

Report of the Workgroup on Patient Care/Health Care Needs

Background and Progress Since Coolfont

During the 2 years since the Coolfont report (1) was issued, the number of cases of clinical AIDS has tripled. The number of people infected with the HIV has also increased. Although the precise extent of this increase is unknown, it is clear that the responsibility of caring for AIDS patients and others infected with HIV will be a major concern to the Nation for some time to come.

Certain basic points of agreement have guided PHS decisions on the approach to organization of care. Health care delivery issues generated by AIDS and HIV infection need to be evaluated within the context of the entire American health care delivery system whenever possible. Ideally, care for patients with AIDS and HIV infection should be delivered in the same manner as that for other patients with similarly severe illnesses. To this end, initiatives recommended at the Coolfont Conference and implemented by PHS have attempted to encourage the mainstreaming of AIDS health care delivery by building on existing services and systems. The alternative approach--fostering a separate or parallel health care system--would have segregated the care for those patients with AIDS and HIV infection and would have laid the burden of responsibility on a few health providers. PHS believes that integration of care will, in the long run, improve the quality of care, increase access to care, and prove to be more economical.

However, PHS acknowledges that significant barriers impede both access to and integration of care. PHS initiatives support community efforts to overcome these barriers and at the same time help to fill gaps created by unmet demands for health care delivery. These health care needs, although not necessarily unique to AIDS, have placed a particularly difficult burden on communities where the pressures of the epidemic have not allowed the health care system time to develop an appropriate response.

There has come to be an increased appreciation for the complex care needed by people with HIV infection, as well as the similarities in care needed by patients with HIV infection and those with other chronic, debilitating illnesses. PHS believes that the knowledge and experience gained from studying these health care models may have widespread application.

In the coming years, it is possible that the life span of HIV-infected patients--asymptomatic persons as well as those with clinical AIDS--will be significantly lengthened by the development of effective interventions. As a result, the design of the care model will need to shift from one that addresses the needs of the terminally ill to one that addresses the needs of persons who are chronically ill. Moreover, the total number of people who seek medical care may greatly exceed the number with clinically overt AIDS, thereby substantially increasing the need for adequate medical management by active, informed primary health care providers.

Efforts to organize the health care delivery system to deal more effectively with AIDS and other HIV-related illnesses require the knowledge that can be gained from health services research. In particular, further research is needed in the following areas: cost and financing of care; quality of care; provider and financial barriers to care; and improved measures of functional status and longitudinal data bases to permit analyses of resource-effectiveness and better clinical decision-making. Research in these areas will help decisionmakers be more sensitive to the benefits of particular services and treatments when allocating scarce resources for the care of people with HIV-related illnesses.

Responses to the Coolfont Recommendations

Since Coolfont, much progress has been made toward achieving the goals that were established there. Several planning groups have been appointed at various levels within the Federal Government to review its role and make recommendations on approaches to combatting the epidemic. Specific areas of progress include the following:

- The call to establish a blue-ribbon commission on the AIDS epidemic was answered by the appointment of the Presidential Commission on the Human Immunodeficiency Virus Epidemic. The Commission has released its final report, which contains recommendations on virtually every aspect of the epidemic. Among other groups that have addressed various aspects of the problem is the Secretary's Work Group on Pediatric HIV Infection and Disease.
- Cooperative efforts to develop a coordinated approach to AIDS services and financing between Federal and State Governments have been supported by CDC grants and programs in testing, epidemiology, and education. The Alcohol, Drug Abuse, and Mental Health Administration

(ADAMHA) has fostered coalitions of private groups and local governments to provide psychological services and respond to the needs of IV drug abusers. Work begun by the Intragovernmental Task Force on AIDS Health Care Delivery is being continued by the Patient Care subgroup of the PHS Executive Task Force on AIDS. To date, private sector involvement in the financing and delivery of services has been limited. With the exception of a few States with a high incidence of AIDS, State involvement in planning and coordinating services has been limited.

