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AUTHOR McKinney, Martha M.
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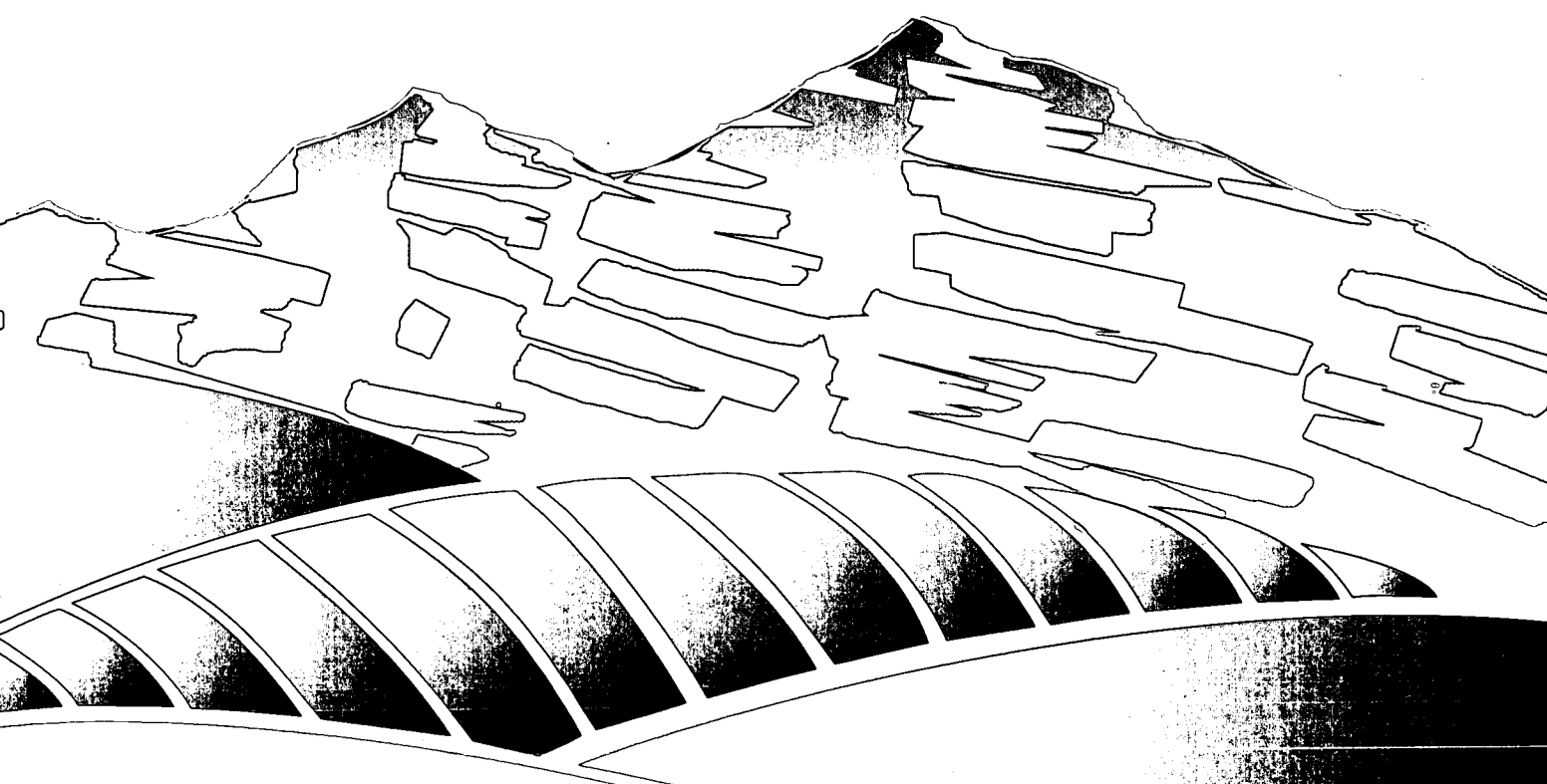
ABSTRACT

The Northeast Conference on Rural HIV Service Delivery was attended by 51 health and social service professionals, people with HIV, and federal and state health officials with expertise or interest in developing HIV care capacity in rural areas. Low population density, low prevalence of HIV/AIDS, rugged topography and climate, and limited health care infrastructure were identified as access barriers for rural people living with HIV. Three models presented for delivering health and support services to rural residents with HIV were urban outreach, community-based physician networks, and shared care. HIV continuing professional education programs for rural providers should be responsive to local variations in health care delivery, time effective, case-specific, and provided at little or no cost. Rural areas need primary care physicians and mid-level practitioners who are trained to recognize the signs and symptoms of HIV infection and to work with HIV specialists. Linkages with urban-based specialists need to be strengthened through telemedicine, telephone consultations, and visits by specialists to rural sites. Rural areas also need to plan for changes in HIV care that may be required by changing Medicaid policies and payment arrangements. Funding and training are needed to provide the higher levels of support required by increasing numbers of HIV-positive patients with chemical dependence, mental disorders, and hepatitis C. Resources were identified to help rural areas develop HIV service capacity. (TD)

Northeast Conference on Rural HIV Service Delivery
October 23-24, 2000
Burlington, Vermont

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SUMMARY REPORT



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HRSA
Health Resources and Services Administration

Summary Report

Northeast Conference on Rural HIV Service Delivery

(October 23-24, 2000)

This publication was funded by the
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and prepared by Martha M. McKinney, Ph.D.
Community Health Solutions, Inc., Richmond, KY

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Executive Summary

On October 23-24, 2000, the HIV/AIDS Bureau (HAB), Health Resources and Services Administration (HRSA) convened the Northeast Conference on Rural HIV Service Delivery in Burlington, Vermont. The 51 invited participants included health and social service professionals, people living with HIV disease, and Federal and State health officials with expertise and/or interest in developing HIV care capacity in rural areas. A steering committee, composed of representatives of the Comprehensive Care Clinic, Fletcher Allen Health Care (Burlington, VT), the Vermont Department of Health, U.S. Senator James Jeffords' office, and HRSA's HIV/AIDS Bureau, established four objectives for the conference:

- 1) To identify the major barriers to health care access and utilization faced by people living with HIV disease in rural areas of the Northeast;
- 2) To identify models of delivering HIV-related health and support services that are appropriate for the rural Northeast;
- 3) To determine the most important continuing education needs of existing and potential HIV care providers in rural areas of the Northeast; and
- 4) To suggest provider training models and quality assurance procedures that will enhance the quality of HIV-related health and support services in the rural Northeast.

This report summarizes the major issues, models, and strategies emerging from conference presentations and workgroup discussions.

Regional Variations in the Epidemiology of Rural AIDS

In 1999, 7 percent of the 44,388 new adult/adolescent AIDS cases reported to the Centers for Disease Control and Prevention (CDC) were residing in nonmetropolitan areas (< 50,000 population) at the time of diagnosis. Two-thirds of the newly reported rural residents were living in the South. The remaining incident rural AIDS cases were concentrated in the Northeast and North Central regions. Regional comparisons of 1999 incident AIDS cases also show that:

- Nonmetropolitan adult/adolescent AIDS rates were highest in the South (11 per 100,000) and the Northeast (9 per 100,000). Within the Northeast, the nonmetropolitan AIDS rate for the Middle Atlantic States (11.7 per 100,000) was twice that of the New England States (5.3 per 100,000).

- Rural residents accounted for 12 percent of the adult/adolescent AIDS cases reported in the South but less than 5 percent of the cases reported in the Northeast and West. Within the Northeast, Vermont had the highest proportion of nonmetropolitan AIDS cases (47 percent), followed by Maine (38 percent) and New Hampshire (25 percent).
- The female proportion of nonmetropolitan AIDS cases was highest in the South (27 percent) and lowest in the Northeast and West (15 percent).
- The Northeast had the highest proportion of Hispanic individuals residing in nonmetropolitan areas at the time of AIDS diagnosis (26 percent). The South had the highest proportion of black, non-Hispanic individuals (61 percent). In the North Central and Western regions, two-thirds of the people reported with AIDS were white, non-Hispanic.

Barriers to Health Care Access and Utilization

Conference participants identified four characteristics of rural areas that create unique access barriers for people living with HIV disease:

- ***Low population density*** – limits the number of health and social services that can be offered locally, increases the distance that must be traveled to obtain medical care, reduces public transportation options, and impedes efforts to organize HIV planning and advocacy groups
- ***Low prevalence of HIV/AIDS*** – discourages State and community support for HIV initiatives, makes it difficult for service providers to achieve economies of scale, and limits opportunities for rural clinicians to gain HIV management experience
- ***Rugged topography and climate*** – increase travel time and burden
- ***Limited health care infrastructures*** – restrict service options and choice of service providers

Models for Rural HIV Service Delivery

Conference speakers presented three models for delivering health and support services to rural residents with HIV disease:

- ***Urban outreach models*** extend the services of an urban-based HIV clinic to rural residents through regional satellite clinics. *Example:* Dr. Christopher Grace, Director, Infectious Diseases, Fletcher Allen Health Care, described three regional HIV specialty clinics established by the University of Vermont.
- ***Community-based physician networks*** develop the HIV care capacity of local physicians. *Examples:* Dr. Bruce Williams, Medical Director for the Partners in Care Program, University Hospital, University of New Mexico Health Sciences Center, described two types of networks: (1) a statewide network of physicians who provide HIV care on a fee-for-

service basis, and (2) regional “health management alliances” that receive capitated payments to provide a comprehensive array of medical, behavioral health, and support services to people with HIV disease.

- **Shared Care Models** involve an HIV specialist and a primary care physician in co-managing patient care. In contrast to the urban outreach model, where participation by primary care physicians is optional, the shared care model requires joint management. *Example 1:* Dr. Ted Holloway, District Health Director for the Southeast Health Unit (Waycross, GA), described how his public health district developed “wellness centers” for HIV-positive residents and involved local physicians in co-managing their care. *Example 2:* Bengie Hair, HIV Program Manager for Roper Hospital/CareAlliance, described an HIV specialty clinic in Fayetteville, North Carolina that was jointly developed by an academic medical center, an area health education center, a local hospital, two HIV care consortia, and local physicians.

HIV Training and Quality Assurance Models

Dr. Laura Cheever, Chief, HIV Education Branch, HRSA HIV/AIDS Bureau, presented national and regional models for educating rural clinicians about the medical management of HIV infection. Workgroup participants suggested building a continuum of HIV professional education to accommodate varying levels of interest and expertise. They identified four principles for developing and delivering HIV professional education programs:

- **Provider training models should be responsive to variations in rural health care delivery systems and resources.** For example, the roles and responsibilities of non-physicians, such as nurse practitioners and case managers, may vary greatly from one rural area to another.
- **Provider training models should be “time effective.”** Since many rural clinicians do not have the time or back-up support to travel to urban centers, training should be provided on-site or through teleconferences whenever possible. Audiotapes and videotapes also should be considered as training modalities.
- **The content of training programs should be case-specific.** Rural clinicians in small busy practices need information that they can put into effect right away.
- **Training should be provided at little or no cost.** Most rural clinicians have very little funding for continuing education.

