FOIA Number: 2018-0756-F

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[Profile of the Current AIDS Service System in Four States February 26, 1993]

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DEPARTMENT OF HEALTH & HUMAN SERVICES

Health Care Financing Administration

6325 Security Boulevard
Baltimore, MD 21207

AUG 20 1993

for our services & finance leads

Ms. Kristine Gebbie
Office of National Aids Coordinator
Executive Office of the President
Washington, D.C. 20500

Dear Ms. Gebbie:

This is to follow-up on a question in our recent meeting with Bruce Vladeck pertaining to activities of the Office of Research and Demonstrations (ORD) in evaluating current HIV and AIDS services delivered under home and community-based waivers.

ORD is conducting a study of the current status and features of State Medicaid home and community-based waiver programs for persons with AIDS. Our evaluation contract for an AIDS demonstration mandated by OBRA '90 was modified to study this issue when no States submitted applications for this demonstration.

The contractor, Mathematica Policy Research, will profile the current AIDS service delivery systems to understand the changes that are occurring in the programs. Other States that are experiencing growing caseloads but have not applied for the waiver program may also be contacted. Four States also will be studied to help HCFA understand more fully the significance of Medicaid policy on the AIDS epidemic in States with emerging AIDS caseloads. The report will include both descriptive information and operational issues pertaining to waiver programs. I have attached the study designs for these evaluations as prepared by our contractor for your information. I am also attaching a brief synopsis of ORD's other research activities in the area of HIV and AIDS. I hope you will find these materials useful. Please do not hesitate to call me should you or your staff have any questions. My telephone number is (410) 966-6507.

Sincerely,

Joseph R. Antos Ph.D.
Director
Office of Research and Demonstrations

Attachments

Persons with HIV Related Illness and Medicaid
Research and Program Activity

An average of 40 percent of all persons with AIDS nationally are estimated to be served by the Medicaid program. In some geographic areas, especially those with large numbers of IV drug abusers, the percentage of persons served by Medicaid rises as high as 65 to 75 percent. Medicaid pays on the average about 25 percent of all direct medical expenditures for persons with AIDS nationally. Medicaid State and Federal expenditures for persons with AIDS are estimated to be $1.7 billion in fiscal year 1991, and rising to $3.5 billion in fiscal year 1996.

Future projection of total Medicaid utilization and expenditures for this population is difficult. Within geographic areas, persons with HIV illness vary by demographic, economic and severity of illness characteristics. Also, new technologies are becoming available so that persons with AIDS are living longer and require a network of medical and social services. In order to assess the impact of this population on the program and have a better understanding of Medicaid utilization by persons with HIV illness, HCFA has sponsored the following research projects.

The Costs of Treating AIDS Under Medicaid: 1986-1991

HCFA through the Rand Policy Center performed a study using available information from the health services literature focusing on projections of Medicaid costs for AIDS patients for this time period. This report was prepared for HCFA in May 1987, A RAND Note, N-2600-HCFA.

The Costs of AIDS to the American Health System

The Rand Policy Center continued to review health services research data for information on AIDS pathology, treatment costs, and intervention services. This project tested the feasibility of data collection from a group of AIDS patients in Los Angeles, on AIDS treatment costs and financing. A report was prepared for HCFA in February, 1990, RAND/N-3060-HCFA. Also, the project examined state policies and the availability of information on financing of AIDS services. The report was published in the Health Care Financing Review, Fall 1989.

AIDS-Specific Home and Community-Based Waivers for the Medicaid Population

This study reviewed the various state home and community based waiver projects for persons with AIDS. Current state programs as well as programs in development were analyzed to identify differences in the application of waivers to selected AIDS populations. Also, states with larger AIDS populations which have not applied for a

waiver were studied to investigate other ways states have been able to provide this population with home care. A report on Medicaid home and community-based waivers for AIDS patients was published in the Health Care Financing Review, 1990 Annual Supplement.