- The Health Resources and Services Administration (HRSA) has awarded service demonstration grants to develop comprehensive service delivery systems, to support coordination and regionalization of health care resources, and is conducting evaluations of these projects. Pediatric AIDS health care demonstration grants are also being funded by HRSA to support coordination and collaboration in many areas. In addition, HRSA has begun a program to support construction or renovation of facilities that will provide nonhospital services to HIV-infected individuals.
- Many PHS agencies have provided technical assistance to public and private sector organizations through a variety of meetings, federally sponsored conferences, programs, workshops, and consultation with individual PHS staff.
- Specialized AIDS training programs emphasizing the need for education and training of health care providers for many types of professions have been funded through CDC and the National Institutes of Health. HRSA's AIDS Regional Education and Training Centers will train primary and secondary care providers and evaluate the effectiveness of the training programs. ADAMHA is funding training for mental health providers, and HRSA has held conferences on provider training and education needs. HRSA-supported community health centers are developing and utilizing protocols for AIDS patient care.
- A Surgeon General's workshop examined the needs of HIV-infected children and their families, focusing on minority and ethnic issues to developing culturally sensitive educational materials and service programs. A Latino conference on AIDS dealt with Hispanic issues, and other studies are under way to identify and address the special health care needs of black and Hispanic populations. Programs are being developed to provide HIV education for American

Indians and Alaska Natives and other ethnic/cultural minorities, and to study risk behaviors in these populations.

- Medicaid has instituted programs that are playing a role in evaluating the cost-effectiveness of differing types of care. It has granted some States waivers to permit coverage of home and community-based services instead of institutional services. In addition, Medicaid is allowing States to experiment with case-management techniques (which allow a single coordinator to supervise social as well as medical care services), using special reimbursement rates to induce providers to care for HIV-infected persons. The Robert Wood Johnson Foundation and HRSA are supporting studies of the costs of various types of care through service demonstration projects.
- The National Center for Health Services Research and Health Care Technology Assessment (NCHSR) is studying the cost-effectiveness of care models and developing projections of costs of treating AIDS patients, based on inpatient data, and is studying costs and utilization of care in various institutional settings. NCHSR is expanding its research interests to address issues of quality of care, barriers to care, integration of delivery systems, and methodologies. A contractor is developing protocols to study variations in costs in terms of severity and stage of illness, geographic area, risk group, treatment setting, and mode of care. The cost-effectiveness of various treatments and the effect of case management are also to be evaluated. The NCHSR is supporting investigator-initiated research into cost and financing issues, and plans to continue to support research on variations and changes in the cost, cost-effectiveness, and financing of health service delivery for AIDS.

Issues, Goals, and Objectives

Issue: Community Assessment and Coordinated Services Delivery

In many areas, the coordinating mechanisms needed to support comprehensive, integrated care for HIV-infected people are incomplete or entirely missing. These include the basic mechanisms for determining the system's present and future needs in order to allocate resources, determining the ease of altering system restrictions to meet new needs, identifying the system resources required for a

specific patient, and managing the system resources and services needed by patients.

Closer Federal-State-local collaboration would enhance the effectiveness of government responses at all levels. Federal assistance aimed at stimulating the most effective service delivery mechanisms needs to be tightly focused. These Federal dollars must be allocated by mechanisms sensitive to and responsive to the critical role played by volunteer organizations as well as to variations in local needs.

Goal: Promote in an interactive manner the assessment of community needs for services, facilities, and health personnel through 1993, with emphasis on the needs in specific geographic areas.

Objectives:

- Project the distribution of the HIV-infected patient population through the year 1993, by severity of illness and/or levels of care required.
- Project needed services and facilities for people with HIV infection through the year 1993. These projections should be sensitive to the anticipated increase in the life expectancy of HIV-infected persons as new therapies are developed.
- Project the quantity and types of health manpower needed for all facets of HIV prevention and care.

Goal: Assist in coordinating service delivery.

Objectives:

- Implement a plan to achieve system coordination among AIDS grantees working in related areas of service delivery and receiving Federal support.
- Devise a plan to provide technical assistance to communities for the development of mechanisms to coordinate care for HIV-infected people, or for development of integrated care delivery systems that can meet the needs of HIV-infected people. Seek the involvement of minority populations in this process.
- Encourage appropriate policy-making and planning approaches at the State level, as part of a Federal-State-local response to the HIV epidemic, based on State-specific data bases and Federal aid in developing projection and planning methods.
- Continue the service demonstration grant program as a means of providing technical assis-

tance and leadership in the development of coordinated health care delivery systems for HIV-infected persons.

- Identify specific mechanisms to support adequate resource allocation and capacity development, within minority communities, so as to address health care delivery for minorities with HIV infection.
- Establish a program to develop systems of care for areas with low AIDS prevalence.
- Consolidate, where appropriate, by agency, Federal funding for service delivery programs that will encourage priority-setting and coordination at the State and local levels.

