Report of an Invitational Workshop held July 16 - 17, 1990

HIV Infection in Rural Areas: Issues in Prevention and Services

Sponsored by
Associate Administrator for AIDS
and
Office of Rural Health Policy

U.S. Department of Health & Human Services
Public Health Service
Health Resources & Services Administration

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Department of Health and Human Services
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April 1991

The views expressed in this report are those of the invited participants, and do not necessarily reflect the scientific priorities or recommendations of the workshop sponsors, other components within the Department of Health and Human Services, or the Federal employees attending the workshop.

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David Sundwall, M.D., workshop facilitator, made a significant contribution through his skillful focusing of participants' energies, and sharpening of the recommendations.

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Special appreciation goes to Peter Lee, consultant, for his development of the workshop guidance and his major role in the preparation of this report.

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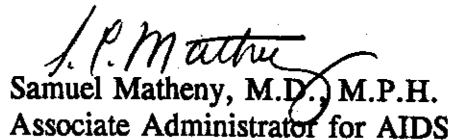

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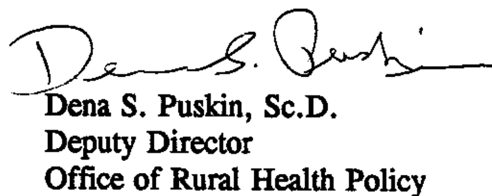

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The Honorable Louis W. Sullivan, M.D.
Secretary
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Hubert H. Humphrey Building
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Dear Dr. Sullivan:

I am pleased to forward to you the recommendations of a workshop on HIV and AIDS in rural America sponsored by the U.S. Public Health Service. I had the honor to facilitate and participate in this outstanding workshop which was attended by a remarkable group -- clinicians, providers, caregivers, state officials, persons living with HIV disease, and others from across the country with expertise in AIDS-related prevention, and health care and support services.

The recommendations focus on HIV infected individuals and their need for appropriate care in our nation's small communities. There is no question about the urgency of the epidemic. The Centers for Disease Control recently announced that over 100,000 Americans have died of AIDS, and that tens of thousands more will die of complications of HIV infection during each year of this decade. A tremendous increase in HIV infection in non-urban areas has been documented over the past few years and projections for the future indicate that rural America faces a very serious challenge, if not a crisis. Thousands of individuals with HIV infection, either residing in rural communities or returning to their home towns, will be seeking care and compassion.

Understandably, attention until recently has been primarily on cities with the highest incidence of infection or illness. But with the incidence of HIV infection increasing most rapidly in rural areas, which generally are unprepared for it, greater attention must be given to the problems of smaller communities. When people become seriously ill, from whatever cause, they often want to "go home," to be with loved ones and their families, in settings where they can be comfortable for the remaining months and years of their lives. This has an emotional logic that is widely understood. But without a concerted effort and fundamental changes, many individuals with HIV infection and AIDS will be denied this choice.

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Our workshop had two linked goals: 1) to assess the prevention and care needs resulting from the increase in HIV/AIDS in rural areas and 2) to suggest ways to improve the Federal response to HIV in the rural communities across America. The workshop recommendations reflect the need for expansion of rural HIV prevention activities; improved financing and delivery of health care to those in need; better information on the extent of the rural HIV epidemic; and increased HIV educational opportunities for rural health care professionals and caregivers.

We learned a great deal. We learned of hate and fear and prejudice and discrimination. And we learned also about extraordinary compassion, caring, affection, and sacrifice. Apparently the full range of human emotions and behavior is more evident in small towns, where there are fewer places in which feelings, attitudes, and actions can be hidden.

I would like to take this opportunity to thank you and the Public Health Service for sponsoring this timely and productive workshop. I, along with my fellow participants, hope that our report will provide useful guidance for Federal policy makers to improve the services available to address HIV/AIDS in rural America. Moreover, we hope our efforts will stimulate towns and regions across the country to conduct their own workshops, and develop their own culturally and socially appropriate ways of dealing with the HIV epidemic.

Sincerely yours,

David N. Sundwall, M.D.
Vice President and Medical Director

TABLE OF CONTENTS

PARTICIPANTS ii

FEDERAL RESOURCE PERSONS iv

WORKSHOP STAFF v

REPORT

I. WORKSHOP MEMBERSHIP, PURPOSE, AND PROCESS 1

II. THE CHALLENGES OF THE HIV EPIDEMIC IN RURAL AREAS 4

III. GUIDING PRINCIPLES AND ASSUMPTIONS 5

IV. RECOMMENDATIONS 7
A. INFORMATION NEEDS 7
B. PLANNING, COORDINATION AND RESOURCE ALLOCATION 10
C. TRAINING AND TECHNICAL ASSISTANCE 14
D. DISSEMINATION 17
E. FINANCING 18
F. OTHER 22

APPENDICES

I. Workshop Agenda

II. AIDS/HIV Recommendations of the National Advisory Committee on Rural Health

III. Map: Cumulative Number of AIDS Cases Reported in Non-Metropolitan Counties, to January 1, 1990, by State

IV. Development of Clinical Guidelines for the Diagnosis and Treatment of Persons with HIV Infection - Agency for Health Care Policy and Research

V. AIDS Education and Training Centers - Bureau of Health Professions

VI. National AIDS Information Clearinghouse -- Centers for Disease Control

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HIV INFECTION IN RURAL AREAS: ISSUES IN PREVENTION & SERVICES

I. WORKSHOP MEMBERSHIP, PURPOSE, AND PROCESS

The **Workshop on HIV Infection in Rural Areas** was convened on July 16 and 17, 1990, in Washington, D.C. The goals of the workshop were to assess the prevention and care needs resulting from the increase in HIV/AIDS in rural areas and to suggest ways to improve the Federal response to HIV in the rural communities across America. The 2-day meeting was jointly sponsored by the Associate Administrator for AIDS and the Office of Rural Health Policy, Health Resources and Services Administration (HRSA), United States Department of Health and Human Services.

The workshop's twenty-eight invited participants brought to the meeting a wide range of personal and professional experience directly relevant to rural health care delivery, clinical care, rural prevention efforts, social services, community-based supportive services, health care financing, medical education, living with HIV disease, and providing care to people with HIV disease. In addition, Federal employees currently working in agencies administering HIV-related programs served as resource people. Participants were charged to provide guidance to the Health Resources and Services Administration and, more broadly, to the U.S. Public Health Service on how to respond to HIV/AIDS in rural areas. They were asked to develop concrete recommendations, including proposals for Federal action, changes to existing policies, proposals for fostering partnership activities with states, and guidance for future Administrative or legislative activities.

Workshop participants were welcomed by Dr. O. Marie Henry, Deputy Surgeon General, and Dr. Robert Harmon, Administrator of the Health Resources and Services Administration. Plenary presentations in the opening session of the workshop provided participants with shared background information for their later deliberations. David McIntyre, legislative assistant to U.S. Senator John McCain, provided a overview of current Congressional HIV/AIDS related rural activities. Dr. Patricia Fleming of the Centers for Disease Control presented information on the epidemiology of HIV disease, and delineated the limit of knowledge about its prevalence in rural areas. Dr. Dena Puskin, Deputy Director of the Office of Rural Health Policy, provided an overview of the rural health care system and issues related to HIV disease. Personal perspectives on AIDS care in rural areas were presented by Mary Emily Rothgeb, mother of an AIDS patient, and Ron Jerrell, president of the National Association of People with AIDS.

The product of this workshop was largely developed by deliberations of all the participants in the work group sessions. The basic work plan of the work groups included identification of problems and development of recommendations in their respective issue areas. All workshop participants took part in one of the three work groups:

- Prevention and Education
- Finance and Systems of Care
- Service Delivery

The reports of the three work groups were brought to the full membership of the workshop for discussion and amendment. The two-day process was designed to elicit a representative range of opinions. While no formal consensus process was followed, the recommendations generally reflect the views of the "group as a whole."

Workshop participants hope these recommendations will provide useful guidance to the Department of Health and Human Services (DHHS) in its HIV/AIDS prevention and service efforts in rural areas. Some recommendations are addressed to particular DHHS agencies and/or programs; others are relevant to a range of agencies and to sectors outside of the Federal government. Recommendations made to multiple agencies incorporate principles that, in most cases, are also relevant to state and local health departments and private sector organizations responding to HIV disease.

Since the meeting of this workshop on July 16 and 17, 1990, the Ryan White Comprehensive AIDS Resources Emergency (C.A.R.E.) Act of 1990 has been enacted and incorporated as Title XXVI of the Public Health Service Act. The four Parts (A-D) of Title XXVI correspond to the C.A.R.E. Act's four titles (Titles I-IV).[1] This legislation includes a number of provisions which have preempted or necessitate reevaluation of some of the workshop's recommendations. In estimating the potential impact of Title XXVI on rural areas, it is necessary to recognize that the authorized FY 1991 funding level is $881 million while the FY91 appropriated funding for Title XXVI purposes was $347 million. As a result, a number of the Title XXVI provisions are not funded in FY 1991, including some which would provide rural programs.

A number of the Title XXVI provisions are for broad programs, some of which may include rural HIV prevention and service activities. In addition, some provisions bear directly on specific recommendations of the workshop. These include the following:

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[1] References to Parts A through D and *SEC.* numbers in this passage are to Title XXVI of the Public Health Service Act.