AIDS in California's Medicaid Program, 1981-1984

This study uses a set of specific ICDA-9 diagnosis codes representative of AIDS patients to identify the study population. It focuses on males, age 18-50, with AIDS in 1981-1984. An analysis of the changes in utilization and expenditures from Medi-Cal, by type of service for this time period is presented. This report was published in the Health Care Financing Review, Fall 1988.

Persons with AIDS in California's Medicaid Program, 1983-1986

This study uses the previously described diagnosis algorithm to identify AIDS patients and examines their utilization and expenditure patterns for the period 1983-1986. Also, the feasibility of extending the identification algorithm to women and children was explored. The study examines the longitudinal experience, annual trends and population differences in Medicaid use and expenditures. This report will be published in the Health Care Financing Review, Winter, 1991.

AIDS in Michigan and Georgia's Medicaid Programs, 1983-1986

This study examines utilization and expenditures for AIDS patients in two states with mid-range incidence of the disease. Eligibility and claims files from the Medicaid Tape-to-Tape project have been used to analyze trends in utilization rates per person and per month. A Tape to Tape working paper is available.

The Economic Consequences of AIDS and ARC on the Medicaid and Medicare Programs

This project was a cooperative agreement with the George Washington University. It used available information to explore AIDS financing and policy issues. Several papers were completed in the following areas; (1) the economic consequences of HIV infection for the Medicaid and Medicare programs, (2) private insurance and the HIV epidemic, (3) service needs of persons with AIDS, and (4) AIDS cost modeling. A report is published in the Health Care Financing Review, 1990 Annual Supplement.

AIDS Case Management in San Francisco: Trends and Issues

This report presents a descriptive analysis of the evolution of case management to provide medical care services for AIDS patients in San Francisco. The report is published in the Health Care Financing Review, 1988 Annual Supplement.

Research on AIDS Patients: Cost and Utilization Experience in New York and California

The study objectives of this project were (1) to use epidemiological techniques to produce an incidence analysis of AIDS over a four and a half year time period (October, 1982 to March, 1987), (2) to study the eligibility patterns of AIDS patients in Medicaid, (3) to develop a disease staging algorithm for AIDS Medicaid patients, and (4) to provide a utilization and cost analysis of this population. A report on this project is published in the Journal of Acquired Immune Deficiency Syndromes, Vol.4, No.10, 1991.

Survey of State Medicaid Coverage of AIDS-Related Drugs

This report focuses on an examination of policy among state Medicaid programs regarding drug coverage related to AIDS treatment and the approval process for drugs within each program as of June, 1990. A project working paper is available.

AIDS Related Drugs and State General Assistance Programs

This report presents information on eligibility, service coverage, recipients and expenditures for state general assistance programs with a particular focus on AIDS related drugs. A HCFA Medicaid Information Report, May 1991 is available.

The Effects of Human Immunodeficiency Virus (HIV) Epidemic on Uses of Medicaid by Women and Children

This study will determine the changes in State Medicaid programs that resulted from the spread of the epidemic of HIV-related diseases. An analysis of the effects of the AIDS epidemic on Medicaid expenditures, and service utilization will be performed. In particular, the study will review State AIDS programs to examine Medicaid use for women and children. Medicaid utilization for the AIDS population will be compared to use of the program by similar non-AIDS groups.

IDS Comprehensive Monitoring System Pilot Project

This project was funded under the Small Business Innovation Research Program. The project addresses the need for a comprehensive data collection, management and monitoring system for persons with HIV-related illness in alternative care settings. The objectives of the project are: (1) the identification of the service components and source of payment for services provided to persons with HIV-related illness receiving care in alternative care settings, (2) the identification of services requested by a patients with HIV-related illness which are currently unavailable through alternative care programs, (3) the development of standardized protocols for the collection of service and cost data under a model of comprehensive alternative care, and (4) the development of a microcomputer based system for the entry, management, and monitoring of costs in alternative care setting.