Issue: Community Care for HIV-Infected People

Caring for HIV-infected people in the community health care system requires continuity of care and availability of a comprehensive range of services and facilities. This means developing new types of services or facilities required by HIV-infected people and/or tailoring existing services or facilities to meet their particular needs.

People with HIV infection require comprehensive primary medical care for their health problems. Because the population of people with HIV infection includes large numbers of people from minority groups and people with special needs, it is important that community health systems have special sensitivities, tailored outreach programs, and specific facilities and services.

Goal: Identify and respond to the special needs of minorities in HIV prevention and care.

Objective:

- Using resources such as HRSA's AIDS service demonstration projects, community health centers, migrant health centers, and maternal and child health programs, develop targeted programs of risk reduction, health education, and comprehensive primary care for minorities at risk for HIV infection.
- Develop similar programs for other populations with special needs not addressed by general programs, e.g., homeless and/or runaway children, or the hearing impaired.

Goal: Mainstream AIDS prevention and treatment services into existing community health care systems whenever possible.

Objectives:

- Initiate programs to assist in the expansion of the delivery of health care services to minorities, women, children, and adolescents with HIV infection.
- Initiate a program to improve the range of health services provided to IV drug abusers, using community health centers and paying particular attention to preventive care and comprehensive primary care.
- Modify methadone maintenance regulations to allow for expansion of treatment capacity and inclusion, in primary care settings, of all types of drug abuse treatments (i.e., methadone maintenance, drug-free treatment, detoxification, day care for disabled adults, etc.).
- In order to improve the clinical management of HIV-infected patients, develop a system to improve information exchange and the linkage of care systems between health care providers and the clinical research community.
- Develop and implement a plan to increase private sector participation in the delivery of care to HIV-infected persons, by following the patterns of care provided to people with other diseases. This should include involvement of corporate America, the insurance industry, the volunteer community, and community-based service organizations.
- Develop incentives to increase the capacity of comprehensive primary care for HIV-infected people, including women and their families (drug treatment, dental care, nutrition counseling, mental/emotional health services, foster care, respite care, and day care).
- Develop and implement a plan to support and provide appropriate training of primary care dental providers and dental specialists, to alleviate a recognized deficiency in dental services for HIV-infected persons.

Goal: Encourage that the appropriate level of care be provided for persons with HIV infection.

Objectives:

- Develop mechanisms that assist in the reduction of the use of inappropriate specialized acute inpatient care facilities for HIV-infected people.

- Encourage programs that provide the use of a medical and social evaluation and placement service for patients with HIV infection.

Goal: Promote a comprehensive range of services for HIV-infected persons that will be appropriate for various stages of illness.

Objectives:

- Continue efforts to include case management in the delivery of health care to HIV-infected people, utilizing the experience of HRSA's AIDS service demonstration projects, community health centers and maternal and child health programs.
- Encourage programs that develop appropriate alternatives to traditional facilities and care programs for HIV-infected people, recognizing the full range and diversity of types of facilities and services needed. These include both transitional and longer-term housing.
- Continue to improve hospital discharge planning for people infected with HIV, with special emphasis on identifying the post-hospital care needs of the patient and matching them with an appropriate care source and/or facility.
- Formalize agreements with appropriate bodies to encourage the adaptation of licensure requirements and reimbursement restrictions so as to permit development of new types and combinations of nonacute care facilities and services for people infected with HIV.

Goal: Provide training to health care professionals and volunteers working with HIV-infected people.

Objectives:

- Institute a program to increase the involvement of minority providers (especially physicians) in primary care, health systems planning, risk reduction, health education, and HIV-training programs.
- Develop innovative approaches to expand training for health professionals.
- Develop appropriate training programs for volunteer workers, case managers, health educators, counselors, and related professionals dealing with HIV-infected people.

Goal: Improve access to care and expand treatment capacity and services for HIV-infected people, in-

cluding providing family-centered care where appropriate.

Objectives:

- Provide broader support of community-oriented primary care practice sites--such as community health centers, migrant health centers, and maternal and child health programs--in delivering care to HIV-infected people.
- Develop a plan to ensure training of enough primary health care providers to meet the needs of HIV-infected patients.
- Conduct research to determine the extent to which the compensation system is a barrier to care.
- Encourage States to review licensing of facilities and regulations related to infectious diseases.

