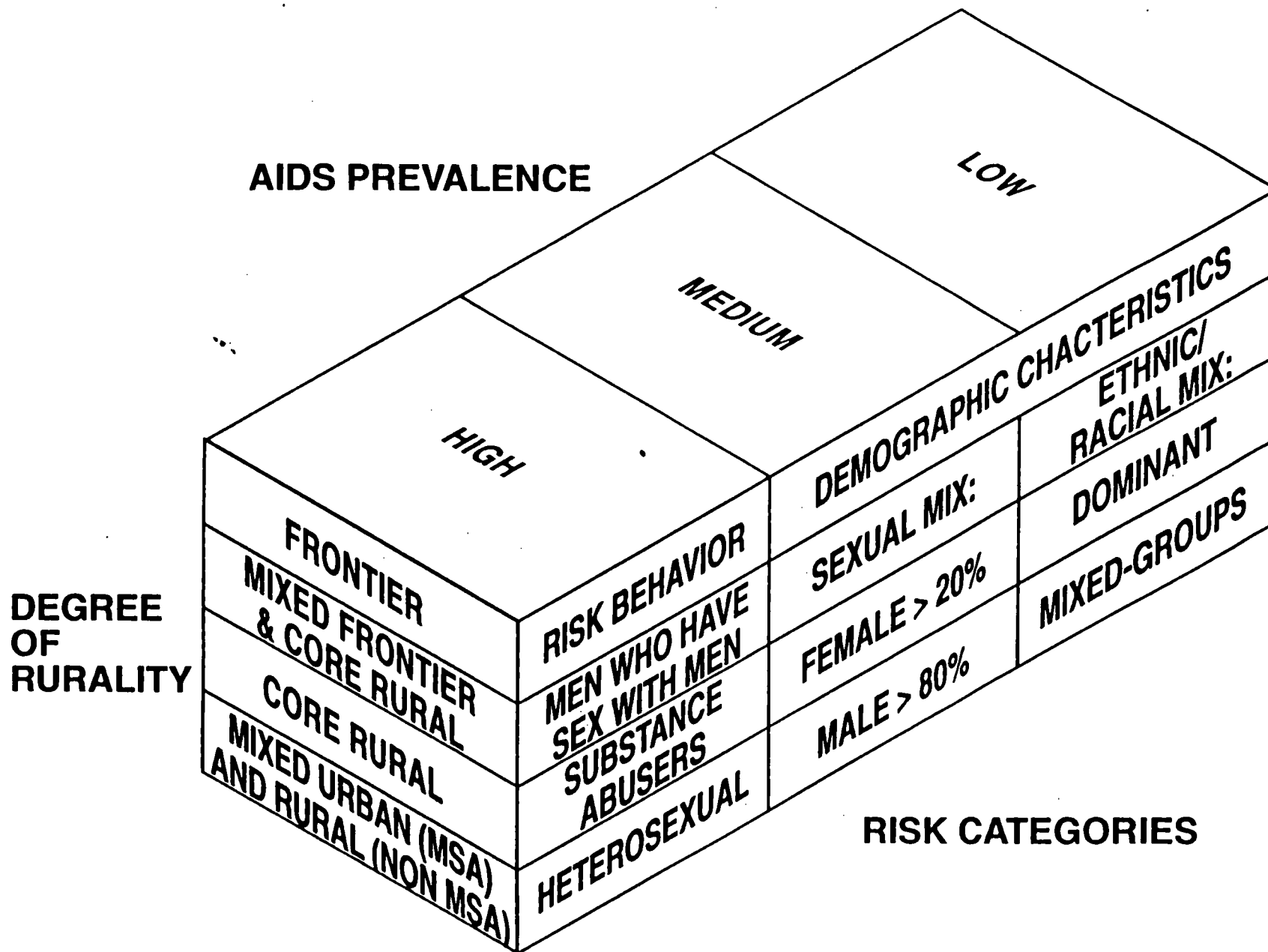


FIG JRE 1 AN ENVIRONMENTAL