Financing of AIDS and ARC Treatment Costs by Medicaid and Medicare

This project is a cooperative agreement with Maryland Department of Health and Mental Hygiene. The study objectives are: (1) continuation and linkage of other health data bases to the Maryland Human Immunodeficiency Virus Information System (HIVIS), (2) refinement of a disease staging methodology for predicting resource consumption and treatment outcome, and (3) retrospective assessment of health services use by pediatric, adolescent, and adult persons with HIV-related disease.

Compendium of Medicaid Responses to Human Immunodeficiency Virus Infection and Acquired Immune Deficiency Syndrome

This report presents descriptive information regarding State Medicaid responses to the HIV and AIDS epidemic. This compendium provides a basis for States to compare their differing approaches to addressing HIV disease and making improvements in service availability and access for affected populations. A working paper is available.

Also, the following articles are available:

Roper, W. L., AIDS and the Role of the HCFA. Journal of the American Medical Association, 258(24):3489.

Roper, W. L., Winkenwerder, W., Making Fair Decisions About Financing Care for Persons with AIDS, Public Health Reports, 103(3):305-308.

Winkenwerder, W., Kessler, A., Stolec, R., Federal Spending for Illness Caused by Human Immunodeficiency Virus, New England Journal of Medicine, 320(24):1598-1603

For further information in this area, please contact Penny Pine at (410) 966-7718.

Evaluation of Medicaid Coverage for HIV-Positive Individuals

HCFA solicited applications from State Medicaid Agencies for demonstration projects mandated under section 4747 of the Omnibus Budget Reconciliation Act of 1990. The legislation mandated the implementation of a demonstration to assess the impact of Medicaid-covered services provided to HIV-positive individuals in the early stages of infection, and prior to Medicaid eligibility, compared to control group participants who receive the standard Medicaid benefit package once they become eligible for Medicaid coverage. The legislation provided for two demonstration projects in different States, limited to an enrollment of not more than 200 individuals. The projects were to have access to a control group of such individuals who were not receiving State or Federal payments for medical services before developing symptoms of AIDS. The closing date for applications was February 10, 1992. No State responded to the solicitation.

The contractor selected to conduct the evaluation of this demonstration was retained for one year to provide to derive information about State Medicaid coverage of individuals with HIV/AIDS. The contractor will undertake two separate studies.

The first study will examine the current service delivery system for persons with HIV/AIDS in the following four States: Illinois, Pennsylvania, Texas, and Georgia. These States were selected based on the following criteria: 1) a substantial number of reported AIDS cases, 2) a notable rate of growth of cumulative cases between 1991 and 1992, 3) a meaningful number of reported cases of women with AIDS, and 4) an adequate distribution of risk factors across the four States. The contractor is in the process of conducting site visits to these States and will compile the findings in a report.

The second study will address the current status and features of the 15 State Medicaid waiver programs for persons with AIDS. The contractor will examine the 7 States in particular that have been, or are in the process of being renewed in order to understand the changes that are being made to the programs during the renewal process and why. Other States that are experiencing growing caseloads but have not applied for the waiver program may also be contacted. The report will include both descriptive information and operational issues pertaining to the waiver programs.

For further information, please contact Debbie Van Hoven at (410) 966-6625

MATHEMATICA
Policy Research, Inc.

Contract No.: 500-87-0028; Mod. 36; D.O. 17
MPR Reference No.: 8027

PROFILE OF THE CURRENT MEDICAID WAIVER PROGRAMS FOR PERSONS WITH AIDS

STUDY DESIGN

DRAFT

February 26, 1993

Authors:

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Health Care Financing Administration
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Project Officer:
Debbie Van Hoven

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Project Director:
Craig Thornton

The Medicaid Home and Community-Based Waiver for persons with AIDS offers states an opportunity that is both enticing and frustrating. These waivers offer states considerable flexibility to design a service package to meet the health care needs of persons with AIDS. In this way, the waivers are attractive to states seeking to respond to the rapid growth of AIDS cases and the changing nature of the AIDS-related health care. At the same time, the requirement that the waiver programs be cost-neutral imposes a significant constraint. States must work to ensure that any expansions in community-based care are balanced by equivalent reductions in institutional care.