Additional discussion revealed a critical need for standards and tools that can help rural HIV service providers assess and improve the quality of health and support services. Technical assistance also is needed on effective ways of obtaining client feedback in rural areas where HIV is highly stigmatized and infected residents have limited service options.

Lessons Learned and Ongoing Challenges

Conference presentations highlighted the varying characteristics of rural environments that should be considered when planning HIV services. Speakers encouraged conference participants to design HIV service delivery systems that fit with their environments. They also stressed the importance of building HIV care capacity through existing resources and partnerships and continuously reviewing and updating HIV service plans.

Much of the dialogue focused on challenges that rural areas must meet to keep pace with the growing HIV epidemic. At the most basic level, rural areas need primary care physicians and mid-level practitioners who are trained to recognize the signs and symptoms of HIV infection and to co-manage patient care with HIV specialists. Linkages with urban-based specialists need to be strengthened through telemedicine, telephone consultations, and visits by specialists to rural sites. Rural areas also need to plan for changes in HIV care that may be required by changing Medicaid policies and payment arrangements.

Like urban HIV clinics, rural medical care providers are seeing increasing numbers of HIV-positive patients with chemical dependencies and mental disorders. Additional funding is critically needed to expand behavioral health services and assistance with housing and other basic subsistence needs. Case managers need to be trained and appropriately reimbursed to provide the higher levels of support required by these individuals. Clinical guidance and resources also are needed to treat HIV-positive patients who are coinfecting with hepatitis C.

Conference discussions highlighted resources that are available to help rural areas develop HIV service capacity. For example, nonprofit organizations in rural and underserved areas have priority for HIV planning and capacity-building grants under Title III of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. Dr. Christopher Grace urged conference participants to seek creative ways of organizing and delivering HIV services. “The key to development of any model is going to be the passion and power that people bring to the system,” he said. “Providing compassionate, state-of-the-art medical care to a diverse rural population is difficult, but it can be done.”

Introduction

Over the past 20 years, the United States has witnessed rapid changes in the populations and geographic areas affected by HIV/AIDS. In the early years of the epidemic, HIV infection was most prevalent among gay white men and injection drug users living in large metropolitan areas. As the medical community struggled to understand the etiology of the disease and to find effective treatments, the disease quickly spread to women, youth, and people of color within these epicenters and to vulnerable populations in smaller cities and rural communities. By December 1999, people residing in nonmetropolitan areas (< 50,000 population) at the time of AIDS diagnosis accounted for 6 percent of the cumulative reported AIDS cases and 7 percent of newly reported AIDS cases.¹

The Centers for Disease Control and Prevention (CDC) estimates that, in December 1999, almost 21,000 adults and adolescents were living with AIDS in nonmetropolitan areas of the United States.¹ Fifty-eight percent of these individuals were living in the South, 16 percent in the Northeast, 14 percent in the North Central Region, and 12 percent in the West.² Because some States do not report cases of HIV infection or have only recently implemented HIV surveillance systems, reliable estimates of HIV prevalence in nonmetropolitan areas are unavailable.

The Northeast, which is most often associated with high metropolitan AIDS rates, had the second highest nonmetropolitan adult/adolescent AIDS rate in 1999.³ As HIV continues to spread throughout the rural Northeast, local communities are being challenged to find new models and strategies for meeting the health and support service needs of HIV-positive residents. To encourage a regional dialogue on these issues, a group of HIV care providers from Vermont joined with HRSA's HIV/AIDS Bureau to plan an invitational conference on rural HIV service delivery. This report summarizes the major issues, models, and strategies discussed at the conference.

Conference Objectives and Agenda

The Northeast Conference on Rural HIV Service Delivery was held in Burlington, Vermont, October 23-24, 2000, with financial support from HRSA's HIV/AIDS Bureau. The 51 invited participants included health and social service professionals, people living with HIV disease, and

Federal and State health officials with expertise and/or interest in developing HIV care capacity in rural areas. A steering committee, composed of representatives of the Comprehensive Care Clinic, Fletcher Allen Health Care (Burlington, VT), the Vermont Department of Health, U.S. Senator James Jeffords' office, and HRSA's HIV/AIDS Bureau, established four objectives for the conference:

- 1) To identify the major barriers to health care access and utilization faced by people living with HIV disease in rural areas of the Northeast;
- 2) To identify models of delivering HIV-related health and support services that are appropriate for the rural Northeast;
- 3) To determine the most important continuing education needs of existing and potential HIV care providers in rural areas of the Northeast; and
- 4) To suggest provider training models and quality assurance procedures that will enhance the quality of HIV-related health and support services in the rural Northeast.

The conference agenda included a mix of presentations and workgroup discussions (see appendix). On the first day, conference participants heard presentations on recent trends in the rural HIV/AIDS epidemic, models for improving the accessibility and quality of HIV services in rural areas, and provisions of the Ryan White CARE Act Amendments of 2000 that will benefit rural areas. An evening panel discussion, facilitated by Terje Anderson, Executive Director of the National Association of People with AIDS, provided an opportunity for speakers and conference participants to further explore the issues involved in building rural HIV care capacity.

On the second day, conference participants met in facilitated workgroups. Workgroup #1 discussed models and strategies for increasing access to high quality HIV clinical care in rural areas of the Northeast. Workgroup #2 discussed ways of addressing the access barriers and support service needs of marginalized rural populations living with HIV disease. Both workgroups reported key findings and recommendations at a concluding plenary session.

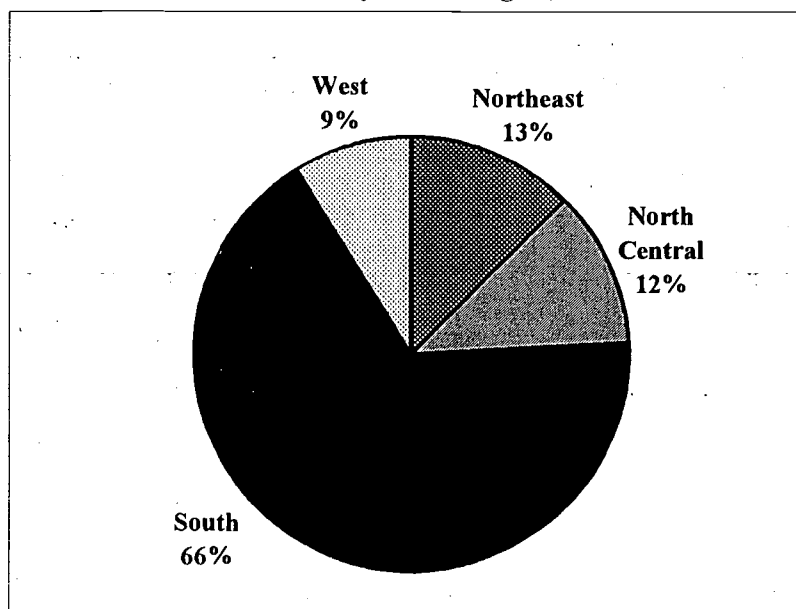
This report presents the issues and strategies discussed at the conference in five sections. The first section describes regional variations in the epidemiology of rural AIDS. The second section discusses the major barriers to health care access and utilization faced by people living with HIV/AIDS in the rural Northeast. The third section describes HIV service delivery models with

potential for replication in rural areas of the Northeast. The fourth section presents provider training models and strategies for promoting and monitoring high quality HIV care. The last section summarizes the major lessons learned and ongoing challenges.

Regional Variations in the Epidemiology of Rural AIDS

In 1999, 7 percent of the 44,388 new adult/adolescent AIDS cases reported to the CDC were residing in nonmetropolitan areas at the time of diagnosis.¹ Two-thirds of the newly reported rural residents (N=2,187) were living in the South (figure 1). The remaining incident rural AIDS cases were concentrated in the Northeast (N=411) and North Central (N=376) regions.

FIGURE 1. Distribution of Nonmetropolitan Adult/Adolescent AIDS Cases by Census Region, 1999



The South and the Northeast had the highest nonmetropolitan adult/adolescent AIDS rates in 1999 (figure 2).³ Within the Northeast, the nonmetropolitan AIDS rate for the Middle Atlantic States (11.7 per 100,000) was twice that of the New England States (5.3 per 100,000).¹

FIGURE 2. Nonmetropolitan Adult/Adolescent AIDS Rates by Census Region, 1999

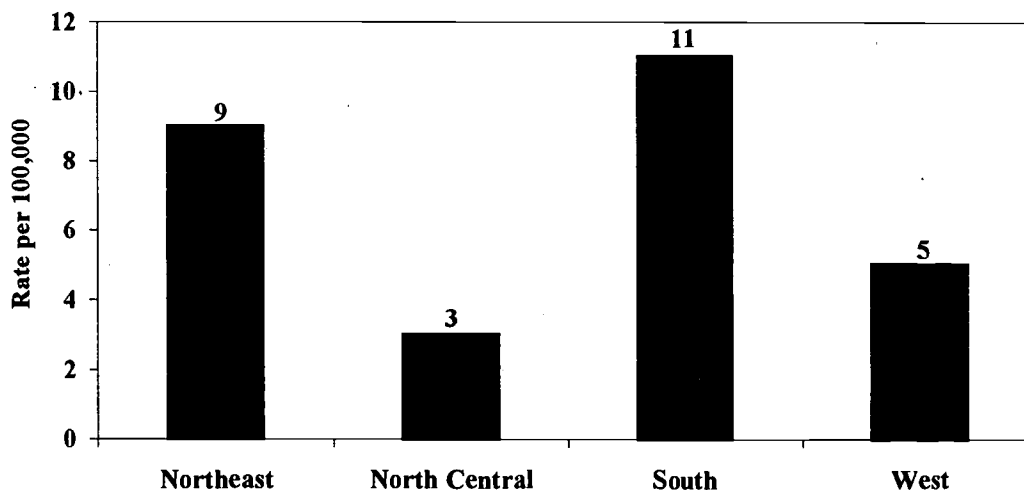
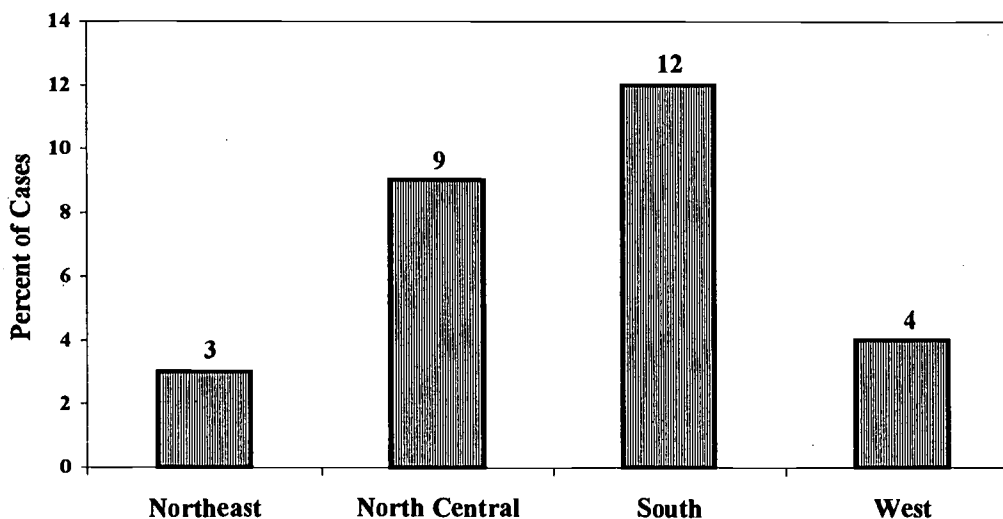