- *Collection of information about the extent, characteristics, and impact of HIV disease in rural areas.* Part D mandates the collection of this information, with the report due by one year after the date of enactment. Also the Agency for Health Care Policy and Research is mandated to prepare a summary report on the unmet needs in health care, mental health care, early intervention, and support services for individuals and families with HIV disease in urban and rural areas. *SEC. 2673(a)(4).* (See Recommendation 1.) Part D of Title XXVI did not receive an appropriation in FY 1991, and therefore these mandated studies will not be conducted this year. The outlook for future appropriation for these provisions is uncertain.
- *Participation of representatives of the communities affected by HIV on planning councils and in consortia.* States and consortia receiving Title XXVI funds must involve representatives of the communities affected by HIV in decisions on use of the grant funds and the delivery of services. For example, *SEC. 2602(b)(1)*, and *SEC. 2613(c)(1)(A)(ii).* (See Recommendations 4 and 8.)
- *Matching funds.* States that have more than one percent of reported AIDS cases are required to match Part B funds with State funds. *SEC. 2617(d).* (See Recommendation 6.)
- *Coordination of efforts.* There are financial incentives for public and private organizations to form consortia to target resources and coordinate their activities. *SEC. 2613 (b)(1)(C).* (See Recommendation 6.)
- *Consortia receiving Federal HIV/AIDS grant funds are to allocate these funds on the basis of needs assessments of their entire catchment areas.* A consortium applying for Federal HIV/AIDS funds must conduct a needs assessment of the entire geographic area to be served and allocate funds on the basis of the identified needs. *SEC. 2613(c)(1)(B).* (See Recommendation 7.)
- *Funding for continuation of private health insurance.* States may use Title XXVI funds to pay for the continuation of health insurance for low-income individuals with HIV disease. *SEC. 2615(a)(1).* Also, Title XXVI mandates a review of private sector financing mechanisms for the delivery of HIV-related health and support services and an assessment of strategies for maintaining private health benefits for individuals with HIV disease. *SEC. 2673(a)(2).* (See Recommendation 20.) There was no appropriation in FY 1991 for the conduct of this review, and future appropriations are uncertain.
- *Case management costs covered.* Case management services may be included in the comprehensive package of services to be provided by a consortium funded with Part B funds. *SEC. 2613(a)(1)(A).* Consortia that provide services for individuals residing in rural areas are required to deliver case management services. *SEC. 2613(c)(1)(B)(iii).* (See Recommendation 22.)

- *Development of model programs for the care and treatment of rural individuals with HIV disease.* In awarding grants for special projects of a national significance, the Secretary may include projects designed to improve HIV health care and support services to individuals and families with HIV disease located in rural areas. *SEC. 2618(a)(3)(F).* Although not embodied in a recommendation, the need for the development of such models was enunciated by many of the workshop's participants.

II. THE CHALLENGES OF THE HIV EPIDEMIC IN RURAL AREAS

In this, the tenth year of the AIDS/HIV epidemic, HIV disease is an increasing problem in the small towns and rural areas of America. The number of new AIDS cases being diagnosed in rural areas is growing at an alarming rate. In 1989 compared to 1988, the number of diagnosed AIDS cases increased 37% in rural areas compared to 5% in large metropolitan areas. In Georgia, where the number of AIDS cases has tripled in the past two years, the percentage increase in AIDS cases in rural areas and small cities has equalled that in metropolitan Atlanta.

Identification of HIV issues specific to rural areas is just beginning. This workshop is the first major effort within the Department of Health and Human Services to address HIV/AIDS in rural areas. The U.S. Congress and the President, in the Ryan White Comprehensive AIDS Resources Emergency Act of 1990, recognized the growing rural epidemic of HIV and the need for HIV health care services and prevention activities in rural communities.[2] In April 1990, the National Commission on AIDS made a field trip to rural Georgia and, in its third report, speaks to the rural needs for HIV services and prevention activities.[3] The National Advisory Committee on Rural Health, which advises the Secretary of Health and Human Services on rural health care services issues, made eight recommendations which address rural concerns about HIV/AIDS in its 1990 report.[4]

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[2] See pages 2-4 above for a description of the C.A.R.E. Act provisions which overlap with this workshop's recommendation.

[3] National Commission on AIDS, *Report Number Three: Research, the Workforce and the HIV Epidemic in Rural America.* August, 1990. Washington, D.C.

[4] National Advisory Committee on Rural Health (NACRH), *Third Annual Report to the Secretary of Health and Human Services.* December 1990. U.S. Department of Health and Human Services, Office of Rural Health Policy. The NACRH recommendations bearing on HIV/AIDS in rural areas are reproduced in Appendix II.

Providing care for the HIV infected people in rural areas will present a major challenge to rural health care systems. Before the coming of the AIDS epidemic, rural health care in some areas of the United States was already in crisis, with many areas unable to meet the health care needs of the local populations. The problems of rural health care systems include shortages of health care professionals, financially fragile hospitals, gaps in public and private health insurance which leave many rural residents without the ability to pay for necessary care, lack of ready access to specialty care, and lack of care coordination services. The spread of AIDS to rural areas places even greater pressure on already stressed health care systems. The challenge is how to provide AIDS services in communities which are already deficient in health care services, and have limited financial resources to develop new services. Workshop participants are unanimous in their conviction that mastering this challenge will require the collaboration of Federal, state and local governments, public and private providers of health care and social services, and community organizations.

Preventing the spread of HIV in rural areas is another major challenge which will require new strategies and programs. The models of HIV prevention which have proved effective in urban areas -- street outreach programs for IV-drug users and community-wide programs targeting the gay community -- are simply not appropriate for rural areas.

III. Guiding Principles and Assumptions

Workshop participants enunciated a series of principles and assumptions which underlie the recommendations developed by this workshop:

- THE HUMAN FACTOR
  The human experience of those living with AIDS and HIV should frame any discussion that addresses HIV. The people behind the numbers should consistently guide our efforts in developing prevention and service programs.

- DENIAL
  In many rural communities, there is denial that HIV disease is a problem that must be addressed. Factors which may contribute to this denial include disapproval of behaviors associated with AIDS transmission and health professionals' unfamiliarity with the symptoms of HIV disease.

- BARRIERS TO CARE
  Individuals in rural areas with HIV/AIDS confront a series of obstacles to receiving adequate care. For example, rural residents with HIV/AIDS have difficulty identifying primary care physicians and other health care personnel who are trained and willing to treat

HIV disease; lack adequate insurance coverage to pay for costly care; have limited access to new drugs and experimental protocols; and may find that referral networks to appropriate social services or medical specialists are lacking. These problems are exacerbated by long distances to specialty centers, and lack of supportive care services.

- NEED FOR COORDINATION OF EXISTING SERVICES
  Coordination of medical and social services is lacking in many rural areas, for people with AIDS and the many others needing this service. In some urban areas, a variety of care coordination/case management programs have evolved to more efficiently deliver care to people with AIDS. Given the geographic dispersion of rural providers and other access problems, care coordination is perhaps an even more critical need in rural areas. Yet most rural areas do not have care management services.

- INTEGRATION OF PREVENTION AND TREATMENT
  HIV prevention and HIV care activities must be explicitly integrated in rural areas. Workshop participants felt strongly that HIV/AIDS prevention and treatment activities need to be closely linked. Prevention and education programs need to clearly articulate the benefits of early intervention and assure access to early treatment. Care and service activities need to incorporate prevention activities and reinforcements for risk-reduction behaviors.

- DIVERSITY OF RURAL POPULATIONS
  Policies to fill the gaps in rural HIV/AIDS prevention and care must be sensitive not only to urban/rural differences, but also to the diversity of rural areas and the differences among special populations within those areas. Rural areas differ in their public health structures, health care resources, and populations in need of services. In addition, within each rural area, HIV disease may manifest itself very differently across ethnic, cultural, sexual orientation or risk behavior patterns. These differences need to be considered in the design and implementation of programs for particular groups.

- NEED FOR PUBLIC HEALTH LEADERSHIP
  Effective coordination of public and private HIV activities in rural areas is the responsibility of state and local public health sectors. These agencies should be the organizers of an integrated approach to HIV/AIDS. In some areas, state and local health agencies appear to be indifferent to the growing HIV threat to their communities. This indifference has engendered mistrust of these agencies by rural AIDS organizations and by individuals with HIV disease.

IV. Recommendations

Workshop recommendations are grouped into five broad categories which cut across health care service and prevention activities:

A. Information Needs
B. Planning, Coordination, and Resource Allocation
C. Training and Skill Development
D. Dissemination
E. Financing
F. Other

Most of the recommendations are aimed at Federal policies, but many also are relevant to others responding to HIV disease in rural areas, including state and local public agencies and private medical and social service providers. Each group of recommendations begins with a general recommendation, followed by more detailed recommendations and rationales.

A. Information Needs

The Federal government should collect accurate, comprehensive information about the extent, characteristics, and impact of HIV disease in rural areas.