Our study will examine this tension in the Medicaid Waiver programs for persons with AIDS. We will start by documenting the programs fielded by the 15 states that have had AIDS-specific waivers. We will then draw on the information contained in waiver-program assessments conducted by HHS regional office staff and the states themselves to assess the cost-neutrality and operational success of the waiver program. In dong so, we will draw on a variety of data sources including (1) the documentation available at HCFA on the state waiver programs, (2) the prior literature about the waiver programs in general and about the waiver programs specifically for persons with AIDS, and (3) information collected during the site visits conducted in Study I.

While we have identified the types of data available at HCFA, the quality of the data is still uncertain. More specifically, we expect to find most of the data necessary for the documentation of the past and current AIDS waivers, although we may find some pieces missing. We are less confident, however, about the quality of the state and regional office assessments. We may find that these assessments are driven primarily by the cost-neutrality formula and thus provide us with too little detail to evaluate other aspects of the programs. Conversely, we may find that the evaluations are too unfocused to support more detailed analysis and synthesis. Thus, our analysis plan is contingent upon the quality of the data. In addition, we may utilize other sources of information, possibly including telephone discussions with state Medicaid directors or HCFA's Medicaid waiver staff to assess their decisions, plans, and opinions pertaining to the waivers.

In this design report, we present a brief discussion of the background and prior studies relevant to Medicaid AIDS-specific waivers, our analysis plan, data sources we expect to use in the study, and how we expect to report our results.

A. MEDICAID HOME AND COMMUNITY-BASED WAIVERS

Less than two weeks following his inauguration, President Clinton told an assembly of State Governors that he hoped to encourage states to obtain Medicaid waivers by easing the application process and administrative requirements of these waivers. These waivers allow states the flexibility to bypass certain Medicaid regulations in an effort to provide more and better-tailored services to persons on Medicaid while providing these services in a cost-efficient manner. One type of Medicaid waiver is known as the Home and Community-Based waiver, or the 2176 waiver. These waivers were originally authorized under Section 2176 of the 1981 Omnibus Budget Reconciliation Act (Section 1915[c] of the Social Security Act) to allow states to apply for a waiver of certain Medicaid regulations in order to provide an array of community-based services to 200 or more Medicaid-eligible persons who would otherwise be at risk of institutionalization. The legislation requires that waivers be cost-effective: average State per-capita expenditures for persons served by waiver programs may not exceed expected per-capita expenditures were there no waiver. Originally, Medicaid Home and Community-Based Waivers could direct services to four specific groups: (1) to persons who are over 65 years of age, (2) persons with disabilities, (3) persons with mental retardation, and (4) persons with mental illness. In 1985, persons with AIDS were added as a group to which 2176 waivers could be directed. Foster children under five years old who have HIV infection or were born dependent on heroin, cocaine, or phencyclidine were added to the legislation in 1988. In addition, states may apply for model waivers that are limited to groups smaller than 200 individuals who must all have the same condition and who would otherwise need to be treated in an institutional setting.

This study will profile the current Medicaid waiver programs that serve persons with AIDS. While the waiver programs account for a relatively small share of all Medicaid spending for persons

with AIDS, their targeting and flexibility make them an important program component to study. In 1991, Medicaid expenditures for persons with AIDS were approximately $1.7 billion of which less than 2 percent was for the waiver programs.[1] What makes these programs interesting to policy makers is the flexibility they give states to pursue innovative service-delivery programs that offer the promise of improving the quality of life for persons with AIDS while not increasing overall Medicaid costs. Thus, the waiver programs provide a testing ground for programs that may have applicability to other states, to the overall Medicaid program, or to the general system of services for persons with AIDS and HIV-infection.