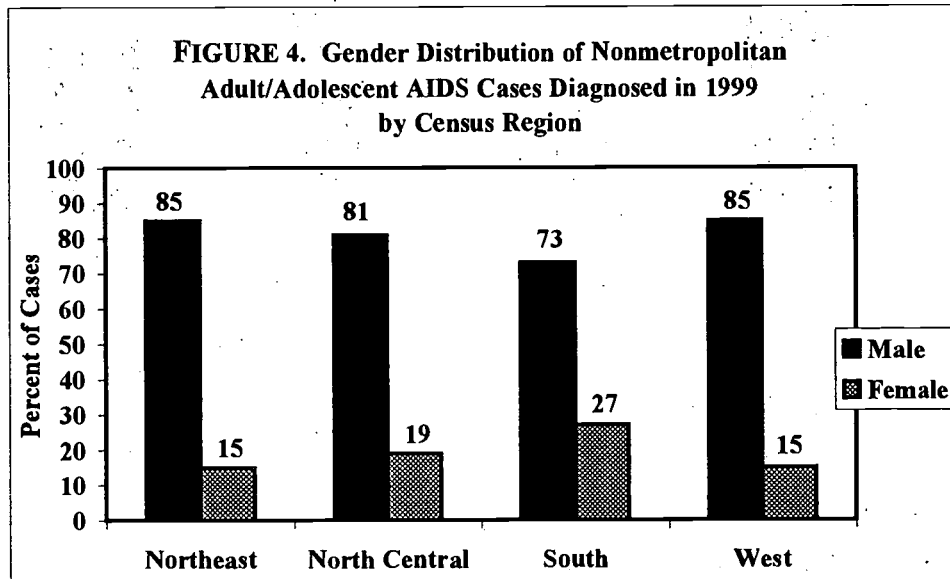
Figure 3 shows the nonmetropolitan proportion of each region's new adult/adolescent AIDS cases in 1999.¹ Rural residents accounted for 12 percent of the adult/adolescent AIDS cases reported in the South but less than 5 percent of the cases reported in the West and Northeast. Within the Northeast, Vermont had the highest proportion of nonmetropolitan AIDS cases (47 percent), followed by Maine (38 percent) and New Hampshire (25 percent).⁴ Nonmetropolitan AIDS cases accounted for less than 10 percent of the new AIDS cases reported in other northeastern States.

FIGURE 3. Non-Metropolitan Proportion of Adult/Adolescent AIDS Cases by Census Region, 1999



Distribution of Nonmetropolitan AIDS Cases by Gender

Figure 4 compares the male and female proportions of nonmetropolitan adult/adolescent AIDS cases diagnosed in 1999 by Census Region.¹ The female proportion of nonmetropolitan AIDS cases was highest in the South (27 percent) and lowest in the Northeast and West (15 percent).



Distribution of Nonmetropolitan AIDS Cases by Race/Ethnicity

Table 1 shows the racial/ethnic distribution of nonmetropolitan adult/adolescent AIDS cases reported in 1999 by Census Region.¹ The Northeast had the highest proportion of Hispanic individuals residing in nonmetropolitan areas at the time of diagnosis (26 percent). The South had the highest proportion of black, non-Hispanic individuals (61 percent). White non-Hispanic individuals accounted for two-thirds of the nonmetropolitan AIDS cases reported in the North Central and Western regions but less than one-half of the cases reported in other Census regions.

TABLE 1. Racial/Ethnic Distribution of Non-MSA Adult/Adolescent AIDS Cases by Census Region

Region	Percent White, non-Hispanic	Percent Black, non-Hispanic	Percent Hispanic	Percent Other*
Northeast	43	31	26	< 1
North Central	67	26	6	1
South	33	61	5	1
West	68	8	16	8

*Other includes Asian/Pacific Islander and American Indian/Alaska Native.

Barriers to Health Care Access and Utilization

Unique Characteristics of Rural Areas

Conference participants identified four characteristics of rural areas that create unique access barriers for people living with HIV disease:

■ Low Population Density

Low population density limits the number of health and social services that can be offered in rural communities. When rural populations are too small and geographically dispersed to support specialized health services, HIV-positive residents may have to travel long distances to obtain medical care. Few, if any, public transportation options are likely to be available. Lower population density also impedes efforts to organize HIV planning and advocacy groups. “In rural areas, people are spread out,” a case manager explained. “They have different issues and problems, and they don’t connect with each other.”

■ Low Prevalence of HIV/AIDS

Most rural areas have relatively few people living with HIV/AIDS. Although the actual numbers may be higher than reported, low HIV prevalence makes it difficult to procure the resources needed to develop and sustain HIV services. “Our greatest barrier is the belief that HIV is not real,” said one rural clinician. “People don’t think there is any HIV, so they don’t understand why we’re putting money into it.” Small numbers of HIV-positive residents spread over large geographic areas make it difficult to achieve economies of scale. Service providers may be unable to generate sufficient revenue to cover the cost of low-volume services or services requiring home visitation. Low HIV prevalence also limits clinicians’ opportunities to gain HIV management experience, which may result in lower quality care.

■ Rugged Topography and Climate

Many rural areas in the Northeast have mountainous terrains. Long, harsh winters and limited highway systems make travel across these mountains especially challenging. A physician commented: “The travel from small towns in southern Vermont across the Green Mountains is extremely difficult, especially in the winter, because there are no major highways. There are just two-lane roads going up and down those mountains.”

■ Limited Health Care Infrastructures

Declining economies, high poverty rates, and the out-migration of younger residents have reduced the tax bases of many rural northeastern communities. As a result, rural areas are less likely to have the well-developed health care infrastructures enjoyed by urban residents.

Physician recruitment efforts have been hampered by the inability to offer the range of financial incentives, continuing medical education opportunities, and local amenities for family members that would be available in larger cities. Most rural areas also lack adequate counseling and treatment services for people with chemical dependencies, mental disorders, and other HIV-related comorbidities.

General Access Barriers

Conference participants identified additional access barriers that, while not unique to rural areas, may be more severe in these settings. These barriers encompass four levels of analysis: individual, clinician, organization, and health service delivery system.

■ Individual Barriers

Many HIV-positive individuals in rural areas do not understand the disease or why they should be seeking medical care when they do not “feel sick.” People with chemical dependencies or mental disorders may be too involved with these issues to seek medical care. Knowledge of available services also may be limited. Because the stigma associated with HIV/AIDS is particularly strong in rural areas, some infected individuals may be afraid to seek care locally. Breaches in confidentiality can lead to rejection by family and community members, job discrimination, and/or loss of employment. Rural individuals also may postpone or forgo HIV primary care when they do not have sufficient funds to meet basic subsistence needs. Studies indicate that people living in rural areas are more likely to be unemployed, self-employed, or working part-time than their urban counterparts.^{5,6}

■ Clinician Barriers

Many rural physicians fail to recognize the signs and symptoms of HIV infection. HIV antibody testing may not be offered even when HIV is suspected. A conference participant from Vermont said that physicians are reluctant to test because of social stigmatization issues:

This disease is associated with negatively perceived social norms — homosexuality, drug use, and prostitution. Docs say, “HIV passed through my mind in differential diagnosis, but I can’t test this person. How do I even bring the topic up?”

Rural physicians face additional challenges when they try to integrate HIV care into their practices. In addition to dealing with staff and patient fears about contracting the disease, they must keep abreast of rapidly changing standards of HIV care. A conference participant from Maine commented:

I think it gets very difficult bringing [rural] physicians up to the speed needed to feel comfortable caring for HIV-positive patients. They don’t have time to spend up front, so when that person walks through the door and they don’t know how to respond, they will likely do a referral, which may or may not be a bad thing.

Other conference participants suggested that rural physicians might be more willing to care for HIV-positive patients if case management and behavioral health services were more readily available. A physician summarized their views as follows:

There must be a team approach to comprehensive HIV care. It is not just medical care but also [dealing with] psychiatric illness, drug abuse problems, monetary issues, housing issues, food issues, and so on. One human being, no matter how skilled, cannot provide the level of services needed by people with HIV.

■ Organizational Barriers

Some hospitals, clinics, and physician practices try to avoid or minimize their involvement with HIV care because of concerns about possible financial losses. An AIDS coalition director from Pennsylvania observed: “Medicaid reimbursement for HIV services is so low in some States that, if you diagnose someone with HIV, they are immediately going to have an access-to-care problem because no one will take them.” Other conference participants described rural hospitals’ concerns about being “flooded” with uninsured and underinsured HIV/AIDS patients. Although rural-based clinics and community health centers could seek Title III (CARE Act) funding to develop their HIV care capacity, many lack grant-writing skills and experience.⁷

Several conference participants noted that “organizational attitudes” sometimes discourage HIV-positive individuals from seeking medical care. A public health official described the problem as follows:

People with HIV disease might be able to get to a service agency but, when they get there, they are treated so badly that they don't want to come back. People sometimes are treated badly because they are poor, use drugs, or they just look dirty. . . . There are so many policies and procedures that are set up to humiliate people. Prove you are worth this drug. Prove that you are worth this appointment. People who are marginalized and don't have that sense of self-empowerment have to fight to get what they need.

As additional organizational barriers, conference participants identified inconvenient days and hours of operation, inability (or unwillingness) to accommodate walk-in patients, and long waiting times for initial and follow-up appointments.