Those involved in planning and allocation of resources for HIV disease are severely handicapped by the lack of sufficient epidemiologic data, particularly in terms of HIV infected, asymptomatic individuals, the in- and out-migration of people with AIDS, and the nature and impact of HIV disease in rural areas. Our understanding of the rural HIV epidemic is based largely on anecdotes, personal observations and isolated studies. Current surveillance and medical care information indicate an increase in HIV disease in rural areas, but its extent and dimensions are unknown. The Federal government should provide leadership and resources to collect and disseminate information on the HIV disease and its impact on rural areas.

Recommendation 1: The Department of Health and Human Services should conduct studies to improve understanding of HIV epidemiology, the demographic characteristics of HIV infected individuals, and health service and prevention needs in rural America. The findings of these studies should be disseminated to agencies and providers in rural areas. Additional special studies, with appropriate agencies indicated in parentheses, should include:

a) ***Migration of people with AIDS.*** **Expansion of HIV/AIDS surveillance activities to include tracking the migration of people with AIDS (Centers for Disease Control).**

b) ***Health services needs.*** **Assessment of HIV service needs in rural areas and the availability of services for rural residents with HIV disease (Agency for Health Care Policy and Research).**

c) ***HIV risk behaviors.*** **Implementation of the proposed national survey on drug use and sexual behaviors, with design modifications to provide data for understanding rural/urban similarities and differences. Also needed are special focus studies of rural populations at high risk. (Centers for Disease Control, the Alcohol, Drug Abuse and Mental Health Administration, and the Agency for Health Care Policy and Research).**

d) ***Evaluation of usefulness of existing health statistics as indicators of HIV risk.*** **Study of the potential usefulness of existing health statistics as indicators of HIV risk behaviors in targeted rural populations (Centers for Disease Control.)**

Current surveillance and medical care information point toward an increase in HIV disease in rural areas. The lack of sufficient epidemiologic data, and information on the nature and impact of HIV disease in rural areas severely handicaps those involved in planning and allocation of resources for HIV disease. The Federal Government should provide leadership and resources to collect and disseminate information on the HIV disease and its impact on rural areas.

Migration of people with AIDS. It is important for services planning and for equitable allocation of HIV/AIDS funds to have accurate information on the number and geographic location of people with HIV disease. The Federal government uses the measure "reported residence at time of initial AIDS diagnosis" to estimate the geographic distribution of AIDS cases and to allocate Federal HIV funds. Sole reliance on this data element may yield a significant underestimation of the extent of HIV disease in rural areas, and result in rural areas receiving less than their fair share of Federal HIV funds. There is a large body of anecdotal evidence suggesting substantial migration of people with AIDS from the cities of their initial diagnosis "back to their home towns" in rural areas. The Centers for Disease Control should conduct studies in a small number of rural areas to document the number of people with AIDS, their place of initial diagnosis, and the migration of people with AIDS from and to rural areas. From the study findings, the Centers for Disease Control should develop a correction factor for use in its official estimates of the geographic distribution of AIDS cases.

Health services needs. The Federal government should develop specific data on rural areas relating to the demographic characteristics of HIV infected individuals, their service needs,

and the availability of services, including those services often provided at little direct cost to people with AIDS by community-based organizations. Survey respondents should include people with AIDS who are recipients of the services.

HIV risk behaviors. The lack of comprehensive information on drug use and sexual behaviors severely hampers efforts to target HIV prevention programming. The proposed National Institute of Drug Abuse national drug and sex survey will provide important information for development of effective HIV prevention methods. The sampling frame should be designed to provide the data needed to analyze differences based on rural/urban residence as well as other social and demographic factors.

Also, the differences in the prevalence of HIV infection between and within rural areas must be better understood in order to effectively target limited prevention and treatment resources. In particular, the differing patterns of drug and alcohol use and sexual risk behaviors within special populations need to be documented. Special populations that should be studied include racial/ethnic communities (Black, Hispanic, Native American, Asian and Pacific Islander), migrant farmworkers, recent immigrants, adolescents and youth, elderly, homeless, and persons with disabilities (e.g., deaf or blind).

Usefulness of existing health statistics as indicators of HIV risk. Many state and rural agencies already collect statistics which may be useful indicators of HIV risk levels in vulnerable populations, e.g., teen pregnancy rates, rates of other sexually transmitted diseases, and emergency room admissions for drug overdose, alcohol abuse and related cases. Empirical studies should be conducted of the utility of these measures for targeting prevention activities.

Recommendation 2: The Secretary should develop appropriate mechanisms to assure that Federally funded research on HIV/AIDS is coordinated and incorporates consideration of rural areas.

A wide range of research projects are being conducted to increase understanding of the nature and scope of HIV disease. These include studies conducted or underwritten by the Center for Disease Control, the Alcohol, Drug Abuse and Mental Health Administration, the National Institutes of Health, and the Agency for Health Care Policy and Research, as well as studies undertaken by academic institutions and other agencies in the private sector. The Secretary should provide leadership in the coordination of these research efforts. Also, the Secretary should ensure that the federally funded research agenda includes the needed research on HIV in rural areas.

B. Planning, Coordination and Resource Allocation

The Federal government should ensure the maximum benefit from resources allocated to HIV disease in rural areas -- Federal, state, local and private sector -- through coordination of efforts and effective targeting of programs.

The need for HIV prevention programs and service delivery continues to far outstrip available resources. The Federal government should provide leadership in developing creative solutions, encouraging private sector participation, and targeting resources.

Recommendation 3: The Secretary should develop a concise and understandable statement of the Federal government's role in promoting effective services and prevention efforts in rural areas.

A comprehensive Federal plan for response to HIV disease in rural areas should be developed. Such a Federal plan would recognize the government's current role as catalyst, partner, payer, and provider of last resort for persons with HIV/AIDS. A coherent Federal plan would provide a model and needed guidance for HIV planning and service integration at the local level. The Federal plan should not be limited to "AIDS specific" programs. Rather it should integrate the HIV-relevant elements of all Federal programs, for example, the National Institute of Drug Abuse's Office of Substance Abuse Prevention's programs targeting IV-drug users, and the Area Health Education Center programs of the Health Resources and Services Administration's Bureau of Health Professions.

Recommendation 4: All Federal agencies administering HIV disease programs in rural areas should include the advice and leadership of HIV infected individuals and their caregivers in the planning, design, and review of the Federal programs. These representatives should reflect the broad spectrum of population groups affected by this disease.

The inclusion of those directly affected by AIDS/HIV is consistent with sound public health policy and current practice. Inclusion of these representatives ensures the appropriateness of the programs to the targeted populations, whether defined by ethnicity, sexual orientation, behavior, or other characteristic (e.g., migrant workers and disability). Applicants for Federal funding should be required to demonstrate the inclusion of input and leadership from affected population groups in their planning and operation. Where such leadership does not exist, programs should be implemented to develop leadership in these groups.

Recommendation 5: Federal HIV funds for services and prevention should be allocated on the basis of need. To this end, the Centers for Disease Control should develop improved allocation formulas. The HOPE allocation formula should not be used to distribute prevention funds to states.

Services. Allocation formulas for HIV services funds should be based on current, accurate measures of the geographic distribution of HIV disease cases. The measure in common use, "number of AIDS cases, by reported residence at time of initial AIDS diagnosis" may systematically underestimate the extent of HIV disease in rural areas. (See Recommendation 2, above, *Migration of people with AIDS.*) Also, underreporting of AIDS cases may be more likely in rural areas where there is less experience with the disease.

Prevention. It is important that HIV prevention activities be started in the early stages of the epidemic. For this reason, allocation formulas for prevention funds should include measures of HIV seroprevalence and frequency of HIV risk behaviors instead of measures of the incidence of AIDS. (See Recommendation 2, above - *Usefulness of existing health statistics as indicators of HIV risk.*)

HOPE formula. The Health Omnibus Programs Extension of 1988 (known as HOPE) established a new allocation formula for certain HIV/AIDS education programs. This formula does not adequately reflect the needs of areas with low population density but a relatively high incidence of HIV. Use of the HOPE formula will reduce funding to rural and low incidence areas.

Recommendation 6: In the awarding of Federal grants for HIV activities, it is important to build on existing systems and avoid duplication of effort. To this end:

a) ***Block grants to states.*** **Federal grants to states for HIV activities should be contingent upon the existence of a statewide plan that effectively addresses rural HIV/AIDS needs, and the designation of a single state agency to coordinate the statewide response to HIV disease, and all Federally funded HIV/AIDS programs.**

b) ***Public-private partnerships.*** **Priority should be given to applications which demonstrate effective public-private partnerships that build on existing resources.**

c) ***The "HIV Services Planning Grant Program"*** **(funded in 1990 by the Health Resources and Services Administration, PHS), which provides direct support to planning and coordination activities in rural areas, should be reinstituted and expanded.**

Block grants to states. State agencies play a pivotal role in mobilizing or inhibiting an effective response to HIV disease, particularly in predominantly rural states. Given that role and the freedom of state action in the use of Federal block grants, it is imperative that states demonstrate their commitment and capacity to lead the AIDS response in their state. A state should have a statewide HIV plan which demonstrates access to care for all, and includes provisions for very remote areas. A single state agency should be charged with responsi-

bility for coordinating the state's HIV activities, including Federally funded HIV programs. Because these activities are likely to be spread across a number of state agencies, their coordination will maximize the effective use of scarce resources. In the absence of these state measures, funding should be awarded to appropriate non-state entities through a competitive bidding process so as not to penalize individuals in states without a statewide plan and a coordinating agency.