B. AIDS AND THE MEDICAID WAIVERS

As States are trying to determine the best ways to serve persons with HIV infection, the service system and the target population are changing rapidly. When the first cases of AIDS were diagnosed in the early 1980's, the condition was treated as an acute terminal disease. However, now HIV infection can be diagnosed long before any AIDS symptoms develop and there are treatments that help prolong the healthy stage of life with the disease. HIV infection is now considered a chronic condition, with AIDS being a late stage in the disease process (Arno and Shenson, 1990; Merzel, et al, 1992). As a chronic condition, persons with HIV spend most of their time in the community rather than in inpatient settings. Thus, treatments and services for persons with HIV are shifting from institutionalized settings to the community (Arno and Shenson, 1990). Thus, the changing service system makes it difficult for states to know how to best serve persons with HIV infection.

Another change affecting the HIV/AIDS service system is the changing population of persons infected with HIV. While HIV originally affected primarily homosexual men, it is currently growing fastest among intravenous drug users, women, and children. While the homosexual community has played an important role in providing a service system for homosexual men with HIV, other at-risk

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[1]These figures were calculated from information obtained from unpublished tables prepared by the Health Care Financing Administration, Office of the Actuary and the Budget and Grants Branch.

groups are less likely to be able to develop strong community networks. Thus, these groups are more likely to require services provided through government programs.

Medicaid Home and Community-Based Waivers for AIDS may offer states the flexibility they need to expand the service system for persons with AIDS. Waiver programs can start small; in fact, they can provide services for a single person who would otherwise require a more expensive package of institutionalized care. As waivers waive the Medicaid requirement for services to be provided to all eligible persons in the state, states can target specific groups of persons served (perhaps persons with AIDS from a single urban location, a single age group, or gender) in order to provide benefits in the most cost-effective way. States can carefully tailor their service packages to a specific community's needs. In addition, the waivers' emphasis on community care is consistent with the AIDS service system's move towards home and community-based care. Finally, providing these services under Medicaid allows states to develop and test programs for persons with AIDS while over half of the cost is borne by Federal matching funds.

While Medicaid AIDS Waivers may provide many opportunities for States to expand their service systems for persons with AIDS, the cost-neutrality criteria pose a serious constraint on states' abilities to use the waivers. Medicaid waivers require that the total cost of serving persons under the waiver (including both waiver and non-waiver services) does not exceed the total cost of care for these persons in the absence of the waiver. Medicaid waivers for elderly persons or persons with disabilities typically try to reduce nursing home care in order to fund more community-based care. However, AIDS patients use virtually no nursing home care. States argue that cost-neutrality can be achieved for persons with AIDS by reducing hospital care in order to offset the costs of community-based care. In particular, they expect home and community-based services to reduce the inpatient costs of persons who would otherwise be the most expensive users of hospital services.

C. PRIOR RESEARCH

When Medicaid Home and Community-Based Waivers were first established in 1981, they marked an important change in the long-term care policies of the federal Medicaid program. Previously all Medicaid long-term care policies focused on medically-related services provided in institutional settings. For the first time in the history of the program, policies concerning social, community, and family services were incorporated into Medicaid (Laudicina and Burwell, 1988). The shift in policy seems to have reflected the hope that home and community-based care would be a cost-effective alternative to institutionalized care. It was believed that home and community-based care would delay or eliminate an elderly or disabled person's need for institutionalized care. Thus, home health care could pay for itself through the cost savings of reduced institutionalized care.

However, there has been extensive research suggesting that home and community-based care is not a cost-effective alternative to institutionalized care (Kemper, et al, 1986; Weissert, et al, 1988). While variations among research findings do exist, it is generally accepted that:

- The use of community-based care often has little effect on the use of nursing homes, hospitals, or other medical services.
- Community-based care is seldom a cost-effective alternative to institutional care. Cost-effectiveness requires that savings in institutional care offset the costs of community care. With no significant reduction in the use of institutional care, it is impossible to generate sufficient savings to pay for expanded community-based care.
- Targeting individuals who would be expensive long-term users of institutional care improves the ability to generate cost-effective home-based care. However, targeting has proven to be very difficult.
- Targeting appears to be most successful when it is directed at people already in or about to enter institutional settings.
- The use of community-based care may increase patient and caregiver's well being even if it fails to save money.