Issue: Financing and Reimbursement

The American health care system is financed primarily through private insurance and self-pay efforts (59 percent) and secondarily through public sector programs at the Federal, State, and local levels (41 percent). The problem of underwriting health care for persons with HIV infection and clinical AIDS has seriously strained this system in a variety of ways. Barriers to care include refusal by private insurers to underwrite individual policies for persons who test positive for HIV, loss of employment-related group health insurance, variable coverage and eligibility policies of State Medicaid programs, reimbursement levels by private insurance and public programs at levels that do not encourage use of services and facilities commensurate with needs, and lack of coordination between health care and social service systems. There is the additional problem of uninsured persons who do not qualify for public program support. As a result of the combination and interaction of these elements, care tends to be provided in relatively expensive, acute care settings.

As new therapies are developed, the gaps in the financing system may present even greater problems. In addition to the direct cost of therapy, the therapies' success in prolonging life may result in additional costs. If new therapies are effective for asymptomatic HIV-infected persons, who may outnumber patients with clinical AIDS by 20 to 1, the cost implications will be profound. Moreover, as patients live longer, many may become eligible for Medicare, having outlived the 24-month waiting

period following determination of disability. As patients live longer, many more also will outlive the limits of insurance coverage.

Goal: Assess the implications, for financing mechanisms, of HIV infection's becoming a chronic disease.

Objectives:

- Support a joint review, by HRSA and the Health Care Financing Administration (HCFA), of the ability of the existing financing mechanisms, including Medicare and Medicaid, to meet the expected increase in demand for services and facilities as longevity increases. The review should identify barriers to the financing of appropriate care in private and public programs. HRSA and HCFA will work together to identify barriers in Medicaid policies, and to find solutions.
- Institute a study of the financial implications of HIV infection as a chronic illness requiring long periods of care at various levels of disability.
- Explore the advisability of awarding grants to States/communities to pay for care for HIV-infected individuals, including, for example, block grants to States, and categorical grants to providers.

Goal: Demonstrate innovative public/private financing for the prevention and treatment of AIDS.

Objectives:

- Institute a program to demonstrate innovative funding, financing, and reimbursement mechanisms, emphasizing noncategorical mechanisms including capitation.
- Through collaborative effort by HRSA and HCFA, seek ways to increase use of the current Medicaid waiver authorities to facilitate the availability of and access to appropriate services at various levels of care.
- Establish a program--using existing flexible Medicare and Medicaid experimental, demonstration, and waiver authorities--to support health care service delivery in residential settings that are cost-effective alternatives to long-term care for persons with HIV infection who are eligible for these programs.
- Project the need for financing the increased costs of health care delivery necessary to comply

with PHS recommendations to control the transmission of infection in health care settings.

Goal: Preserve and extend the private sector role in financing of care for people infected with HIV.

Objectives:

- Fund a study to explore the implications of private insurance coverage practices.
- Develop a strategy to review existing financing mechanisms and eliminate barriers to care caused by these mechanisms.

Issue: Counseling and Testing

As new therapies are shown to be effective, especially in asymptomatic persons, many more people "at risk" are likely to demand testing, possibly repeatedly. Under such a scenario, issues surrounding confidentiality will become more critical, and more counselors and test sites will be needed. All of these projected events will be of particular significance to those delivering health care.

Goal: Eliminate barriers to care resulting from fear of discrimination and concern about confidentiality.

Objectives:

- Support efforts to protect HIV-infected persons from discrimination in the health care system.
- Support efforts to protect confidentiality of information about persons who are counseled and tested for HIV infection.

Goal: Assess current needs and adequacy of services associated with voluntary counseling and testing, support the provision of these services in settings where high-risk populations receive medical care, and assess future needs.

Objectives:

- Identify the special counseling and testing needs of minorities, women with high-risk spouses, children, and families with AIDS.
- Review carefully the adequacy of counseling services in the present testing/screening process.
- Develop a plan to provide increased services as the availability of new therapies increases demand and project the expected increase in

need in test sites and trained counselors, and the costs associated with such an increase.

- Project the manpower needed to implement fully the PHS guidelines on counseling and testing in high-risk populations.
- Examine the implications for the health care delivery system of the expected sharp increase in counseling and testing over the next several years.

Issue: Health Services Research

Only minimal information is available on the cost, financing, and quality of health care services for HIV-related conditions. Most studies conducted are retrospective, focus on one risk group (homosexual/bisexual men), abstract data from small samples, have limited geographic scope, and deal solely with inpatient care. As a result, very little is known about the total national cost of treating the disease, let alone the variations in resource utilization by different risk groups or geographic areas. Particularly lacking is information on resource utilization by IV drug abusers, women, minorities, and children, and on the financial and provider barriers to care faced by entire families afflicted with the illness. Even less is known about the distribution of the financial burden across payers. Given the changing nature of the disease, its treatment, and the distribution of the populations suffering from the illness, much more needs to be known about the future public and private resources required to care for those with HIV-related conditions.