■ Service Delivery System Barriers

Conference participants cited the lack of communication among medical, behavioral health, and social service providers as a major impediment to quality care. “There is no co-management across service providers,” said one health professional. “Clients don't receive a coherent message or even a coherent plan.” To illustrate how clients are affected, a case manager gave the following example:

Traditional kinds of substance abuse programming can undermine all of the work we're trying to do with clients. They are trying to do the [substance abuse] treatment programs, but their big concern is, “When I walk out of here, I don't have any place to live. I haven't seen a doctor in six months, and I'm not feeling good.” So we're trying to help people find housing, get to the HIV clinic, and figure out what they are going to do when they get out of treatment. Meanwhile they are being told, “You're not sufficiently working your program.”

Workgroup #2 discussed problems with discharge planning. Because some rural hospitals do not have designated discharge planners, HIV/AIDS patients sometimes are discharged before adequate provisions can be made for home health care, medications, and other support services. The quality of discharge planning for HIV-positive prisoners also varies greatly from one rural area to another.

- **Vermont** – This State does not offer discharge planning for HIV-positive prisoners. To relieve overcrowding, prisoners often are given early release with no planning for follow-up HIV care or medications.⁸
- **Northwest Pennsylvania** – Community-based case managers work with correctional institutions to help HIV-positive prisoners apply for Medicaid, schedule clinic appointments, and obtain housing before they are released.
- **Massachusetts** – The Massachusetts Department of Health is funding a statewide program to help HIV-positive inmates in county jails prepare for discharge. Part-time case managers assigned to the jails help inmates enroll in the AIDS Drug Assistance Program⁹ and make arrangements for ongoing medical care.

Improving Access for Marginalized Rural Populations

Workgroup #2 identified eight socially and economically marginalized populations that exist in rural areas of the Northeast:

- 1) Racial and ethnic minorities;
- 2) New immigrants from Africa, Eastern Europe, the Caribbean Islands, and South America;
- 3) Migrant and seasonal workers employed by farms, dog and horse racing tracks, ski lodges, and the tourism industry;
- 4) Substance users;
- 5) People with mental disorders;
- 6) Gay and bisexual men;
- 7) Sex workers; and
- 8) Prisoners.

They emphasized the need for targeted outreach efforts that encourage HIV testing in these populations and that help seropositive individuals access medical care at an early stage of disease. They also discussed the higher levels of emotional and practical support that will be required to keep marginalized individuals in care. A case manager from Vermont explained:

These are people who really need some very intensive kinds of services, often for quite a period of time, to help them get stabilized so they can benefit from

treatment. . . . People whose lives are so marginalized, so disorganized, and so traumatized need to make a connection with someone whom they feel they can trust and who will truly advocate for them.

A Maine public health official reported that, although case managers in his area are seeing people with more complicated life issues, no adjustments have been made in caseloads or the monthly cap on reimbursable visits. There was general agreement that case mix must be considered when assigning caseloads and determining reimbursement rates.

Models for Rural HIV Service Delivery

Conference speakers presented three models for delivering health and support services to rural residents with HIV disease. The key features of these models are described below.

Urban Outreach Model

Urban outreach models extend the services of an urban-based HIV clinic to rural residents through regional satellite clinics. Dr. Christopher Grace, Director, Infectious Diseases, Fletcher Allen Health Care, described how the University of Vermont developed hospital-based HIV specialty clinics in three regions of the State.

Background

Vermont has 590,883 residents, two-thirds of whom live in small towns. The State's population density is 61.5 people per square mile, as compared to a U.S. average of 75.7 people per square mile. The Green Mountains bisect the State north to south, and Interstate I-89 runs east to west, roughly dividing the State into four quadrants. Two major medical centers—Fletcher Allen Health Care (Burlington, VT) and Dartmouth-Hitchcock Medical Center (Hanover, NH)—provide tertiary care.

Fletcher Allen Health Care opened a Comprehensive Care Clinic for HIV-positive patients in 1987. Because this clinic was the only source of specialty HIV care, many people had to travel two to three hours for medical appointments. In 1993, Fletcher Allen Health Care conducted surveys of HIV-positive patients, local hospitals, and primary care physicians to assess the level of support for regional HIV clinics. The survey revealed that patients wanted to receive care

closer to home, and that local hospitals were willing to provide space and ancillary support. Dr. Grace described physicians' reaction as follows:

Fifty percent of the primary care physicians said, "Yes, this is a great idea. Go ahead and do it." The other 50 percent said, "No, we don't need it. We don't have HIV in the State." So, we took that as a positive response and plowed ahead.

In 1994, Fletcher Allen Health Care received funding through the Special Projects of National Significance (SPNS) Program to establish three regional HIV specialty clinics.¹⁰ The planning team established five principles for clinic development:

- 1) HIV/AIDS patients should receive care in their own geographic regions.
- 2) HIV specialists should provide the medical care.
- 3) HIV specialists should collaborate with local primary care physicians.
- 4) Strong patient-provider relationships should be cultivated.
- 5) There should be a team approach to providing comprehensive care.

Since the Comprehensive Care Clinic was serving HIV-positive residents in the Burlington area, the planning team decided to locate the new clinics in the remaining three regions of the State. By negotiating with the largest hospital in each region, they were able to obtain space for the clinics and assistance with appointment scheduling, medical record keeping, billing, and laboratory and radiology services. Two of the three hospitals offered space in multidisciplinary clinics, which allowed HIV/AIDS patients to "blend in" with other outpatients.

Between 1994 and 1996, Fletcher Allen Health Care opened regional clinics in Rutland, Brattleboro (in collaboration with Dartmouth-Hitchcock Medical Center), and St. Johnsbury. The planning team spent 6-12 months per hospital, negotiating space and ancillary services, developing clinic operating procedures, and training hospital staff on the importance of maintaining patient confidentiality. Some clinics required minor renovations. For example, Rutland Regional Medical Center made space available in its cancer clinic. Because this clinic was located directly across from the cafeteria, the clear glass window had to be replaced with frosted glass.

When negotiating with each host hospital, planning team members met with the medical staff to discuss the HIV specialty clinic's services and relationships with local physicians. Local physicians requested that all HIV specialists seek hospital privileges. They also wanted assurance that the HIV specialists would not "steal their patients" or burden them with excessive numbers of HIV-positive patients. Dr. Grace recapped the discussions as follows:

We said, "If you want to be involved and collaborate in this care, we are there. On the other hand, if you don't want anything to do with this, we'll disappear in the background and take care of the patients."

Planning team members also held numerous meetings with AIDS service organizations, HIV/AIDS advocacy groups, and HIV-positive residents to solicit their ideas and involvement.

Clinic Staffing and Services

The regional HIV specialty clinics currently are supported by a Title III (CARE Act) grant. Each clinic has two part-time staff: a nurse practitioner and a social worker. HIV specialists from Fletcher Allen Health Care make monthly visits to each clinic to see new and scheduled follow-up patients. The nurse practitioners see walk-in patients, schedule CAT scans and laboratory tests, monitor patients' responses to antiretroviral therapies, and provide counseling and adherence education. Patients can access them by beeper when the clinics are not open.

Finding qualified nurse practitioners in rural areas proved to be a major challenge. All nurse practitioners and social workers trained for three months at the Comprehensive Care Clinic. Ongoing HIV/AIDS training is provided through attendance at national meetings.

The HIV specialty clinics offer a complete continuum of medical care, including laboratory assessments, immunizations and vaccinations, prophylaxis and management of opportunistic infections, antiretroviral therapy, and education on transmission risk reduction. A half-time nutritionist travels to all clinics to screen patients for nutritional risks and develop dietary interventions. Additional services include benefits advocacy, counseling and support for patients and their families, and referrals to AIDS service organizations. Patients also can be referred for mental health and substance abuse counseling; however, referral resources are very limited.

Thus far, only a few local physicians have expressed interest in learning about HIV management. These physicians are encouraged to participate in “mini-sabbaticals” at the clinics and to collaborate in patient care. When patients are admitted to local hospitals, the nurse practitioners work with the attending physicians to ensure that patients receive appropriate care. “Our collaborations with local physicians range from excellent to horrible,” Dr. Grace said. “The interchange of progress notes basically is one directional—from us to them. We never get any notes back.”

Utilization Trends

Since 1994, the Comprehensive Care Clinic and its three regional clinics have served 428 patients. The number of patients receiving services has increased by approximately 8 percent each year. People of color account for only 1.6 percent of Vermont’s population but 12 percent of the patients receiving care at the HIV specialty clinics. Although the percentages of patients infected through male-to-male sexual contact (~50 percent) and injection drug use (20-22 percent) have remained fairly steady over time, the percentage of patients infected through heterosexual contact has increased from 15 percent to more than 20 percent. At the Comprehensive Care Clinic in Burlington, almost one-third of the HIV/AIDS patients are coinfecting with hepatitis C, and 6 percent are tri-infected with hepatitis B and C.

Quality and Outcomes Assessment

A part-time data manager tracks quality and outcomes indicators for the HIV specialty clinics. Patients give written informed consent for data collection at the time of enrollment. Clinic staff then administer a questionnaire, containing questions on patient demographics, health insurance coverage, employment status, HIV exposure mode, stage of disease, migration history after HIV diagnosis, medications, and perceived barriers to community services. Each quarter, clinic staff administer follow-up questionnaires, inquiring about medications, CD4 cell counts and viral loads, tuberculin status, receipt of gynecologic care (if applicable), number of emergency room visits and hospitalizations, and changes in financial situation. To protect patient confidentiality, unique identification numbers are used for data entry and analysis.

As evidence of the HIV specialty clinics’ effectiveness, Dr. Grace cited the following improvements:

- Among patients on antiretroviral therapy for any period of time, the average decrease in viral load was 0.90 logs. The proportion of patients with undetectable viral loads (HIV-1 RNA < 50 copies/ml) increased from 15 percent to 28 percent.
- Over a 46-month period, the average increase in CD4 cell count was about 60.
- Ninety percent of patients with CD4 cell counts less than 200 cells/mm³ received prophylaxis for *Pneumocystis carinii* pneumonia (PCP). Seventy-five percent of patients with CD4 cell counts less than 50 cells/mm³ received prophylaxis for *Mycobacterium avium* complex (MAC).
- Before the regional clinics were established, most people traveled at least 2 hours to receive HIV primary care. Now, 90 percent of clinic patients travel less than 1 hour and about one-half travel less than 30 minutes.

Limitations of the Urban Outreach Model

Conference participants identified four additional institutions that operate rural HIV satellite clinics: Albany Medical Center (NY), Clarion University (PA), Dartmouth-Hitchcock Medical Center (NH), and University of Pittsburgh (PA). Four limitations of this model were discussed:

- Rural satellite clinics are expensive to operate because of the intensive services provided by nurse practitioners and social workers and the time that HIV specialists spend driving to the clinic sites.
- Satellite clinics located more than two hours from an urban center and serving small numbers of geographically dispersed patients are not cost effective.
- Finding skilled nurse practitioners and/or physician assistants to coordinate patient care when the HIV specialists are not on site can be very difficult.
- HIV specialists are not readily available when patients experience health emergencies that require hospitalization. Local physicians may not be willing or prepared to provide care in these situations.