Public-private partnerships. Because of the extreme shortage of health care resources in certain rural areas, all segments of the private and public health systems must work together. Evidence of coordination can include consortium membership lists, cooperative agreements, letters of agreement, and contracts.

HIV Services Planning Grant program. HRSA's support for community-wide planning provided the only Federal support for planning and coordination in low incidence and rural areas. Continuation and expansion of this program is important for the development of coordinated public-private responses to the HIV disease in rural areas.

This program promoted and fostered local leadership of the HIV response in rural areas. Because many rural areas are lacking local leadership to develop a response to HIV disease, it is important for the Federal government to support programs to encourage the active involvement of leaders from the full range of rural community organizations. Examples include religious organizations, lodges, volunteer service organizations, local health departments, rural electric cooperatives, and local industry, as well as health and social service providers.

Recommendation 7: Applicants for Federal HIV/AIDS prevention and services funds should be required to allocate their grant funds on the basis of a needs assessment of their entire catchment area.

Historically, some urban-based grantees with rural districts in their catchment areas have overlooked rural needs. The requirement of allocation on the basis of a needs assessment of the entire catchment area will correct this oversight.

Needs assessments for prevention activities should include measures of HIV risk behaviors, for example, teen pregnancy rates, rates of other sexually transmitted diseases, and rates of emergency room admissions for drug overdose, alcohol abuse, and other substance abuse diagnoses. The needs assessments should document the participation of all affected groups in the planning and survey processes.

Recommendation 8: Federal programs which fund HIV/AIDS prevention and service activities should designate specific resources to address these needs in rural areas. Agencies which should expand resources directed to rural areas include the Centers for Disease Control and the Health Resources and Services Administration.

This designation of specific resources for rural needs will increase the resources for HIV/AIDS activities in rural areas. The Workshop participants fully recognize the limited Federal resources available for direct program support. At the same time, Workshop participants recognize the Federal government's responsibility to provide leadership in the initiation and support of programs for unmet needs in rural areas. All Federal support should be contingent upon demonstration that prevention and care programs are culturally and linguistically sensitive.

Prevention needs. High rates of increase in HIV infection are now occurring outside of urban centers -- in smaller cities, towns and rural America. However, the prevention models in widest use were developed specifically for urban settings and are often unsuitable for rural communities. The Centers for Disease Control should specifically fund the development of *rural* prevention programs.

Community and migrant health centers play critical roles in serving people with HIV disease in rural areas. These providers need additional funding if they are to meet the care needs of HIV infected people while continuing to meet the care needs of their other patients.

National Health Service Corps assignments. Because the HIV/AIDS epidemic will further aggravate the rural shortage of primary care providers, consideration should be given to methods of increasing their numbers. National Health Service Corps (NHSC) physicians fulfilling their service obligation in rural health manpower shortage areas (HMSAs) are an especially important source of care for rural residents with HIV disease. NHSC physicians may be the only doctors in a rural area willing to care for people with AIDS as many rural physicians are reluctant or refuse to provide HIV care.

Since the number of sites applying for NHSC personnel exceeds the available number of NHSC members, vacancy priority criteria are used to determine placements. In determining placement priorities for 1991, requesting sites were evaluated on seven indicators. One indicator, "percent special populations" included "persons with HIV/AIDS" as a special population. In future years, the Bureau of Health Care Delivery and Assistance should

continue to include "persons with HIV/AIDS" as a factor in determining placement priorities among those rural sites requesting NHSC personnel.[5]

Recommendation 9: Appropriate state health officials should be convened by the Centers for Disease Control and the Health Resources and Services Administration to develop methods of coordinating services and sharing information about HIV seroprevalence and AIDS in populations that move across state lines, in particular, migrant farmworkers.

Although the overall HIV infection rate in the migrant farmworker population is still very low, migrant farmworkers are at high risk for HIV infection. In order to provide needed HIV services and preventive education to this vulnerable population, it is imperative service providers be linked across state lines. Responsible state agencies should develop methods for the sharing this health information across state lines, thereby enabling providers to provide continuity in HIV care and education for agricultural workers and their families. The collaborative undertaking by eastern seaboard states for tracking tuberculosis in individuals who travel up and down the eastern migratory stream can serve as a model.

C. Training and Technical Assistance

The Federal government should enhance the information and skills of health professionals and others responding to HIV disease in rural areas through provision and support of training, skill transfer and technical assistance.

Many rural health professionals do not have training or experience in care of HIV infected people. Training and technical assistance can help ensure that providers are informed about the most recent findings on prevention and treatment of HIV disease.

Recommendation 10: The Health Resources and Services Administration should ensure that the regional AIDS Education and Training Centers (ETCs) earmark funds and design programs to meet the training and information needs of rural providers and professionals in their service areas. In particular:

a) ***Training appropriate to rural environment.*** **The AIDS ETCs should assure that training programs for rural health care professionals are appropriate to the rural environment.**

[5] In 1990, the list of factors which may be considered for determining the HMSAs with the greatest manpower shortages was enacted into law (Public Law 101-597, National Health Service Corps Revitalization Amendments of 1990). Under this new law, "number of persons with HIV/AIDS" is not among the factors which may be considered.

b) ***Training for rural providers with interest in providing HIV care.*** **The AIDS ETCs should establish as one of their priorities training activities for rural providers with a demonstrated interest in the care of HIV infected individuals.**

b) ***Clearinghouse function.*** **All AIDS ETCs should develop an effective clearinghouse function which is able to refer rural providers to training programs and sources of up-to-date information on HIV treatment and drug trials, and to link them with specialists for consultation and referrals.**

Equitable allocation of resources to rural training. The workshop participants recognize the AIDS Education and Training Centers as valuable resources for health professionals caring for those with HIV disease. However, there is concern that activities of the AIDS ETCs have been largely concentrated in major urban centers and insufficient resources are being devoted to the development and implementation of programs for health professionals working in rural settings.

AIDS ETCs which have rural areas in their service regions should be required to demonstrate that an equitable portion of their resources is used in training rural providers. All rural practitioners, especially those who staff rural emergency rooms, need to be able to recognize the diverse symptoms of HIV disease and HIV-related diseases and provide appropriate treatment or referrals.

Training appropriate to the rural environment. Training programs developed for rural health practitioners should take into account special problems of providing health care services in rural areas. To limit duplication of effort, the Bureau of Health Professions should ensure that rural programs, educational modules, and materials developed by one AIDS ETC are shared with all other AIDS ETCs.

Training for rural providers with interest in providing HIV care. In establishing priorities for rural programming resources, ETCs should include training for providers who have demonstrated their interest in caring for HIV infected individuals. There are major differences among physicians and other health care practitioners in their degree of interest and willingness to care for HIV infected persons. These differences should be considered in allocating the limited funds available for training.

Clearinghouse function. Rural providers need a designated, regional source for information on training and medical management issues for patients with HIV disease. Health professionals in rural areas have limited access to current treatment information and new drug protocols. AIDS ETCs should work with other appropriate groups in their regions to develop and disseminate information on how to access new protocols. This information should be disseminated broadly throughout their regions, in particular to rural areas.

Recommendation 11: The Health Resources and Services Administration and, in particular, the Bureau of Health Professions should promote the training of health professionals on HIV disease in the programs it funds and through partnership activities with professional associations and state offices. Specific recommendations are:

a) ***HRSA training programs.*** **Ensure that all HRSA programs which support the education of health professionals incorporate information on HIV care, as appropriate.**

b) ***Knowledge of HIV care for certification.*** **Encourage the inclusion of demonstrated knowledge and training on HIV disease as a requirement for certification across health professional fields.**

c) ***HIV specialist certification.*** **Encourage and disseminate, in collaboration with the Federation of State Licensing Boards, model standards of professional certification which recognize special expertise in caring for those with HIV disease.**

HRSA training programs. The Bureau of Health Professions should require applicants to health professions education programs to document clinical content on HIV/AIDS diagnosis and treatment. Bureau of Health Professions' training programs should give priority funding points for HIV/AIDS-related training activities. Area Health Education Centers should demonstrate that HIV/AIDS training and education is an integral part of their programming.

Knowledge of HIV care for certification. Health professionals are certified by professional associations and, in some cases, state governments. HRSA should work with the Federation of State Licensure Boards, national professional associations and, as appropriate, state governments to develop appropriate standards of knowledge on HIV disease across the spectrum of health professions (e.g., physicians, nurse practitioners, nurses, physician assistants, emergency medical technicians, social workers, and psychologists).

HIV specialist certification. Some health professions now recognize specialized expertise in the care and treatment of HIV disease through advanced degrees and certification, e.g., Master's in AIDS Nursing. These provide important validation to AIDS/HIV care and increase resources which can support rural providers. HRSA should disseminate descriptions of these models to all health professions.

Recommendation 12: The Centers for Disease Control and the Health Resources and Services Administration should develop and support a coordinated program of technical assistance for rural and urban community-based education and service organizations engaged in HIV service and prevention activities.