While the literature generally shows that home and community-based care has not been a cost-effective alternative to institutionalized care for elderly and disabled populations, states argue that

the distinct situations and needs of persons with AIDS may improve the likelihood that home health care be a cost-effective way to provide services for this population. In particular, the high rate of hospital use by persons with AIDS and the possibility of reducing expensive hospitalizations by providing less expensive community services make waiver programs for persons with AIDS more promising than the programs that sought to substitute community-based alternatives for nursing home care for impaired elderly persons.

There are two important studies of Medicaid waivers for persons with AIDS. The first, conducted by RAND (Jacobson, Lindsey, and Pascal, 1989), provides an overview of the authorizing legislation, a review of the literature on home and community-based programs in general, a summary of waiver programs in 1988, and a review of state policymakers' perceptions about the waiver program and its suitability for assisting persons with AIDS. The second, conducted by the Institute for Health, Health Care Policy, and Aging Research at Rutgers University (Merzel, et al., 1992), provides an in-depth description of New Jersey's Medicaid waiver program.

The RAND study described experiences of the first six states to have AIDS-specific home and community-based Medicaid waivers[2]. For these six states, the authors described characteristics of the AIDS populations served, the scope and coverage of the States' Medicaid programs, the types of services the states plan to provide under the waiver, and their experience in administering and monitoring the waiver. In addition to providing descriptive information about active waivers, the study highlights several common concerns of waiver states. These include:

- A perception that the cost-effectiveness formula was difficult to use due to its complexity and data requirements
- The lack of standardized data collection methodologies to support the evaluation process and allow comparisons across programs
- An interest in expanding the list of optional waiver services to include bed and board care

[2] The six states with Medicaid Waivers for AIDS as of January 1, 1989 and thus included in the RAND analysis were California, New Jersey, Ohio, South Carolina, Hawaii, and New Mexico.

The RAND team also surveyed a sample of states that did not have AIDS waivers. They compared state characteristics such as number of AIDS patients, the Federal Medicaid matching rate, and the number of optional Medicaid services that the state provides to form a better understanding of motivations for applying for a waiver. Primary conclusions from this analysis include the following:

- States are motivated to apply for waivers by large projected increases in the Medicaid-eligible AIDS population, state officials' commitment to providing a broad array of services, and the attractiveness of high Federal matching rates.
- States were deterred from applying because of administrative burden (particularly that associated with the cost-effectiveness formula), insufficient flexibility in the provision of services under the waiver, and low incidence of AIDS.
- The cost-effectiveness formula was "probably the most consistent and insistent concern expressed by the states."
- Overall, states (both with and without the waiver) generally find the waiver to be a promising way of expanding home and community services for Medicaid-eligible persons with AIDS.

The RAND study provides a good description of waiver use in 1988 as well as its potential to improve services without increasing costs. However, at the time it was written, the waiver programs were too new to evaluate. Thus, the RAND report raises many unresolved issues. Those concerning program policy and effectiveness include:

- Should states continue to be required to demonstrate cost-efficiency (budget neutrality) or should the expansion of services at some increased cost be acceptable?
- What would be the effect of expanding services to persons with HIV infection but not AIDS?
- Could the application process, evaluation process, and cost-efficiency formula be simplified to be less of a burden on the states while still providing the Federal government with sufficient information to monitor the waiver programs?
- How should volunteerism and family participation in providing care be fostered in the waiver program? How does the trend toward increased care of persons with AIDS by family members affect the types of services most needed?
- Would it be worthwhile to have HCFA supply assistance in data base development in order to ensure that data across states are consistent?

The Rutgers University team focused their study on the New Jersey AIDS Community Care Alternatives Program, the nation's first Medicaid AIDS waiver program. They summarize the organizational, delivery, and financing issues associated with HIV, provide an overview of the research on Medicaid waivers in general, and provide a detailed review of the New Jersey Medicaid waiver program for persons with AIDS. Their analyses used case records, Medicaid claims data, data collected from clients at the time of their enrollment, and interviews with program case managers and clients. The authors provide a thorough description of the population served, program utilization patterns and cost, and access to services.