Community-Based Physician Networks

To make HIV care more accessible to rural residents, some States, HIV care consortia,¹¹ and AIDS service organizations have developed local networks of physicians with HIV management experience. Dr. Bruce Williams, Medical Director for the Partners in Care Program, University Hospital, University of New Mexico Health Sciences Center, described two statewide networks.

Background

New Mexico has 1,739,884 residents and a population density of 14.3 people per square mile. Like Vermont, this State has many mountainous areas. The Rio Grande Valley bisects the State north to south. New Mexico has a centralized health department system and four public health districts. University Hospital in Albuquerque is the State's largest medical center.

■ Partners in Care Network

In 1991, University Hospital obtained a Title III (CARE Act) grant to develop a statewide "Partners in Care" network of physicians, laboratories, and pharmacies. A statewide needs assessment revealed that many rural residents were not receiving adequate HIV care because of their geographic distance from urban centers. To strengthen the HIV management skills of rural clinicians, Partners in Care staff worked with the New Mexico AIDS Education and Training Center to design continuing medical education programs and to create a New Mexico AIDS InfoNet web site (www.aidsinonet.org). This web site contains one-page fact sheets on a wide variety of HIV prevention and care topics. Physicians also can call a toll-free Physician Access Line Service (PALS) 24 hours a day, 7 days a week for case consultations and information on clinical trials. All participating physicians receive a new edition of *Medical Management of HIV Infection*¹² each year and informational newsletters three times a year.

Most physicians in the Partners in Care network are family practitioners. Infectious disease specialists and a 0.2 FTE psychiatrist are available at University Hospital. Participating physicians are reimbursed on a fee-for-service basis, using a modified Medicaid reimbursement rate. The program also pays for specialist visits and for some medications and laboratory procedures.

Quality Assurance Procedures

Partners in Care has adopted a modified version of the U.S. Department of Health and Human Services' HIV treatment guidelines as standards of care for the physician network. Dr. Williams and a nurse visit each site at least once a year to review medical charts for compliance with quality-of-care indicators. Charts with deficiencies are flagged for discussion. Dr. Williams described the exit interview as follows:

The exit interview really turns into an on-site continuing medical education activity. We use that learning moment to identify issues that are relevant to that practice. We review the charts and spontaneously design a CME that focuses on the issues that have been identified. . . . We put the nurses and docs in the same room. We tried doing it separately, and they always wanted to talk to the other person. When we put them together, we found that they really had not been good at communicating and really understanding each other's issues.

Following the site visit, the clinic/practice receives a performance score with specific recommendations for improvement. A Medical Advisory Board, composed of all contracted providers, reviews the composite scores annually. These reviews indicate that most physicians are adhering to the standards, regardless of medical specialty, the number of HIV-positive patients treated, or geographic location.

■ Health Management Alliances

In addition to Partners in Care, New Mexico has a statewide network of health management alliances (HMAs) that provide health and support services to people with HIV disease. Before the alliances existed, the New Mexico Department of Health used Title II (CARE Act) and State funds to contract with many different clinics and community-based organizations for HIV-related services. Because there was no unified planning or supervision, health and support services varied in quality and were sometimes inaccessible to rural residents.

In 1997, the New Mexico Department of Health issued a Request for Proposal (RFP), inviting each public health district to submit a proposal for a health management alliance that would aggregate services previously funded under separate contracts. The RFP required each health management alliance to designate a lead agency to serve as the single point of entry for all health and support services offered by network providers. The lead agencies include the University of New Mexico and New Mexico AIDS Services (Northwest New Mexico), the Southwest Care Center (Northeast New Mexico), the T.A. Ferrell Clinic (Southwest New Mexico), and the Pecos Valley HIV/AIDS Resource Center (Southeast New Mexico).

Each health management alliance receives a capitated payment to provide a comprehensive array of medical, behavioral health, and support services. Payments range from \$352 to \$380 per patient per month and are renegotiated annually. These rates do not include revenues that service providers may receive from Medicaid, Title III of the CARE Act, county indigent funds, and

other sources. HIV prevention services and medications are funded through separate Federal and State programs.

Limitations of the Dual Networks

Dr. Williams said that the coexisting HIV care networks have created a number of problems:

- Although the services offered by the health management alliances and Partners in Care often intersect, they are not well coordinated. Quarterly meetings of Title II and Title III (CARE Act) representatives and cross-title conferences have not resolved this problem.
- The networks have different reimbursement systems (i.e., fee-for-service vs. capitated rates).
- The networks do not have a unified management information system that can be used to analyze where HIV-positive individuals are receiving services, their levels of service use, and clinical outcomes.
- An HIV Early Intervention Program established by the New Mexico Department of Health in 1991 has not been integrated into either network. This program places one registered nurse with specialized HIV/AIDS training in each public health district. HIV counseling and testing sites refer newly diagnosed individuals to these nurses for an initial health evaluation, immunizations, and information on available resources.

The New Mexico Department of Health, health management alliances, and Partners in Care currently are discussing ways of addressing these problems. A major priority will be to integrate all CARE Act and State funds at the regional level by having each health management alliance apply for its own Title III grant. The Department of Health and the New Mexico AIDS Education and Training Center will provide statewide continuing medical education. A new centralized management information system is being implemented in HMA #1 (Albuquerque) and will be expanded to other regions as funding becomes available.

As the health management alliances assume increasing responsibility for HIV services in their regions, it is unclear who will be responsible for statewide needs assessment, service planning, and quality management. Dr. Williams said that some mechanism must be developed for ensuring uniform quality of care:

The Achilles heel of the network model is that you have extraordinary variability in the quality of care and relatively less control over service delivery. Monitoring

quality of care over a large area can be a significant challenge. You have to somehow build into your system a way of regularly monitoring and providing feedback in a constructive and non-threatening way.

Dr. Williams also stressed the need to evaluate the costs and outcomes of services provided under the alliance structures. “Consumers will need to be part of this process,” he said. “Each HMA has a consumer advisory board, but are the members representative?”

Shared Care Model

Shared care models involve an HIV specialist and a primary care physician in co-managing patient care. In contrast to the urban outreach model, where participation by primary care physicians is optional, the shared care model *requires* joint management. Most often, the specialist manages HIV care while the primary care physician sees the patient for non-HIV-related medical problems. However, the primary care physician may monitor the HIV treatment regimen prescribed by a specialist or manage all aspects of HIV care with consultation from a specialist. Two shared care models presented by conference speakers are described below.

■ Community-Based Wellness Centers

Dr. Ted Holloway, District Health Director for the Southeast Health Unit (Waycross, GA), described how his public health district developed “wellness centers” for HIV-positive residents and involved local physicians in co-managing their care.

Background

The Southeast Health District encompasses 16 counties in Southeast Georgia. The counties range in size from 6,000 to 42,000 residents, with an average population density of 33.3 people per square mile. The health district is the poorest in Georgia, with 50 percent of African American children and 26 percent of white children living below Federal poverty level. Thirteen hospitals serve area residents, some of which have average daily censuses of only two to three patients. The nearest infectious disease clinic is located 180 miles from Waycross at the Medical College of Georgia.

The Southeast Health District began seeing HIV-positive patients early in the epidemic. At first, the health district assigned nurse practitioners from its family planning, maternal health, and

chronic disease programs to provide HIV care. They soon discovered that HIV-positive patients did not want to come to the health departments because they feared friends or relatives would see them. In 1987, the health district opened its first HIV wellness center in a rented house in Waycross. A SPNS (CARE Act) grant, awarded in 1991, enabled the health district to open additional wellness centers in Douglas, Jessup, Statesboro, and Vidalia. These centers currently receive funding from Titles II and III of the CARE Act. Local hospitals contribute about \$250,000 from their Medicare disproportionate share payments.

Clinic Staffing and Services

A family practitioner with extensive HIV care experience provides medical direction for the network. This physician is based at the Jessup wellness center, and each of the remaining wellness centers has a full-time nurse practitioner and a clerical worker. Three case managers with registered nurse or social work degrees serve all of the centers.

Each week, the medical director visits one wellness center to see new and scheduled follow-up patients. She prescribes antiretroviral and prophylactic regimens, and the nurse practitioners manage the patients on a day-to-day basis. Each nurse practitioner provides medical case management for 60 to 90 patients.

The wellness centers provide all clinical and laboratory services needed for HIV management. All female patients receive semiannual Pap smears. At one center, a nurse practitioner with specialized training routinely uses a colposcope when performing Pap smears. The remaining centers provide Pap smears with referrals to a district colposcopy clinic as necessary. By paying local dentists their "usual going rate," the district has built a roster of 22 dentists who will serve HIV-positive patients. Patients needing nutritional counseling or social work assistance are referred to county health departments. Patients also can be referred to local mental health and substance abuse programs; however, these programs have long waiting lists.

Four of the five wellness centers are co-located with an AIDS service organization. Although the AIDS service organizations do not exclusively serve wellness center patients, their proximity makes case management, emergency financial assistance, transportation assistance, and other support services easy to access. Two of the AIDS service organizations have developed "buddy

systems” to help clients remember to take their medications. All receive Title II (CARE Act) funding and free rent and utilities. “Our goal is to get the ASOs to completely take over social services,” Dr. Holloway said. “So far, we’ve funded them with kind of a bell-shaped curve of success.”

Shared Care Arrangements

The Southeast Health District requires all wellness center patients to have primary care physicians. Patients without a regular physician are referred to local physicians on a rotating basis. Dr. Holloway described his initial contacts with local physicians as follows:

We told them, “If you will care for the patients when they have broken arms or help them manage hypertension or diabetes, we will manage the HIV medications and complications.” A lot of physicians were kind of drowning with two or three patients, not knowing what to do with them, so they were very relieved.

When the Medical College of Georgia received a grant to pilot-test a telemedicine network, the Southeast Health District applied to be one of the demonstration sites. Health district staff use the telemedicine hookup to seek consultation on a variety of diseases and medical conditions. Monthly HIV clinics enable patients with unusual conditions to be examined by infectious disease specialists without traveling 180 miles to Augusta. Sessions also can be videotaped for viewing by local physicians. Specialists at the Medical College of Georgia bill Medicaid for their consultation time. Because the Southeast Health District uses nurses rather than physicians to make clinical presentations, they are unable to claim Medicaid reimbursement. Their major expense is \$24,000 per year for use of the T-1 telephone line.