The community-based organizations which play a critical role in preventing the spread of HIV and providing needed services to HIV infected people need assistance with organizational development and programming. Community-based organizations serving rural areas should be supported through the provision of technical assistance on organization and programming. Currently, technical assistance is provided by a number of agencies and programs. These are not well coordinated, and there is no assurance that all important areas of training are addressed. Training and technical assistance should address program evaluation, fundraising, organizational development, targeted prevention, and service.

D. Dissemination

Because the HIV epidemic is so new, basic epidemiologic and planning data are only now being collected, and responses to the many aspects of the epidemic are under active development. The Federal government should ensure that, as statistical data are collected and effective responses developed, these are disseminated to all who can use them.

Special measures should be taken to assure that public health agencies, and rural organizations, providers, and practitioners are informed about programs and materials appropriate for their communities.

Recommendation 13: The Public Health Service should identify and disseminate prevention and service models which have proved effective in rural areas.

Currently there is no consistent practice of identifying and disseminating descriptions of effective models. As a result, many rural providers are repeating mistakes made by others and/or are duplicating efforts by designing new programs from the ground up. Federal funding will always be limited to a small fraction of providers; and the lessons learned by those who are funded should be widely disseminated. Factors to be considered in selecting programs for review and dissemination include:

- Model programs selected for dissemination should include programs developed specifically for rural communities.
- Review processes should select for dissemination only programs documented to be highly successful.
- The review processes should be non-governmental, with input from the affected populations.

For example, the Centers for Disease Control's National AIDS Information Clearinghouse should implement a process for evaluation, selection, and distribution of HIV prevention materials for special populations. Materials reviewed should include those developed by the

Federal government and by others. The evaluations of prevention materials should describe both the strengths and the limitations of the materials.

Local agencies in rural areas which operate targeted prevention programs need AIDS educational materials that are clear, accurate, well-designed, and appropriate for specific populations. Rural organizations, which are unlikely to have direct access to prevention experts, would greatly benefit from recommendations of high quality materials for their target audiences.

Recommendation 14: The AIDS Education and Training Centers should develop collaborative arrangements with the National AIDS Information Clearinghouse and the AIDS Clinical Trials Information Service to ensure that information on new HIV treatments, drug protocols, and expanded access to experimental drugs is disseminated to rural practitioners throughout the AIDS ETC service regions.

To enable rural practitioners to provide quality care to HIV infected persons, it is important for them to have convenient, ready access to current information on diagnosis and treatment of HIV infection. The AIDS Education and Training Centers with their programs for rural practitioners, the National AIDS Information Clearinghouse, and the AIDS Clinical Trials Information Service should work together to achieve this end.

E. Financing

Millions of Americans have no public or private health insurance, including a disproportionate number of rural Americans.

The Federal government should seek ways to eliminate the serious barriers to access to health care for individuals unable to pay for medical care. The workshop participants strongly feel that the HIV epidemic provides additional evidence of the need for national health care reform to guarantee all citizens access to basic and long term care.

Many of the health insurance inadequacies experienced by people with AIDS are experienced by millions of other un- and under-insured Americans in obtaining quality health care. These insurance shortfalls are particularly severe in rural areas because of the higher rate of poverty and the underfunded health care systems. In the absence of national health care reform the workshop participants make the following specific recommendations:

Recommendation 15: The Secretary should propose national eligibility criteria for Medicaid. Until such time as national eligibility criteria are in place, the Social Security Administration should strictly enforce the presumptive determination of disability based on the diagnosis of AIDS.

National eligibility criteria. This change will greatly increase the equity of Medicaid access across all fifty states, in contrast to the current variation in Medicaid access from one state to another which results from states' differing Medicaid eligibility criteria. Also, it will increase the number of Medicaid eligible persons in those states now using the most restrictive income eligibility floors; a number of these are states with the highest poverty rates in their rural populations. It would be helpful to many people with disabling diseases, including individuals with HIV disease. The current patchwork of eligibility criteria provides incentives to people with HIV disease to relocate to states with better coverage.

AIDS diagnosis as presumptive evidence of disability. A Social Security finding of disability is an eligibility criterion for Supplemental Security Income (SSI), the Federal income maintenance program. In approximately one-half of the states, SSI eligibility, in turn, qualifies a person for Medicaid. However, the Federally mandated definition of AIDS diagnosis as presumptive evidence of disability is very unevenly applied, particularly in rural areas. The refusal to accept this diagnosis as evidence of disability continues to be a barrier to Medicaid and Medicare access. The Social Security Administration should monitor and strictly enforce compliance with this requirement.

Recommendation 16: The Secretary should propose a waiver of the 24-month waiting period for Medicare where the disability can be demonstrated to be total and permanent.

In rural and urban areas alike, the application of this waiting period for those who can demonstrate total and permanent disability can constitute a denial of access to needed health care. In rural areas with high numbers of uninsured, this is particularly likely to be the case.

Recommendation 17: The Secretary should propose revisions to streamline the application process for state Medicaid waivers for home and community-based services for people with AIDS.

The current waiver program to permit Medicaid payment for home and community-based care for people with AIDS has the potential to widen the availability of high quality, cost effective care for people with AIDS. This program is currently not in effect in many rural states due to the cumbersome application requirements and processes. Demonstration of efficient and high quality care should continue to be a program requirement.

Recommendation 18: The Health Care Financing Administration should expand its distribution to state Medicaid offices of regularly updated information on approved drugs for HIV treatment, to keep these offices current on the latest medical opinion.

The treatment and management of HIV disease changes rapidly, with advances relating to HIV infection itself as well as to better treatment of the myriad range of secondary infections. States should be regularly informed about new and evolving treatments which should be considered for coverage and reimbursement under their Medicaid programs.

Recommendation 19: Federal grant programs to states for HIV/AIDS activities should provide incentives to states to match the Federal dollars.

States receiving Federal funding for HIV prevention and service programs should be encouraged to provide specified ratios of matching funds. The burden of the response to HIV disease must be shared by all levels of government, and the Federal government can encourage sharing through "matching fund" programs. In states which are unwilling to match the Federal funds, the Federal funds should be awarded on a competitive basis to appropriate private agencies. This will assure that services and prevention in these states are not penalized for their states' non-participation in matching fund programs.

Recommendation 20: The appropriate Federal agencies (in particular, the Agency for Health Care Policy and Research, the Health Resources and Services Administration, and the Health Care Financing Administration) should support demonstration projects which encourage the private sector and state and local public sectors to develop creative solutions to financing care.

There are a wide range of innovative private sector and local programs in various stages of development which have the potential to increase the resources available for services for those with HIV disease. The Federal government should encourage these programs and, where appropriate, support demonstrations to document program efficacy. Reports of effective programs should be disseminated widely to encourage replication. Multiplication of these programs could supplement Federal entitlement programs. Programs that should be considered for demonstrations and/or evaluation and dissemination include:

- *Life Insurance "Early Pay-Outs"* -- private insurance company programs that provide for payment of a significant portion of life insurance benefits prior to the death of the insured, based on evidence of imminent demise. Resources made available can be used to finance care.

- *State Payment of Insurance Premiums* -- state programs to pay the private health insurance premiums of low-income persons who are eligible for continued coverage under an employer's insurance plan following loss of employment. This continued coverage was mandated by COBRA. State payment of these premiums for persons who

are Medicaid eligible averts their conversion to Medicaid and/or other state-subsidized health care programs.

- *State Risk Pools* -- state/private insurance programs which create risk pools of otherwise uninsurable individuals and provide them with subsidized insurance. This concept, with its clearly desirable objective of affordable insurance premiums, needs further development. To date, the states implementing state risk pools to date have not been able to achieve affordable premiums.

- *Impact of Private Insurers' Application of "Pre-Existing Condition" Clauses* -- the impact of insurers' use of pre-existing condition clauses to exclude people with HIV infection from private coverage should be studied, and remedies proposed to appropriate state regulatory bodies.

- *Valuation of Volunteers' Services* -- to encourage and sustain voluntary support systems for HIV infected people in rural areas, the impact and value of these volunteer services needs to be documented so that public and private payers can consider financial support of the organizations which mobilize these volunteers.

Recommendation 21: State Medicaid Offices and State Health Departments should assess the need for higher reimbursement for primary care providers, especially in rural areas.

Low Medicaid reimbursement rates are a major barrier to health care access for low income residents of rural areas. Primary care providers are the principal deliverers of care in rural areas, and low reimbursement for their services discourages them from serving people insured by Medicaid, including individuals with HIV disease.

Recommendation 22: In the development of allocation and reimbursement formulas, the Federal government, states, and private payers should take into account the costs of providing care and service coordination, and additional costs in delivering health care in rural areas resulting from such factors as increased travel distances.

Coordination of care and services is a basic service requirement for many people with chronic illness, including people with HIV disease. Insurers should reimburse providers for this time-consuming, essential service. Provision of home and community based services in rural areas is made more costly by the long distances which providers must travel.

Recommendation 23: In the interest of the Nation's public health, the Secretary should pursue means to eliminate Federal financial access barriers, or sanctions against undocumented aliens seeking health care.

Financial barriers and fear of deportation discourage undocumented aliens from seeking health care. To stem the spread of HIV, it is extremely important for undocumented aliens, who are at high risk of HIV infection, to receive health services which include preventive education and reinforcement for safe behaviors. This is of particular concern in rural areas, where many undocumented aliens live and work.