As familiarity with treating the disease broadens and effective treatment modalities multiply, the focal point for treatment may continue to shift to the outpatient sector--a trend that will have implications for access to care as well as for the cost and financing of care. Concerns with access and cost may further escalate as the prospect of effective treatment increases both demand for counseling and testing and subsequent use of additional health services.

Given the above, it is necessary to sponsor research on the cost and financing of HIV-related illnesses, as well as on the effectiveness of health care delivery as measured by such criteria as quality of care, access to care, and barriers to care. In order to achieve maximum benefit from the investment of health resources devoted to HIV-related illnesses, research needs to be conducted in a manner that most efficiently and effectively utilizes or-

ganized and ongoing community and clinical programs, and other existing research resources.

Goal: Support health services research on issues related to the utilization, cost, and financing of HIV-related care.

Objectives:

- Initiate a study to estimate total resource use and the distribution of the financial burden of care for HIV-related illnesses.
- Support research studies and projections on variations in patient care delivery and financing of care across geographic areas, risk groups, severity of illness, provider types, and treatment modalities. Particular attention needs to be paid to groups about which we have little information (e.g., women, children, minorities, intravenous drug abusers, and families facing the illness) and to services about which we know little (e.g., out-of-hospital support systems).
- Support development of models to estimate the ultimate cost and the distribution of the financial burden of HIV-related care, using varying assumptions about the manifestations of the illness, populations afflicted, treatment modalities, organizational setting, and methods of financing.
- Conduct studies to assess the efficiency and effectiveness of various preventive strategies, counseling and testing approaches, treatment modalities, organizational forms of care delivery (e.g., case management approaches), and alternative health care financing strategies.
- Support longitudinal cohort studies on utilization of health services by persons with HIV infection.

Goal: Support the development of measures of health and illness, as well as informational systems for HIV-related care.

Objectives:

- Initiate research to construct new, and improve existing, measures of illness severity and functional status.
- Implement a program to support the development of information systems, longitudinal disease data banks, and longitudinal cohort studies to permit analysis of cost-effectiveness and support for clinical decisionmaking.

- Develop new, and refine existing, health outcome measures, focusing on both quality of life and the quality of health care for those with HIV-related illness.

Goal: Support research on access to care, barriers to care, and quality of care, paying particular attention to special population groups (e.g., the medically disadvantaged, minorities, women, families, children and adolescents).

Objectives:

- Assess variations in the availability and quality of health care services.
- Initiate a study of the impact of barriers to care on health care utilization and outcome.
- Initiate a study to identify community and individual factors that promote or hinder establishment of HIV-related services.

Goal: Support research on health systems issues related to care of HIV-infected persons.

Objectives:

- Focus research on the development of research methods and studies in areas such as chronic care that are applicable to HIV-related patient care, delivery mechanisms, financing, training, or testing.
- Implement a study to assess the consequences of HIV-related illnesses in terms of provision of health care services, organization of health care, and availability of resources for the diagnosis and treatment of other illnesses.

Goal: Support research identifying organizational characteristics associated with efficient and effective delivery of HIV-related care.

Objectives:

- Initiate a study to compare the cost-effectiveness of centralized inpatient care (through use of dedicated units) with decentralized inpatient care (through use of scattered beds).
- Begin to assess the cost-effectiveness of various models of case management and models of patient care for HIV-related illnesses.
- Initiate a study that will analyze the effects of varying concentrations of HIV-related patients within facilities on patient care and facility operations.

- Initiate a study to analyze the effects of community and interorganizational coordination of HIV-related care.

Goal: Support research on issues related to health professionals providing HIV-related care.

Objectives:

- Initiate a project to identify the factors that influence patients' decisions about treatment choices.
- Assess how variations in the mix of health professional skills affect the delivery of HIV-related care.
- Initiate a study to investigate the issues of professional morale, and the financial and organizational inducements that may modify them.
- Project the supply of and requirements for health professionals providing HIV-related care.
- Project the training required for health professionals --and the cost of that training--to improve their knowledge of HIV-related illnesses and their attitudes toward, and treatment of, patients suffering from these illnesses.

Reference.....

1. Coolfont report: A PHS plan for prevention and control of AIDS and the AIDS virus. Public Health Rep 101: 341-348, July-August 1986.