Clinic Utilization Trends

The wellness centers currently are serving 378 patients. Sixty-three percent of these patients are African American — a proportion almost 2-1/2 times higher than their proportion of the district population (26 percent). Almost one-half of the African American patients are female. As patient enrollments continue to grow, the wellness centers are seeing increasing numbers of young adults, patients with substance abuse problems, and patients coinfecting with tuberculosis or hepatitis C. “We’re not sure what to do about hepatitis C,” Dr. Holloway said. “There are no

ID docs and only two gastroenterologists practicing in the area. Getting liver biopsies is a problem, and then what do you do after you get the information?”

■ Duke/SRAHEC HIV Specialty Clinic

Bengie Hair, HIV Program Manager for Roper Hospital/CareAlliance, described an HIV specialty clinic in Fayetteville, North Carolina that was jointly developed by Duke University Medical Center (Duke UMC), the Southern Regional Area Health Education Center (SRAHEC),¹³ Cape Fear Valley Medical Center, two regional HIV care consortia, and local physicians.

Background

The Duke/SRAHEC HIV Specialty Clinic serves 12 counties in South Central North Carolina. With the exception of Cumberland County (250,000 population), most of the counties are rural. Cape Fear Valley Medical Center in Fayetteville is the area's largest hospital. Before the clinic opened, this medical center did not have an infectious disease specialist. As a result, many HIV-positive individuals traveled 2-1/2 to 3-1/2 hours to receive medical care at Duke UMC or the University of North Carolina (UNC) Hospital System.

In late 1996 and early 1997, the two HIV care consortia and a regional HIV planning team surveyed health and social service agencies and clients of HIV case managers to identify unmet service needs. Primary medical care and housing emerged as the most critical needs. Early the following year, a SRAHEC physician contacted Mr. Hair about developing an HIV clinical care plan. Together, they formed an HIV clinic planning team.

For eight months, the HIV clinic planning team held regular meetings to “keep everyone in the loop.” SRAHEC offered space for the clinic and Duke UMC agreed to provide infectious disease specialists. Cape Fear Valley Medical Center offered to provide HIV case managers and to perform laboratory services at the Medicaid rate. The two HIV care consortia committed Title II (CARE Act) funding, and the fiscal agent for one of the consortia agreed to handle financial and programmatic reporting for the clinic. “We constantly looked at opportunities for failure,” Mr. Hair recalled. “Every time we ran across one of those problems in our planning session, we worked right then to come to some resolution.”

One of the planning team's first tasks was to estimate patient enrollment. The regional survey had shown that, although 75 percent of respondents were receiving HIV care 2-1/2 hours away from home, most were willing to seek confidential care in their own communities. Using these percentages as a guide, the planning team estimated that 150 to 200 people would seek clinic services and that, with available resources, the clinic could enroll 25 new patients each quarter.

To determine the cost of clinic visits, the planning team reviewed the records of more than 240 HIV-positive individuals who had received case management. These records contained information on the frequency of medical visits and the amounts expended for medications and laboratory services. By comparing these service utilization data with Medicaid reimbursement rates for new versus returning patients and for differing levels of visits (1-4), team members were able to calculate a "bundled service rate" per visit.

Additional planning activities focused on patient enrollment and wait list procedures. Although the planning team anticipated that case managers would refer most patients, they also wanted to allow for self-referral. The HIV Care Program at Cape Fear Valley Medical Center volunteered to serve as the central point of contact. It was agreed that this program would log in all referrals and forward them to the nurse manager at the Duke/SRAHEC HIV Specialty Clinic for appointment scheduling. In wait list situations, two types of patients would have priority: (1) patients enrolled at Duke UMC or the UNC Hospital System whose advanced disease status made it difficult to travel and (2) patients referred by the high-risk maternity clinic at Cape Fear Valley Medical Center. If no priority patients were waiting, the first person on the waiting list would be enrolled.

Recalling a 10-month period during which the North Carolina HIV Medications Assistance Program shut down due to a budget shortfall, the planning team sought Title II (CARE Act) support for an emergency HIV medications fund. Transportation needs also had to be addressed. Mr. Hair said the group began by mapping transportation routes:

We pulled out a map and looked at where the roads ran. About this time, the NAACP announced plans to get involved with AIDS issues. One of our local ministers was a very active NAACP member, so I went to him and said, "You know, the HIV specialty clinic is part of your organization's initiative. I need

your help. You've got four church vans sitting here during the week not being used and the clinic needs them."

In addition to contracting for the church vans, the planning team "piggybacked" on an existing hospital contract with local taxi companies to obtain their services at a discounted rate.

Clinic Staffing and Services

The Duke/SRAHEC HIV Specialty Clinic opened in September 1998. The operating hours are 8:00 a.m. to 4:00 p.m. every Friday and every other Thursday. At least two slots at each clinic are saved for walk-in patients.

When the clinic first opened, one Duke UMC infectious disease specialist traveled to Fayetteville to see patients. The current medical staff includes two Duke UMC infectious disease specialists, a family nurse practitioner, and a physician assistant. A nurse and a case manager also are assigned to each clinic. Mr. Hair said that the nurse practitioner and the physician assistant work "side-by-side" with the infectious disease specialists:

The mid-level practitioners trained at the Duke UMC infectious diseases clinic. They are familiar with HIV disease issues, and they are as effective as the ID physicians in assessing clinical needs and providing care. By running a mid-level practitioner parallel to the physician, the clinic can see more patients. If they run into a problem, the ID physician is right there to help them.

The clinic has established a patient flow pattern that seems to be working well. Patients first meet with an HIV case manager to discuss their service and resource needs. After the nurse manager checks their vital signs, they see a physician or mid-level practitioner. Nutritional and pastoral counseling are available upon request. Before leaving, they meet with the case manager to make arrangements for medications and laboratory tests ordered by the physician.

Patients with mental health and/or substance abuse problems are referred to an HIV Intensive Outpatient Program (IOP) that integrates behavioral health services with primary medical care. The Duke University Center for Health Policy, Law, and Management received grant support from SPNS and five other Federal programs to develop the IOP in cooperation with the Cumberland County Mental Health Center and the two HIV care consortia. HIV case managers with cross-training in mental health and substance abuse case management make frequent

outreach visits to promote treatment adherence. IOP counselors attend the monthly meetings of the HIV case managers to strengthen referral relationships and team approaches to patient care.

Shared Care Arrangements

All clinic patients are expected to have a primary care physician who will see them for routine illnesses and after-hour emergencies. To encourage the involvement of local physicians, Duke UMC infectious disease specialists made one-on-one contacts with physicians whom the 1996-97 survey had identified as already serving, or willing to serve, HIV-positive patients. Primary care physicians who agreed to co-manage clinic patients received copies of "care maps" developed by infectious disease specialists at Duke UMC, East Carolina University Medical Center, and UNC Hospital Systems as part of a SPNS-funded project. These clinical care guidelines are posted on the Duke University Center for Health Policy, Law, and Management web site (<http://ncsip01.duke.edu>).

SRAHEC provides continuing medical education on HIV-related topics for local physicians. For example, SRAHEC has partnered with Duke UMC physicians and pharmaceutical companies to sponsor tutorial sessions on HIV and pregnancy for local obstetrician-gynecologists. SRAHEC also publishes a quarterly program outline that provides the medical community with periodic updates on the HIV specialty clinic and its linkages with local physicians.

Clinic Utilization Trends

Between September 1998 and August 2000, the Duke/SRAHEC HIV Specialty Clinic served 153 patients. Mr. Hair said that the clinic has had a waiting list since its inception:

We created the clinic and we were inundated with referrals. These were not people currently enrolled at UNC Hospitals or Duke UMC; these were people who had not sought care. Case managers throughout the region started identifying people who previously had been in care, dropped out, and now were willing to come back.

Most patients begin receiving clinic services within three months of application. While waiting to be enrolled, patients are referred to local physicians.

In January 2001, infectious disease specialists from UNC Hospital System plan to open an HIV specialty clinic at the Robeson County Health Department. This new clinic will assume responsibility for five counties in the Duke/SRAHEC Clinic's current service area. The two clinics have agreed to offer similar services and to collaborate on patient issues.

Quality and Outcomes Assessment

To assess the quality and outcomes of clinic services, the nurse manager is documenting two-year clinical progression for about 60 patients. Data are entered on a standardized form, using unique patient identification numbers. The first section of the form documents the original HIV test date, site, and reason for being tested; the original TB skin test date, results, and follow-up; the results of initial laboratory tests; and the length of time that the patient waited for a medical appointment after being referred by the central intake site. The second section contains quarterly entries on diagnostic and screening tests; vaccinations and opportunistic infection chemoprophylaxis; HIV and non-HIV medications prescribed; CD4 cell counts, viral loads, and other laboratory test results; opportunistic infections; emergency room visits for HIV- and non-HIV-related complications; and hospitalizations for HIV and non-HIV-related complications. Service costs also are being documented.

Mr. Hair distributed a summary sheet for 28 patients showing significant improvements in CD4 cell counts and viral loads. During the 1999-2000 program year, the clinic achieved a 92.8 percent attendance rate and greatly reduced the number of emergency room visits. Between April and June 2000, the average cost per patient was \$191.88.¹⁴ During the following quarter (July – September 2000), the average cost per patient was \$230.06. Before the clinic opened, many patients traveled 2-1/2 to 3-1/2 hours to receive HIV care. Now, the longest travel time is 45 minutes.

Limitations of the Shared Care Model

Conference speakers and participants identified two limitations of the shared care model. First, this model requires a strong working relationship between the HIV specialist and the primary care physician that may take considerable time to develop. Dr. Williams commented:

It takes awhile to build mutual trust and communication. The more you interact with your local partners, the more comfortable they are going to feel with what

you say, and the more comfortable you are going to feel with what they're telling you.

Second, when local physicians co-manage patients with urban-based HIV specialists, much of the communication has to occur by telephone. This method of communication increases the complexity of medical decision making. An HIV specialist explained: "Diagnosing medical problems from a two-minute presentation, where you can't talk to the patient, is extremely difficult. You tend to over-treat." Another physician remarked: "It's like trying to see the case through a mask." The lack of reimbursement for telephone consultations was cited as an additional problem. "We get three or four requests for telephone consultations on general ID problems each day," said one specialist. "Since our hospital doesn't have a system to recognize that work, it's just *gratis*."

Hybrid Model

Workgroup #1 suggested that rural areas with small and dispersed HIV populations might be best served by a hybrid model, combining features of the urban outreach, physician network, and shared care models. Under this model, trained local primary care clinicians would provide most HIV care. In addition to receiving continuing education on HIV management, they would meet periodically by teleconference to discuss specific cases. Circuit-riding HIV specialists would visit the rural areas two to three times a year to see patients and provide consultation on difficult cases. The rest of the time, they would be available for telephone consultations.