F. Other

Recommendation 24: The Centers for Disease Control (CDC) should support full evaluations of selected, promising prevention strategies, and require only process evaluations of other CDC funded prevention programs.

Comprehensive evaluations which measure impact and outcomes are critical for assessing the efficacy of different prevention strategies. However, these comprehensive evaluations are costly and lengthy. CDC should fund multi-year evaluations of selected prevention programs, including programs appropriate for rural communities. Other CDC funded prevention programs should be required to perform process evaluations, but should not be nexpected to be able to document outcome effects

APPENDIX I

DEPARTMENT OF HEALTH AND HUMAN SERVICES
PUBLIC HEALTH SERVICE
HEALTH RESOURCES AND SERVICES ADMINISTRATION

AGENDA

WORKSHOP ON HIV INFECTION IN RURAL AREAS: ISSUES IN PREVENTION AND SERVICES

July 16-17, 1990

Holiday Inn Capitol
550 C Street, SW
Washington, D.C.

MONDAY, JULY 16

8:30 - 9:00 **WELCOME**

Marie Henry, Dr.N.Sc., R.N.
Deputy Surgeon General

Robert G. Harmon, M.D., M.P.H., Administrator
Health Resources and Services Administration

WORKSHOP PURPOSE
David Sundwall, M.D., Facilitator

9:00 - 11:45 **PLENARY SESSION**

LEGISLATIVE BACKGROUND
David McIntyre
Legislative Assistant to U.S. Senator John McCain

DATA COLLECTION ISSUES
Patricia L. Fleming, Ph.D.
Centers for Disease Control

RURAL HEALTH CARE SYSTEM ISSUES
Dena S. Puskin, Sc.D.
Office of Rural Health Policy

PERSONALIZED PERSPECTIVES ON AIDS CARE IN RURAL AREAS
Mary Emily Rothgeb
Ron Jerrell

1:00 - 5:00 **CONCURRENT WORKGROUPS**

PREVENTION AND EDUCATION WORKGROUP

SERVICES AND CARE MANAGEMENT WORKGROUP

FINANCING AND SYSTEMS BUILDING WORKGROUP

TUESDAY, JULY 17

8:30 - 10:00 **PREVENTION AND EDUCATION WORKGROUP**
REPORT AND DISCUSSION OF REPORT

10:15-11:45 **SERVICES AND CARE MANAGEMENT WORKGROUP**
REPORT AND DISCUSSION OF REPORT

12:45- 2:15 **FINANCING AND SYSTEMS BUILDING WORKGROUP**
REPORT AND DISCUSSION OF REPORT

2:30 - 4:00 **WRAP-UP**

4:00 **ADJOURN**

APPENDIX II

Excerpted from *The Third Annual Report to the Secretary of Health and Human Services,* **National Advisory Committee on Rural Health,** December 1990.

HEALTH CARE FOR PERSONS IN RURAL AREAS AT RISK OF AND WITH AIDS/HIV DISEASE

The Committee has increasingly become concerned about the potential risk of AIDS/HIV infection in rural areas. Rural communities are already lacking resources to handle common diseases. They are ill-equipped to handle the additional challenge posed by AIDS/HIV. Yet, data from the Centers For Disease Control (CDC) indicate that the greatest percent increase in the number of AIDS cases reported is in small cities and rural areas. From 1988 to 1989, AIDS cases increased 37% in non-metropolitan (rural) areas.

In response to the growth of AIDS/HIV disease in rural areas, the Office of Rural Health Policy, together with the Office of the Associate Administrator for AIDS in the Health Resources and Services Administration, sponsored an invitational workshop on rural AIDS in July 1990. The goal of the workshop was to develop a series of recommendations to assist the Public Health Service in addressing the emerging problem of rural AIDS. The preliminary recommendations from the workshop were presented to the Health Services Work Group at the September meeting. The executive director of the National Commission on AIDS, and a representative of the National Association of People with AIDS addressed the Work Group. The following recommendations emerged from that discussion.

Recommendation 90-11: Improve Federal Data Collection on HIV Disease in Rural Areas

> **The Department of Health and Human Services should collect accurate, comprehensive information about the extent, characteristics, and impact of HIV disease in rural areas. The Agency for Health Care Policy and Research, the Centers for Disease Control, the Alcohol, Drug Abuse, and Mental Health Administration, and other Federal agencies or programs, as appropriate, should fund studies to improve understanding of the epidemiology, demographics, impact, and trends of HIV disease in rural areas.**
>
> Current surveillance and medical care information point toward an increase in HIV disease in rural areas. The lack of sufficient epidemiologic data, particularly on HIV infected, asymptomatic individuals; the in- and out-migration of people with AIDS; and the nature and impact of HIV disease in rural areas severely handicaps those involved in planning and allocation of resources for HIV disease. The Federal Government should provide leadership and resources to collect and disseminate information on the HIV disease and its impact on rural areas.

Recommendation 90-12: Require States to Have a Statewide Plan which Designates a Single State Agency as Responsible for Coordinating State Response to AIDS/HIV and which Addresses Rural AIDS/HIV Needs as a Condition of Receiving Federal AIDS Block Grants.

Federal block grants to states for HIV disease prevention and treatment services should be contingent upon the existence of a statewide plan which effectively addresses rural HIV/AIDS needs and the designation of a single state agency responsible for coordinating the state's response to HIV disease.

State agencies play a pivotal role in mobilizing or inhibiting an effective response to HIV disease, particularly in predominantly rural states. Given that role and the freedom of state action in the use of federal block grants, it is imperative that states demonstrate their understanding, capacity, and commitment to coordinating the HIV response in their region. In the absence of such a state plan, so as not to penalize individuals in states without such a plan, funding should be awarded to appropriate non-state entities through a competitive bid process.

Recommendation 90-13: Provide Federal Support for Technical Assistance to Community-Based Organizations which Address The Needs of HIV Infected Persons in Rural Areas

The Centers for Disease Control and the Health Resources and Services Administration should develop and support a coordinated program of technical assistance for community-based organizations doing HIV prevention and providing services to HIV-infected persons in rural areas.

The community-based organizations play a critical role in preventing the spread of HIV and providing services to HIV-infected persons. These programs need technical assistance with organizational development and programming. Currently technical assistance is provided by a number of agencies and programs. These are not well coordinated, and there is no assurance that all important areas of training are addressed. Training and technical assistance should address at least:

- Targeted prevention programs;
- Service programs;
- Organizational development;
- Program evaluation; and
- Fund Raising.

Recommendation 90-14: Provide Federal Support to Foster Local Leadership to Respond to the AIDS/HIV Challenge in Rural Areas

The appropriate Federal agencies, in particular the Centers for Disease Control and the Health Resources and Services Administration, should support programs to promote and foster local leadership to orchestrate the HIV response in rural areas.

Many rural areas are without local leadership in the response to HIV disease. The Federal Government should support programs to encourage the active involvement of leaders from the full range of rural community organizations, such as religious organizations, lodges, volunteer service organizations, local health departments, schools and colleges, rural electric cooperatives, and local industry.

Recommendation 90-15: Expand the AIDS Education and Training Center Activities To More Effectively Reach Rural Primary Care Providers

The AIDS Education and Training Centers should establish or expand telephone hot line services and other programs to assure that rural primary care providers have easy, rapid access to HIV/AIDS treatment information, drug trials and referrals. Further, the AIDS Education and Training Centers should expand networks linking rural health care providers with major medical centers, to ensure access and quality care to persons with HIV disease.

Many rural primary care providers have little or no training in the care of people with HIV disease. Also, the state-of-the-art in treatment of the disease and its associated conditions is changing rapidly. Rural primary care providers need easy, rapid access to information and assistance if they are to provide quality care to persons with HIV disease.

Recommendation 90-16: Establish State 800 Numbers to Provide Information on Medicaid Eligibility and Coverage of Services for HIV Infected Persons

State Medicaid Offices should establish 800 numbers to provide information on Medicaid eligibility for and coverage of HIV-disease to HIV-infected persons, providers, patient advocates, and the state's local social service offices.

Many persons with HIV disease must turn to the Medicaid program for payment of their medical bills. However, the complexities of Medicaid eligibility and coverage often make it necessary to have expert assistance in establishing eligibility.

Finding expert assistance is particularly difficult in rural areas. Rural residents with HIV disease, concerned about concealing their disease status, are often not willing to go in person to local state benefits offices where they may encounter someone who knows them. Nor can they consult patient advocates knowledgeable about state Medicaid provisions for there are few such advocates in rural areas.

A state Medicaid HIV 800 number, staffed by experts on that state's rules, would provide anonymous access to an expert informant. It also could provide a centralized information source for providers, patient advocates, and the state's local social service offices.

This Medicaid HIV 800 number would be analogous to the state Medicaid 800 numbers which many states now operate as part of general outreach in their Medicaid program for pregnant women and children. The cost of these 800 numbers, which is part of the cost of administering the Medicaid program, is divided 50%/50% by state and Federal governments.

Recommendation 90-17: Provide Federal Guidance to States on Implementation of Ryan White Act

The Secretary should provide guidance to states in their use of the Ryan White Act AIDS/HIV funds to assure attention to the needs of the increasing number of HIV-infected persons in rural areas.