TYPOLOGY FOR DIFFERENTIATING AMONG HIV SERVICE NETWORKS

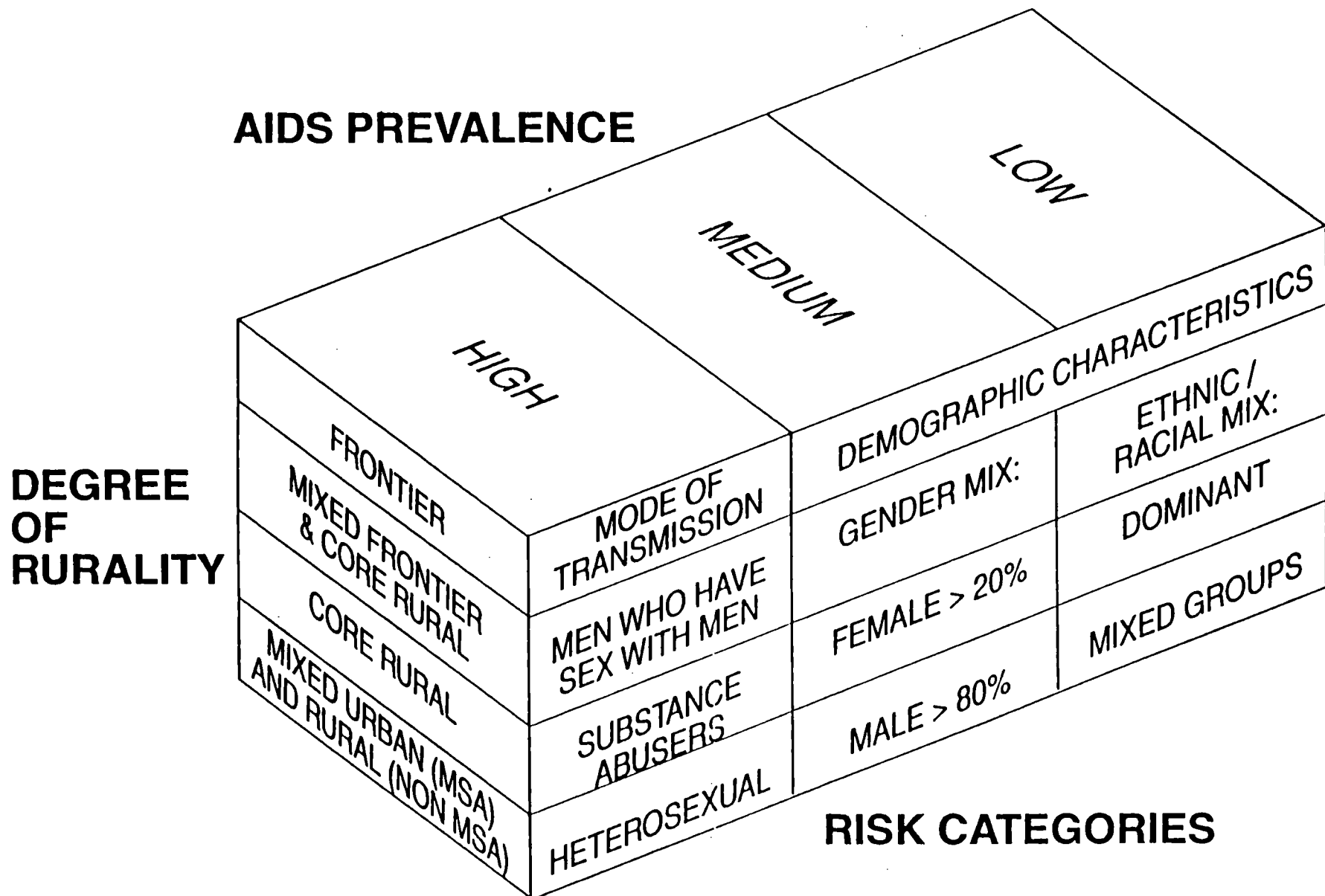
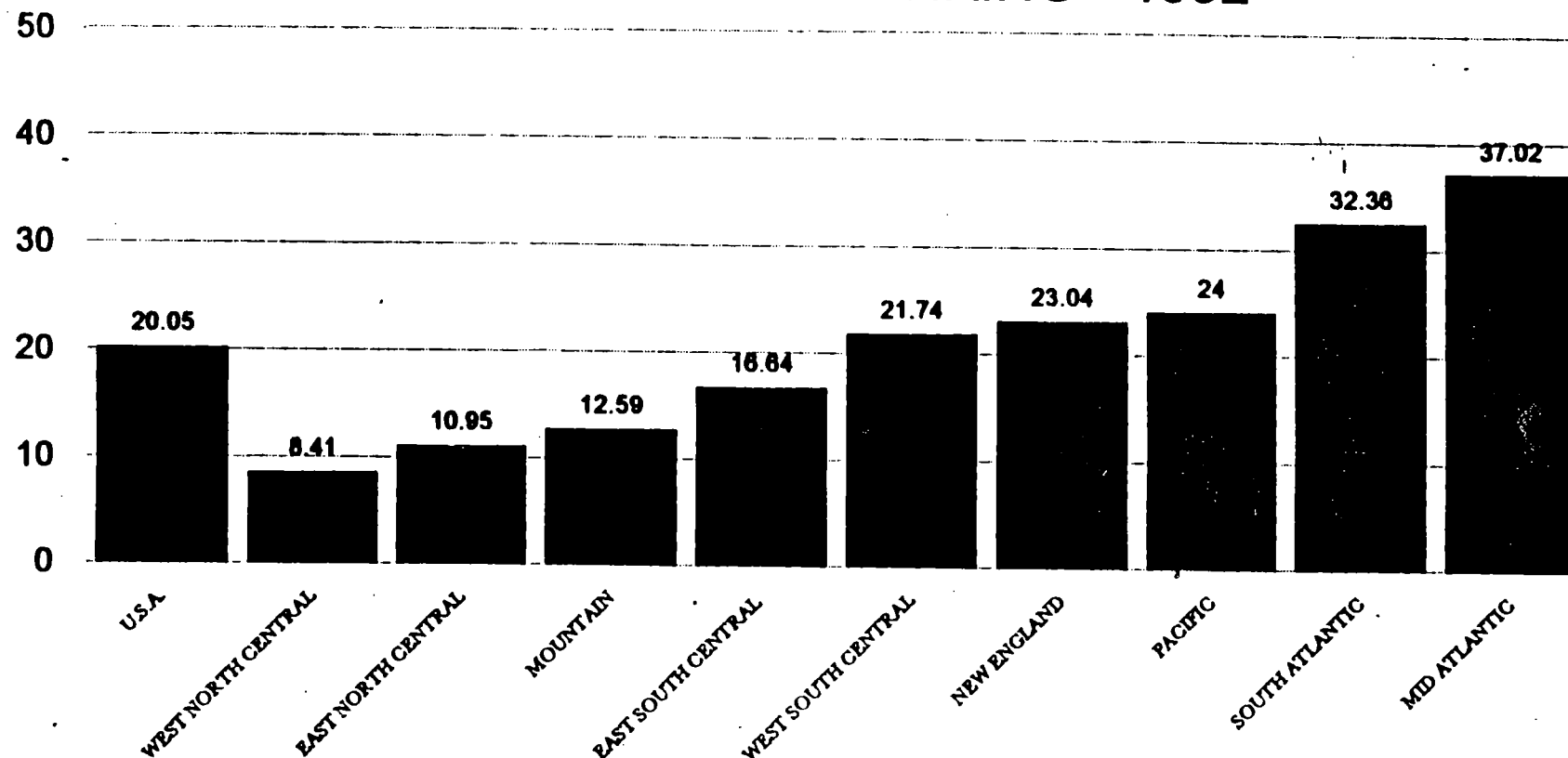