Sally-Lou Patterson, Director, HIV/STD Programs, Maine Bureau of Health, and Bonnie Post, Executive Director, Maine Ambulatory Care Coalition, described a physician network in Maine that has many of these features. Ms. Patterson said the network includes a mix of private physicians and community health centers:

These are groups of clinicians around the State that, for a variety of reasons, are very well connected. . . . They are like a little club of ID's with a couple of family practice docs mixed in.

The Maine Medical Center operates an AIDS Consultation Service staffed by an infectious disease specialist, a nurse practitioner, and a family practice resident. This team provides

statewide telephone consultations and periodically visits rural areas to see patients being co-managed by local physicians.

HIV Training and Quality Assurance Models

A major theme emerging from the conference was the need for educational models that develop rural clinicians' capacity to provide HIV primary care. Workgroup #1 recommended the development of a continuum of HIV professional education to accommodate varying levels of interest and expertise. A physician summed up their views as follows:

All primary care physicians should be doing aggressive screening and risk assessment. If they have patients with HIV infection, they should know the first steps to take in terms of immunizations, medical care, and prophylaxis based on T-cell counts. It should be a graded educational process based on what the primary care doc wants to know.

Workgroup participants also recommended greater consumer involvement in assessing clinicians' HIV training needs. "From the patient perspective, an important measure of the quality of care is the physician's ability to communicate about new medicines and their side effects," one consumer explained. "We need to do a better job of teaching physicians how to incorporate patient education into medical visits."

Workgroup #1 identified four principles for developing and delivering HIV professional education programs in rural areas:

- 1) ***Provider training models should be responsive to variations in rural health care delivery systems and resources.*** For example, the roles and responsibilities of non-physicians, such as nurse practitioners and case managers, may vary greatly from one rural area to another.
- 2) ***Provider training models should be "time effective."*** Since many rural clinicians do not have the time or back-up support to travel to urban centers, training should be provided on-site or through teleconferences whenever possible. Audiotapes and videotapes also should be considered as training modalities.
- 3) ***The content of training programs should be case-specific.*** A workgroup participant explained: "Rural clinicians in small busy practices want information they can use. They don't have time to learn about something they can't put into effect right away because they don't have any patients with that condition."

- 4) *Training should be provided at little or no cost.* Most rural clinicians have very little funding for continuing education.

Provider Training Models

Dr. Laura Cheever, Chief, HIV Education Branch, HRSA HIV/AIDS Bureau, presented national and regional models for educating rural clinicians about the medical management of HIV infection. The key features of these models are described below.

National Training Models

HIV Telephone Consultation Service

The National AIDS Education and Training Center (AETC) Program has sponsored an HIV Telephone Consultation Service since 1991. By calling a toll-free number (1-800-933-3413) between 7:30 a.m. and 5:00 p.m. PST, clinicians can get consultation questions answered by a multidisciplinary team of HIV experts. They also can obtain information on HIV medications, infection control, clinical trials, and sources of specialty care for their HIV-positive patients.

Between September 1991 and March 1999, the HIV Telephone Consultation Service received 23,368 inquiries. Most callers were family practitioners (49 percent) or general internists (24 percent), and almost one-third were caring for three or fewer patients at the time of the call. Thirty-two percent described themselves as practicing in a rural setting. The Southeast had the highest proportion of rural callers (65 percent), and the Northeast had the lowest proportion (25 percent).

As a training tool, the HIV Telephone Consultation Service has three advantages:

- 1) Questions can be answered quickly during the “educational moment” when the clinician really wants the information.
- 2) The consultation team is able to answer the larger questions behind specific questions.
- 3) The consultations have a direct impact on patient care.

The major disadvantages include the inability to provide longitudinal training and to build local networks of HIV care providers. Over the next two years, the telephone consultation line will be linked with regional AETCs to better address these needs.

Targeted Training for Low- and Medium-Volume HIV Care Providers

A new AETC initiative is targeting low- and medium-volume HIV care providers in small cities and rural areas. Continuing education programs for low-volume providers (i.e., ≤ 5 HIV-positive patients) offer instruction on taking sexual and drug use histories, providing HIV counseling and testing, and recognizing the signs and symptoms of HIV infection. These programs also offer guidance on when and why to refer patients for specialty care and provide basic information on antiretroviral treatments and perinatal HIV transmission. Continuing education programs for medium-volume providers (i.e., 6-10 HIV-positive patients) cover prophylaxis for opportunistic infections, antiretroviral treatment strategies, laboratory monitoring, symptom management, and drug interactions.

Regional Training Models

Rural Health Care Provider Training Project

The Mountain-Plains Regional AETC received a SPNS (CARE Act) grant to evaluate the relative effectiveness of three training modalities in increasing rural clinicians' HIV knowledge, skills, and willingness to care for HIV-positive patients. The training modalities included self-study (via the Internet or a booklet), audiovisual teleconferencing, and on-site training. Trainees included physicians, dentists, nurse practitioners, physician assistants, and nurses from rural areas of the Mountain and West North Central Census Divisions. In addition to analyzing changes in knowledge and skill levels, AETC staff evaluated the cost of each training modality and its impact on practice patterns in three areas:

- 1) Prevention services (i.e., risk assessment, risk reduction counseling, HIV counseling and testing);
- 2) Early intervention services (i.e., symptom recognition, HIV-related physical assessment, laboratory tests); and
- 3) Health promotion services (i.e., development of health maintenance and wellness strategies).

All training modalities significantly improved clinicians' HIV knowledge, self-reported HIV management skills, and willingness to care for HIV-positive patients. Clinicians assigned to the self-study group demonstrated the greatest increases in HIV knowledge and skills. The self-

study modality cost only \$25.51 per trainee, as compared to \$43.92 for on-site training and \$51.81 for teleconferences. Regardless of the method of instruction, trainees reported offering significantly more prevention, early intervention, and health promotion services than a comparison group that did not receive training.

The Mountain-Plains Regional AETC currently is developing self-study modules on dental care, perinatal HIV transmission, pharmaceutical issues, and HIV care in correctional institutions. Although the AETC posts all self-study modules on its web site (<http://www.uchsc.edu/sm/aids>), rural clinicians seem to prefer the print versions. "I'm not sure how effective the Internet will be for educating low-volume HIV providers," Dr. Cheever said. "Internet use is going to be somewhat complicated in rural areas where there are not good high-speed lines. Some of the direct PC and satellite linkages probably will solve this problem, but the Internet doesn't build peer networks."

HIV Early Intervention for Community Health Centers

The University of Mississippi Medical Center (UMMC) developed a computer-based distance learning program to strengthen the HIV management skills of rural clinicians. With funding from a SPNS (CARE Act) grant, UMMC installed personal computers and telecommunications equipment in ten community health centers. Small groups of physicians, dentists, and nurse practitioners from each center participated in 12 training sessions through this network. While viewing slides on the computer, they were able to interact with the lecturers and with one another. Participants also used the computers to access Internet web sites, conduct literature searches at the UMMC library, and seek clinical consultations via e-mail.

At the onset of the training project, rural residents accounted for about 60 percent of the HIV-positive patients receiving services at the UMMC infectious diseases clinic. To help community health centers develop HIV care capacity, the UMMC distance learning project included extensive technical assistance on how to plan a comprehensive HIV care clinic and apply for Title III (CARE Act) grant support. Three community health centers, encompassing six clinical sites, have received Title III grants since the project began. Feedback from other participating centers indicates that clinicians feel better prepared to manage HIV care locally.

Targeted Capacity Development

The Midwest AETC is using two approaches to build HIV care capacity in rural and medically underserved areas of Illinois, Indiana, Iowa, Minnesota, Missouri, and Wisconsin. The first approach targets clinics that provide relatively little HIV care, but that have the potential to become significant HIV care providers. AETC staff encourage these clinics to expand HIV services by offering to provide training, technical assistance, and clinical consultation. The second approach targets individual physicians who are willing to expand their HIV practices. These physicians participate in 40 hours of direct patient observation and guided reading and study over a one-year period. HIV specialists mentor the physicians and are available for ongoing patient referrals and clinical consultations.

Strategies for Ensuring High Quality HIV Care

Much of the dialogue on provider training focused on ways of promoting and monitoring high quality HIV care. Dr. Williams recommended on-site chart reviews with case-specific feedback:

You cannot set up a network of docs in rural areas and then just say, "Call me when you need me." That won't work. You have to actually go out there, review charts with them, and see patients with them if they are willing to do that.

As an additional strategy, Dr. Williams suggested that AETCs sponsor regional meetings to involve rural clinicians in developing uniform standards of HIV care.

Humberto Cruz, Director, Division of HIV Health Care, New York State Department of Health AIDS Institute, said that the AIDS Institute distributes a booklet ranking HIV service providers on five quality indicators. Service providers receive a 65-page booklet. Consumers receive a seven-page version with a chart that helps them identify the providers offering the "best service." The AIDS Institute currently is developing a "train the trainers" curriculum to teach consumers how to use the quality indicators to select HIV service providers. Some conference participants questioned whether HIV report cards might discourage rural clinicians from offering HIV care. A rural health professional explained: "When you're initiating HIV services in rural areas, you can't be that selective. HIV report cards could end up turning away providers who are impassioned about their work but don't yet have the technical skills."

Workgroup discussions revealed a critical need for standards and tools that can help rural HIV service providers assess the quality of case management and other support services. Mr. Hair said that case managers in eastern North Carolina developed a “care map” to improve the quality and consistency of their services. The care map includes sections on initial diagnosis/well physical health, initial diagnosis/ill physical health, maintenance, final care planning/end of life, adjunct issues/diagnoses, and HIV infection and pregnancy. Each section lists the client needs that should be assessed and possible interventions. Dr. Williams reported that New Mexico also is implementing uniform case management standards and procedures. Drawing upon these examples, Workgroup #2 proposed regional training institutes for case managers. They suggested that training focus on different levels of intervention (i.e., benefits advocacy vs. intensive case management), the core components of a care plan, and quality standards.

Workgroup #1 discussed ways of integrating client feedback into quality assurance systems. They identified two areas where technical assistance is critically needed:

- 1) What are the most effective ways of obtaining client feedback in rural areas where the stigma associated with HIV/AIDS is so strong that service users are afraid to come together in focus groups?
- 2) In rural areas with limited HIV service options, how can client satisfaction surveys be designed and administered to encourage honest feedback?

Building Rural HIV Care Capacity: Final Thoughts

Conference presentations highlighted the varying characteristics of rural environments that should be considered when planning HIV services. Some of the key factors affecting rural HIV service delivery include:

- Population size and density;
- Number and demographic characteristics of people living with HIV;
- Topography and climate;
- Proximity to an urban area;
- Health and social service infrastructure;

- HIV knowledge and experience of local clinicians;
- Travel patterns for health care;
- Public transportation options;
- Level of State involvement in developing and funding rural HIV services; and
- Level of community support for HIV initiatives.