As HIV disease spreads from the urban areas into rural areas, states will need to revise their HIV resource allocation formulas accordingly. Rural communities with HIV cases should be assured their fair share of Federal AIDS/HIV resources. Too often, rural areas are overlooked because of their low population density. The Committee is concerned that rural areas will again be overlooked because the number of AIDS cases recorded is relatively low. Yet the impact of those cases on the fragile, overburdened rural health care system could be devastating. Moreover, the rapidly increasing numbers of cases in rural areas point to the need for preventive activities in these areas.

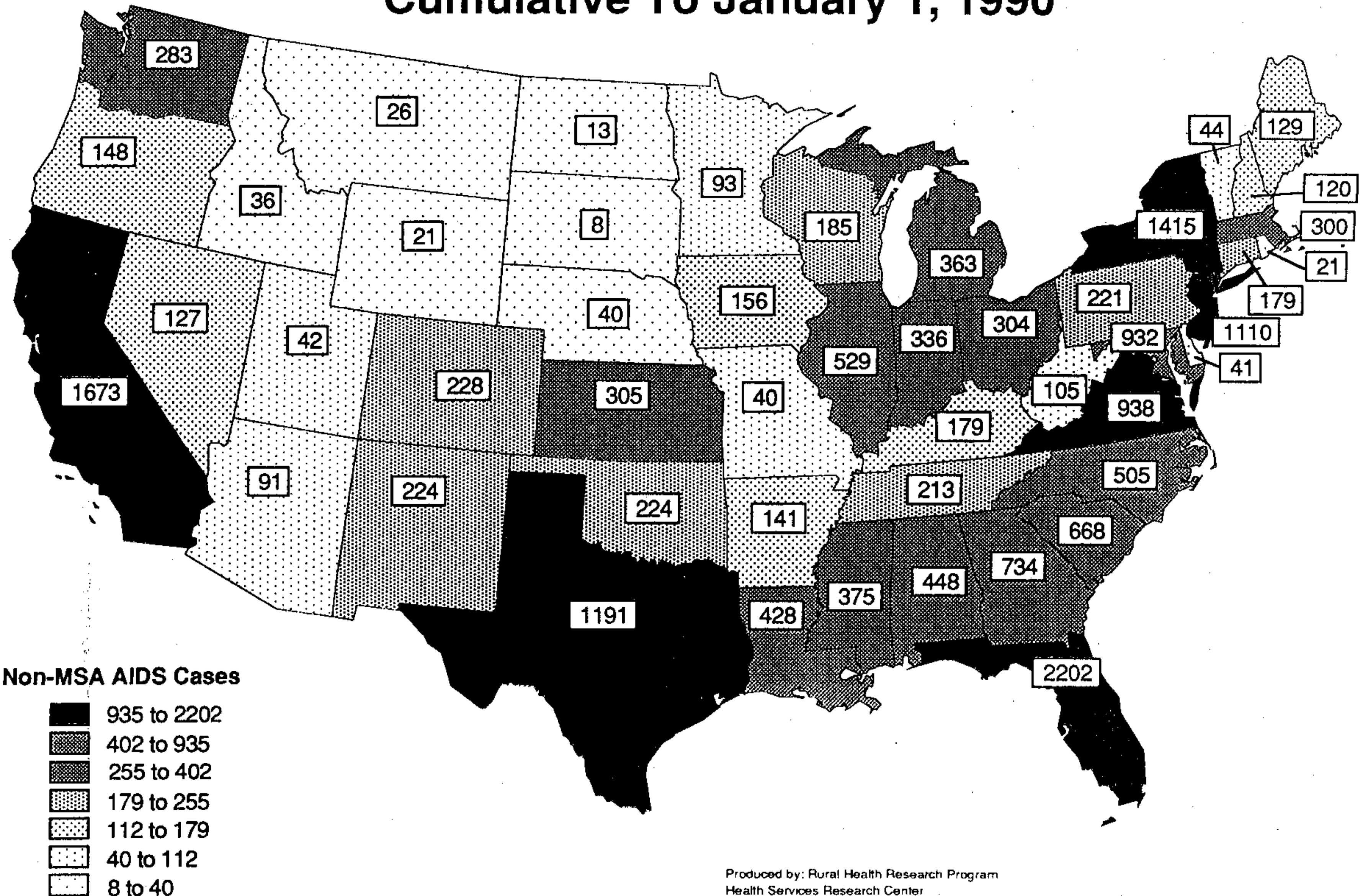
Recommendation 90-18: Accept the Recommendations of the National Commission on AIDS

We recommend that the Secretary accept the recommendations of the third report of the National Commission on AIDS, especially their recommendations to develop comprehensive community-based primary health care systems and to expand AIDS education and outreach services to rural communities. (National Commission on Aids, Report No. 3, Recommendations One and Two.)

Many rural areas have an inadequate supply and range of primary health care services. This shortage affects all residents of these areas, including persons with HIV disease. Creation of community-based primary care programs will benefit everyone. With the spread of the HIV disease to rural communities, it is urgent to establish adequate prevention and treatment programs before the disease overwhelms the capabilities of the fragile rural health care system.

APPENDIX III

AIDS Cases in Nonmetropolitan Counties, Cumulative To January 1, 1990



APPENDIX IV

DEPARTMENT OF HEALTH AND HUMAN SERVICES
PUBLIC HEALTH SERVICE

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

PROGRAM TO DEVELOP CLINICAL GUIDELINES FOR THE DIAGNOSIS AND TREATMENT OF PERSONS WITH HIV INFECTION

The Agency for Health Care Policy and Research (AHCPR), established in December, 1989, is charged with oversight of clinical guideline development for the federal government. The guidelines developed under the auspices of AHCPR are intended to provide scientifically valid information on which to assure the quality and effectiveness of health care provided. The guidelines will be directed to the practitioner and his or her patients as well as medical educators and medical care review organizations.

The guideline development methodology being used by AHCPR requires an exhaustive review of the relevant medical literature and analyses as needed. Clinical judgement is used only in areas where relevant literature is insufficient or unreliable. For such areas, guidelines state explicitly that they are based on expert opinion and that research is needed. The intent of the methodology is to base the guidelines on research findings rather than opinion.

Each panel, including the panel on HIV disease, will hold an open public meeting to receive comments from interested persons. The panel will consider information submitted to the Agency during the guideline development process. In addition, the guidelines will be peer reviewed and pilot tested prior to dissemination.

During 1990, AHCPR established an HIV Clinical Policy Program and is in the process of empaneling experts from multiple disciplines and healthcare consumers to develop clinical guidelines for the diagnosis and treatment of persons with HIV infection. The panel itself will consist of 15 members, at least one of whom will be a primary care physician and at least one of whom will be a person living with HIV disease. A Federal Register notice was published December 10, 1990 calling for nominations for the panel and for panel chair. The HIV panel will be chosen by early spring, 1991, and should have its first meeting by April, 1991.

The charge to the panel is to develop guidelines which are useable by primary care providers and which will be useful in a variety of practice settings, including those in rural areas and settings in which a physician may not be the primary care provider. Diagnosis, treatment, prevention, and counseling will be addressed during guideline development. The needs of drug-using populations, the special needs of infected persons who are the heads-of-household and the needs of other special groups will be addressed as they are identified. In addition, in the course of guideline development, research needs will be identified and recommendations made to address these research needs.

For further information, call the Office of the Forum for Quality and Effectiveness in Health Care: 301/443-8754.

AIDS REGIONAL EDUCATION AND TRAINING CENTERS

AETC FACT SHEET

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES • PUBLIC HEALTH SERVICE • HEALTH RESOURCES AND SERVICES ADMINISTRATION

Fifteen AIDS Regional Education and Training Centers have been established through a grant program of the Health Resources and Services Administration, within the U.S. Public Health Service, Department of Health and Human Services.

The goal of the AIDS ETC Program is to increase the number of health care providers who are effectively educated and motivated to counsel, diagnose, treat and manage individuals with HIV infection, and to assist in the prevention of high risk behaviors which may lead to infection. The ETCs are a national network of centers that have responsibility for designated geographic areas in which they conduct targeted, multidisciplinary education and training programs for health care providers. They also serve as resource centers by coordinating hotlines for current, accurate information concerning HIV, and by making available information about HIV resources, drug trials, and referrals.

Each ETC incorporates the following functions:

- Training community primary care providers to incorporate strategies for HIV-prevention into their clinical priorities
- Training selected trainees to serve as HIV/AIDS educators of health care personnel in their local areas
- Emphasizing HIV/AIDS training for minority providers and providers who serve minority populations
- Needs assessment to better allocate resources
- Emphasis on AIDS epicenters
- 10% set-aside for rural regional training centers
- Linkages with existing clinical trials.

ETCs collaborate with Area Health Education Centers (AHECs), community-based HIV/AIDS organizations, medical and health professions schools, local hospitals, community and migrant health centers, medical societies, and other professional organizations.