FIGURE 2
CUMULATIVE RURAL AIDS CASES PER 100,000 BY CENSUS
DIVISION AND RANKING - 1992



U.S. CENSUS DIVISIONS AND STATES:

WEST NORTH CENTRAL:	Iowa, Kansas, Minnesota, Missouri, Nebraska, North Dakota, South Dakota
EAST NORTH CENTRAL:	Illinois, Indiana, Michigan, Ohio, Wisconsin
MOUNTAIN:	Arizona, Colorado, Idaho, Montana, Nevada, New Mexico, Utah, Wyoming
EAST SOUTH CENTRAL:	Alabama, Kentucky, Mississippi, Tennessee
WEST SOUTH CENTRAL:	Arkansas, Louisiana, Oklahoma, Texas
NEW ENGLAND:	Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont
PACIFIC:	Alaska, California, Hawaii, Oregon, Washington
SOUTH ATLANTIC:	Delaware, Florida, Georgia, Maryland, North Carolina, South Carolina, Virginia, West Virginia
MIDDLE ATLANTIC:	New Jersey, New York, Pennsylvania

Table 1. Degree of Rurality of Case Study Sites

Southeast Idaho	Southeast New Mexico	Edisto District South Carolina	Treasure Coast Florida
Population 277,978	Population 255,816	Population 114,458	Population 380,738
Population density 9.7/square mile	Population density 8.1/square mile	Population density 44.3/square mile	Population density 148.3/square mile
16 counties (8 frontier; 8 core rural)	9 counties (4 frontier; 5 core rural)	3 counties (3 core rural)	4 counties (2 core rural; 2 MSA)
NonMSA	NonMSA	NonMSA	Mixed MSA/nonMSA

Table 2. Rates of Cumulative Reported AIDS Cases and Characteristics of Adult/Adolescent AIDS Patients at Case Study Sites - 1993

<i>Southeast Idaho</i>	<i>Southeast New Mexico</i>	<i>Edisto District South Carolina</i>	<i>Treasure Coast Florida</i>
42 cumulative AIDS cases (1985-6/30/93)	35 cumulative AIDS cases (1981-6/30/93)	99 cumulative AIDS cases (1981-3/31/93)	605 cumulative AIDS cases (1981-5/31/93)
15.1 cumulative AIDS cases per 100,000	13.7 cumulative AIDS cases per 100,000	86.5 cumulative AIDS cases per 100,000	158.9 cumulative AIDS cases per 100,000
90% Male 10% Female	97% Male 3% Female	76% Male 24% Female	73% Male 27% Female
93% White 5% Hispanic 2% Unreported	60% White 26% Hispanic 11% Black 3% Unreported	85% Black 15% White	59% Black 38% White 3% Hispanic
60% MSM 14% Blood Products 14% Unspecified 7% Heterosexual 5% IDU	51% MSM 15% Unspecified 14% IDU 14% MSM and IDU 6% Heterosexual	31% IDU 23% MSM 21% Heterosexual 15% Unspecified 6% MSM and IDU 4% Blood Products	43% Heterosexual 28% MSM 17% IDU 7% Unspecified 4% MSM and IDU 1% Blood Products

Key: MSM = men who have sex with men
 IDU = Injecting drug use
 MSM and IDU = men who have sex with men and who inject drugs
 Heterosexual = sex with an injecting drug user, bisexual male, person with hemophilia, transfusion recipient with HIV infection, or with an HIV-infected person whose risk is not specified
 Blood Products = hemophilia/coagulation disorder or receipt of blood transfusion, blood components, or tissue
 Unspecified = risk not reported or identified

Sources: Florida Department of Health and Rehabilitative Services (9/93)
 Idaho Department of Health and Welfare (9/93)
 New Mexico Department of Health and Rehabilitation Services (6/93)
 South Carolina Department of Health and Environmental Control (3/93)

Table 3. Application of Environmental Typology to Case Study Sites

	Predominant Transmission Category			
	MSM ¹	IDU ²	Heterosexual Contact	Other
AIDS Prevalence	Low		High	
Degree of Rurality				
Frontier rural				
Mixed frontier & core rural	S.E. Idaho S.E. New Mexico			
Core rural			Edisto District South Carolina	
Mixed MSA/ non-MSA			Treasure Coast Florida	

¹ MSM = men who have sex with men

² IDU = injecting drug use