Many of these factors are interrelated. For example, sparsely populated rural areas tend to have low HIV prevalence and limited health, social service, and transportation infrastructures. Low prevalence areas tend to have physicians with less HIV management experience and lower HIV testing rates. These conditions perpetuate the image of HIV/AIDS as an “urban disease” and make it difficult to generate State and community support for prevention and care initiatives.

Lessons Learned

Dr. Grace encouraged conference participants to design HIV service delivery systems that fit with their environments:

There is no *one* model that will fit everywhere. People can take little bits and pieces from each model and blend them together to create unique systems.

All speakers recommended that rural communities build HIV care capacity through existing resources and partnerships. “If you’re thinking about implementing an HIV care program, look at existing partnerships,” Mr. Hair advised. “There probably is a lot of energy in those relationships that you really have not drawn on.” Dr. Grace suggested creating a planning team of physicians, nurses, social workers, and clients to assess HIV service needs and to bring key issues to the table. “You have to go to people who have a vested interest and sell the programs by explaining how they will help,” he said.

Conference speakers identified hospitals as “major players” in developing and supporting rural HIV service delivery systems. They suggested several strategies for gaining their support:

- Emphasize the potential of the HIV outpatient clinic (or physician network) to reduce emergency room visits and hospitalizations. Follow up with actual data.

- If hospitals agree to provide financial and/or in-kind support, find ways to publicly recognize their contributions. For example, Vermont's regional HIV specialty clinics bear the names of the hospitals in which they are housed.
- Show how the HIV outpatient clinic (or physician network) can bring resources to local hospitals. For example, one of the infectious disease specialists at the Duke/SRAHEC HIV Specialty Clinic provides consultative services at Cape Fear Valley Medical Center one-half day each week.

As another "lesson learned," speakers emphasized the importance of long-range planning. "I wouldn't say you are going to accomplish anything in 1 year or even 5 years," Dr. Grace said. "I think you have to map out a plan that will go over a long time because there are going to be ups and downs." Other speakers noted that plans must be continuously reviewed and updated to accommodate changes in patient characteristics, demand for services, resource availability, and other environmental conditions.

Ongoing Challenges

Conference speakers and participants identified a number of challenges that rural areas must address to keep pace with the growing HIV epidemic. At the most basic level, rural areas need primary care physicians and mid-level practitioners who are trained to recognize the signs and symptoms of HIV infection and to co-manage patient care with HIV specialists. Linkages with urban-based specialists need to be strengthened through telemedicine, telephone consultations, and visits by specialists to rural sites. Rural areas also must find ways to expand dental care, home health care, and nursing home options for residents with HIV disease.

Like urban HIV clinics, rural medical care providers are seeing increasing numbers of HIV-positive patients with chemical dependencies and mental disorders. Additional funding is critically needed to expand behavioral health services and assistance with housing and other basic subsistence needs. Case managers need to be trained and appropriately reimbursed to provide the higher levels of support required by these individuals. Clinical guidance and resources also are needed to treat HIV-positive patients who are coinfecting with hepatitis C.

The extension of Medicaid managed care to rural areas presents an additional challenge.

Conference participants questioned how changing Medicaid policies and payment arrangements

will affect rural residents' access to experienced HIV service providers and clinically appropriate care. A physician commented:

There are two opposing movements in the medical system. One is to go faster and see more patients. The other is the growing complexity of HIV care and the parallel issue of bringing the patient into the discussion and assuming risk responsibility for clinical decisions.

There was general agreement that rural medical care providers will need to carefully track the costs and outcomes of HIV services in order to win managed care contracts and to negotiate fair capitation rates.

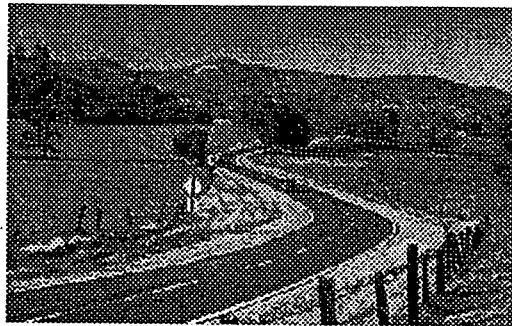
Conference discussions highlighted resources that are available to help rural areas develop HIV service capacity. For example, nonprofit organizations in rural and underserved areas have priority for Title III (CARE Act) HIV planning and capacity-building grants. Dr. Grace urged conference participants to seek creative ways of organizing and delivering HIV services. "The key to development of any model is going to be the passion and power that people bring to the system," he said. "Providing compassionate, state-of-the-art medical care to a diverse rural population is difficult, but it can be done."

Notes and References

1. Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Supplemental Report*, 2000; 6(no. 2): 1-16.
2. The States in each Census Region are as follows: *Northeast* (CT, MA, ME, NH, NJ*, NY, PA, RI, VT), *North Central* (IA, IL, IN, KS, MI, MN, MO, NE, ND, OH, SD, WI), *South* (AL, AR, DE, FL, GA, KY, LA, MD, MS, NC, OK, SC, TN, TX, VA, WV), and *West* (AZ, CA, CO, HI, ID, MT, NM, NV, OR, UT, WA, WY). *New Jersey does not have any nonmetropolitan areas.
3. Centers for Disease Control and Prevention. HIV/AIDS surveillance in urban-nonurban areas, L206 slide series (through 1999). Available at: <http://www.cdc.gov/hiv/graphics/rural-urban.htm> >. Accessed February 11, 2001.
4. Gallagher K. Recent trends in the rural AIDS epidemic. Presented at the Northeast Conference on Rural HIV Service Delivery, 2000 October 23; Burlington, VT.
5. Ormond BA, Wallin S, Goldenson SM. *Supporting the Rural Health Care Safety Net*. Washington, DC: The Urban Institute, 2000. Available at: <http://newfederalism.urban.org/html/op36/occa36.html>>. Accessed May 2, 2000.
6. University of Colorado Health Sciences Center. *Interdisciplinary Rural Team Training IRT Resource Manual, Module 2*. Aurora, CO: University of Colorado Health Sciences Center, 1997. Available at: <http://www.uchsc.edu/ahec/finaid/manual/mod2.htm>>. Accessed September 8, 2000.
7. Title III of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act awards competitive grants to community and migrant health centers, health departments, and other community-based clinics to provide "early intervention services" to medically underserved individuals with HIV disease. These services include outpatient primary health care, dental care, antiretroviral therapies, and support services such as case management and nutritional counseling.
8. Workgroup participants reported that many HIV-positive inmates in county jails are not receiving needed medications while incarcerated.
9. Title II of the Ryan White CARE Act awards formula funding to the 50 States, District of Columbia, Puerto Rico, and the U.S. Pacific territories and associated jurisdictions to improve the quality, availability, and organization of health and support services for people living with HIV disease. Most States use a portion of their base award to support AIDS Drug Assistance Programs (ADAPs) that provide medications to low-income individuals with HIV disease who have limited or no coverage from private insurance or Medicaid. States also receive earmarked Title II funds to support ADAPs.

10. The Special Projects of National Significance (SPNS) Program of the Ryan White CARE Act awards competitive grants for projects that demonstrate and evaluate innovative methods of reaching underserved populations and delivering HIV/AIDS care.
11. Most States use some Title II (CARE Act) funds to contract with “HIV care consortia” of public and nonprofit health and support service organizations to plan, develop, and deliver HIV services in designated localities or regions.
12. Bartlett JG, Gallant JE. *Medical Management of HIV Infection*. Baltimore, MD: Johns Hopkins AIDS Service, 2000. Copies can be downloaded from the Johns Hopkins AIDS Service web site (http://www.hopkins-aids.edu/publications/book/book_toc.html).
13. The Southern Regional Area Health Education Center (SRAHEC) is affiliated with Duke University Medical Center. SRAHEC provides community-based family medicine residencies, pediatric and adult specialty clinics, and continuing education for health professionals.
14. The costs include physician and mid-level practitioner time, nursing services, laboratory costs, medications, case management time, clerical support staff, facility charges, transcription services, and office supplies.

Appendix: Agenda



Northeast Conference on Rural HIV Service Delivery Sheraton Burlington Hotel

Monday, October 23rd

- 7:30 Registration/Continental Breakfast**
- 8:30 Welcome**
Lois Eldred, Dr.P.H., M.P.H.
Joseph O'Neill, M.D., M.P.H.
- 8:45 Targeting Rural Areas Through the Ryan White CARE Act**
The Honorable James Jeffords
- 9:00 Recent Trends in the Rural HIV/AIDS Epidemic**
Kathy Gallagher, D.Sc., M.P.H., Division of HIV/AIDS Prevention-Surveillance
and Epidemiology, Centers for Disease Control and Prevention
- 9:30 Questions/Discussion**
- 9:45 Break**
- 10:00 The Vermont Model – Regional HIV Specialty Clinics**
Christopher Grace, M.D., Fletcher Allen Health Care, Burlington, VT
- 11:00 Questions/Discussion**
- 11:15 HIV Training Models for Rural Clinicians**
Laura Cheever, M.D., HRSA/HAB Division of Training & Technical Assistance
- 12:00 Questions/Discussion**
- 12:15 Lunch (Group Event)**

- 1:15** **The Southeast Georgia Model – Community-Based Wellness Centers**
J. Ted Holloway, M.D., Southeast Health Unit, Waycross, GA
- 2:15** **Questions/Discussion**
- 2:30** **Break**
- 2:45** **The New Mexico Model – Health Management Alliances**
Bruce Williams, M.D., University Hospital/Partners in Care, Albuquerque, NM
- 3:45** **Questions/Discussion**
- 4:00** **The Fayetteville, North Carolina Model – Integrated Care Management Clinic**
Bengie Hair, Roper Hospital/CareAlliance, Charleston, SC
- 5:00** **Questions/Discussion**
- 5:15** **Free Time**
- 6:30** **Dinner and Guest Speaker**
Terje Anderson, National Association of People with AIDS
- 7:30** **Building Rural HIV Service Capacity**
Panelists: Cheever, Grace, Hair, Holloway, and Williams
Facilitator: Terje Anderson

Tuesday, October 24th

- 7:30** **Continental Breakfast**
- 8:15** **Remarks**
Jan Carney, M.D., M.P.H., Vermont Department of Health
- 8:30** **Workgroups**
- **Increasing Access to High Quality HIV Care in Rural Areas**
Facilitators: Christopher Grace, M.D., Bruce Williams, M.D., and Laura Cheever, M.D.
 - **Making Health and Support Services Accessible to Marginalized Rural Populations with HIV/AIDS**
Facilitators: Bengie Hair and J. Ted Holloway, M.D.
- 10:30** **Break**
- 10:45** **Reports from Workgroup Discussions**

11:45 **Conference Wrap-Up**
Christopher Grace, M.D.

12:00 **Adjourn**



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