Current Roster of AIDS Education (ETCs) and Training Centers

Serving Nevada, Arizona, Hawaii, California (excluding 5 southern counties)

- University of California/Davis
  AIDS Education and Training Center
  5110 East Clinton Way, Suite 115
  Fresno, California 93727-2098
  Clark Jones
  (209) 252-2851 FAX: (209) 454-8012

Serving Washington, Alaska, Montana, Idaho, Oregon

- University of Washington
  AIDS Education and Training Center
  820 NE 45th Street, Suite 1, XD-20
  Seattle, Washington 98105
  Ann Downer, M.S.
  (206) 543-9750 FAX: (209) 545-0553

Serving Ohio, Michigan, Kentucky, Tennessee

- Ohio State University
  East Central AIDS Education and Training Center
  B0902 UHC, 456 West Tenth Avenue
  Columbus, Ohio 43210
  Lawrence L. Gabel, Ph.D.
  (614) 292-1400 FAX: (614) 293-4318

Serving New York City and Long Island, Puerto Rico, Virgin Islands

- New York University
  AIDS Education and Training Center
  429 Shimkin Hall
  Washington Square
  New York, New York 10003
  Erline McGriff, Ed.D.
  (212) 998-5335 FAX: (212) 995-3143

Serving Alabama, Georgia, North Carolina, South Carolina, Florida (excluding Dade and Monroe Counties)

- Emory University
  Emory AIDS Training Network
  735 Gatewood Road, NE
  Atlanta, Georgia 30322
  Kathleen R. Miner, M.P.H., Ph.D.
  (404) 727-2929 FAX: (404) 727-4562

Serving Arkansas, Louisiana, Mississippi

- Louisiana State University
  Delta Region AIDS Education and Training Center
  1542 Tulane Avenue
  New Orleans, Louisiana 70112
  William Brandon, M.D.
  (504) 568-3855 FAX: (504) 568-2026

Serving North Dakota, South Dakota, Utah, Colorado, New Mexico, Nebraska, Kansas, Wyoming

- University of Colorado
  Mountain Plains Regional AIDS Education and Training Center
  4200 E. Ninth Avenue, Box A-096
  Denver, Colorado 80262
  Richard Call, D.M.D.
  (303) 270-5885 FAX: (303) 355-1448

Serving Iowa, Minnesota, Wisconsin, Illinois, Indiana, Missouri

- University of Illinois at Chicago
  Midwest AIDS Training and Education Center
  840 S. Wood Street M/C 779
  POB 6998
  Chicago, Illinois 60612
  Nathan L. Linsk, Ph.D.
  (312) 996-1373 or (312) 996-1426
  FAX: (312) 413-0086

Serving Pennsylvania, New York State (excluding New York City and Long Island)

- University of Pittsburgh
  Pennsylvania/New York AIDS Education and Training Center
  Parran Hall, Room 207F
  Pittsburgh, Pennsylvania 15261
  Linda Frank-Hertweck, M.S.N., R.N.
  (412) 624-1895 or (412) 624-9118
  FAX: (412) 624-4767

Serving Florida

- The University of Miami
  AIDS Education and Training Center
  P.O. Box 016960 (D-90)
  Miami, Florida, 33101
  Leonard Hoenig, M.D.
  (305) 549-7836 FAX: (305) 324-4931

Serving Maryland, District of Columbia, Virginia, West Virginia, Delaware

- University of Maryland at Baltimore
  Mid-Atlantic AIDS Education and Training Center
  East Hall, 520 West Lombard Street
  Baltimore, Maryland 21201
  Moses B. Pounds, Ph.D.
  (301) 328-8334 FAX: (301) 328-5483

Serving Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont

- University of Massachusetts
  New England AIDS Education and Training Center
  55 Lake Avenue North
  Worcester, Massachusetts 01655
  Donna Gallagher, M.S.N.
  (508) 856-3255 FAX: (508) 856-6128

Serving 5 counties in Southern California: Riverside, San Bernardino, Los Angeles, Orange, Ventura

- University of Southern California
  AIDS Education and Training Center
  1420 San Pablo Street, B207
  Los Angeles, California 90033
  Peter V. Lee, M.D.
  (213) 224-7711 FAX: (213) 221-1235

Serving Texas and Oklahoma

- The University of Texas
  AIDS Education and Training Center
  1200 Herman Pressler Street
  POB 20186
  Houston, Texas 77225
  Richard M. Grimes, Ph.D.
  (713) 794-4075 FAX: (713) 791-1369

Serving New Jersey

- University of Medicine and Dentistry of New Jersey
  AIDS Education and Training Center
  Office of Continuing Education
  30 Bergen Street
  Newark, New Jersey 07107
  Charles McKinney, Ed.D.
  (201) 456-3690 FAX: (201) 456-7128

For further information please contact:

AIDS ETC Program
Bureau of Health Professions
5600 Fishers Lane,
Room 4C-03
Rockville, Maryland 20857
(301) 443-6364 FAX: (301) 443-8890

Rural AIDS Resource Listing. A resource listing on *AIDS in Rural or Low Incidence Areas* has been developed by the ETC AIDS Resource Network. The latest version of this listing, including an up-to-date bibliography, is available from:

Judy A. Stephenson, East Central AIDS Education and Training Center, Department of Preventive Medicine, University of Kentucky College of Medicine, MS129X, Chandler Medical Center, Lexington, KY 40536-0084; TEL: (606) 257-1234.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES ■ PUBLIC HEALTH SERVICE ■ CENTERS FOR DISEASE CONTROL

NAIC

National AIDS Information Clearinghouse

A Comprehensive Resource for Health Professionals

The National AIDS Information Clearinghouse is a comprehensive information service for public health managers and officials at the State and local levels, health and social service professionals, and AIDS-service providers.

As a service of the U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control (CDC), the Clearinghouse collects, classifies, and distributes up-to-date information and provides expert assistance to HIV- and AIDS-prevention professionals.

The Clearinghouse serves health professionals including physicians, nurses, nurse practitioners, physician assistants, nutritionists, emergency personnel, social workers, and health educators. These professionals work in a variety of settings, such as public health departments, hospitals, primary care clinics, extended care facilities, community-based organizations, and AIDS-service organizations.

Experienced Reference Specialists

An experienced team of reference specialists with a broad knowledge of AIDS organizations and materials can access a wealth of information. Call toll free at 1-800-458-5231, and these specialists will answer inquiries, make referrals, and help locate publications pertaining to HIV infection and AIDS. Spanish- and French-speaking reference specialists are also available.

Reference specialists use information databases—computerized files—to put callers in touch with organizations that provide HIV- and AIDS-related services and materials:

- The Resources Database contains descriptions of more than 14,000 organizations that provide HIV- and AIDS-related services and resources.
- The Educational Materials Database includes a collection of information on more than 6,900 hard-to-find HIV- and AIDS-related educational materials.
- The AIDS School Health Education Database is produced by CDC's Center for Chronic Disease Prevention and Health Promotion, Division of Adolescent and School Health. It offers citations and descriptions of educational resources for professionals to use to teach children and youth about HIV infection and AIDS.
- The Funding Database describes funding opportunities for community-based HIV- and AIDS-service organizations. It includes information about the application process, deadlines, and eligibility requirements.

The Clearinghouse urges its users to share descriptions of their HIV- and AIDS-related education programs, outreach efforts, and materials developed for target audiences. Please forward materials to the Clearinghouse for possible inclusion in the databases.

Materials From the Clearinghouse

The Clearinghouse is a direct source for free HIV and AIDS educational materials—brochures, posters, fact sheets, and more. Some materials are also available in Spanish.

Orders for multiple quantities of publications can be placed by calling the Clearinghouse's toll-free telephone line: 1-800-458-5231.

Outreach and Networking Services

Outreach staff are available to meet with health professionals to discuss individual needs. The Clearinghouse has provided assistance to representatives of various organizations:

- AIDS Education and Training Centers, Health Resources and Services Administration
- American Psychological Association
- Association of Nurses in AIDS Care
- National Hemophilia Foundation
- National Student Nurses Association
- Office of the Assistant Secretary of Defense, Health Affairs
- U.S. Public Health Service Professional Association

Contacting the Clearinghouse

For all Clearinghouse services, call Monday through Friday 9 a.m. to 7 p.m. eastern:

toll free 1-800-458-5231
TTY/TDD 1-800-243-7012
FAX 1-301-738-6616
International line 1-301-217-0023

Or write to:

National AIDS Information Clearinghouse
P.O. Box 6003
Rockville, MD
20850

11/90 *#181*

AIDS Clinical Trials Information Service

The AIDS Clinical Trials Information Service (ACTIS) provides the latest information on federally- and privately-sponsored clinical trials currently being conducted to evaluate experimental drugs and other therapies for adults and children at all stages of HIV infection. ACTIS provides information on all AIDS clinical trials sponsored by the National Institute of Allergy and Infectious Diseases as well as studies sponsored by other institutes of the National Institutes of Health. ACTIS also covers every experimental treatment undergoing clinical testing for effectiveness in treating AIDS or AIDS-related conditions in privately-sponsored trials approved by the Food and Drug Administration.

Physicians, health care practitioners, individuals infected with HIV and their families and friends can find out more about clinical trials on HIV and AIDS by calling toll free: 1-800-TRIALS-A (1-800-874-2572).

All calls are completely confidential. Bilingual specialists are available to speak with Spanish-speaking callers.

Resource ID#: 2063

HIV Infection in Rural Areas: Issues in Prevention and Services: Report of an Invitational Workshop Held July 16-17