Their most important conclusions include:

- The Medicaid waiver has enabled New Jersey to expand the number of persons who can receive benefits through Medicaid while keeping expenditures well below the federally established ceiling.
- Waiver patients in New Jersey have shorter inpatient stays and less acute hospital care than do other inpatient New Jersey or Medicaid AIDS populations.
- Further research will be necessary to determine whether the addition of waiver services might reduce overall Medicaid expenditures for persons with AIDS.
- Other services beyond the scope of the home and community-based waivers (in particular, housing) continue to need to be addressed in order to more fully meet the needs of poor persons with AIDS.

D. ANALYTIC APPROACH

In examining the tension states face between the benefits of having a Medicaid AIDS waiver versus the difficulty in making the waiver services cost-neutral, we will focus on three research issues. First, we will update RAND's work by documenting the programs in the states with AIDS waivers on such topics as population served, services covered, expenditures, and trends over time. There are nine additional states that have had Medicaid waivers for persons with AIDS since the time of the RAND report. Thus, we will be able to document the service packages and eligible populations of the new programs and see how these may have changed over the years as the AIDS services system

and the population of persons with AIDS changes. In addition, we will see if the first states with AIDS-specific waivers have modified or eliminated their waiver program. Second, we will analyze the cost-neutrality requirement. We will start by documenting HCFA's measures of cost-neutrality. We will then see whether states have successfully met some or all of these criteria. In particular, we will try to determine which state programs have had the most success in meeting the cost-neutrality requirements. Third, we will document operational issues that arise from the HHS regional-office evaluations and the state evaluations. Topics covered in this part of the analysis will depend on what we find in the program evaluations. However, we hope to address such issues as access to services, quality of care, and program perceptions.

1. Descriptive Information on Home and Community-Based Waivers Serving Persons with AIDS

The descriptive portion of this analysis will focus on four topics. First, using the waiver documentation and other reference materials, we will collect data for all states on their overall population, AIDS population, and basic Medicaid eligibility requirements. We will present this data highlighting the states that have waivers serving persons with AIDS. Using this data we will compare states with waivers to those without waivers. This will help to provide the context for considering the AIDS pandemic and its effect on the States. This may also reveal specific characteristics of the states that have chosen to apply for AIDS-specific waivers. Second, we will collect descriptive characteristics of the waiver programs. In particular, we will look at eligibility requirements and program coverage. From the eligibility requirements (for example, whether services are provided to persons with HIV infection who are not AIDS symptomatic), we hope to compare the generosity and targeting of the various programs. Program coverage may allow us to identify trends in community-based care for persons with AIDS and the service issues addressed by the waiver programs. Third, we will document the program expenditures for each year and compare these to what was expected with the waiver and without the waiver in the application materials. From this analysis, we hope to determine whether waiver programs proceeded as planned by the state. In particular, we will see

whether programs were over or under budget and whether there were appreciable savings due to reductions in use of institutional care. Fourth, we will collect information on the number of persons served each year under each state's waiver program. We will compare these figures to the expected number served found in the application materials. Like the expenditure data, this information will help us to determine whether the waiver proceeded as planned. It will also help us to explain ways expenditures differed from what was expected. Tables 1 through 5 illustrate how we will present the results of our data collection. We will also try to obtain this information for the states that serve persons with AIDS under waiver programs targeted more broadly to persons with disabilities, to the extent that persons with AIDS can be identified in the program reports and statistics.

2. Cost-Effectiveness

HCFA's waiver staff apparently use several criteria in determining a program's cost-effectiveness. Therefore, we will begin our look into the cost-effectiveness requirement by analyzing the different formulas used and describing which aspects of cost-control each formula highlights. In comparing the formulas, we will discuss ways in which we believe certain programs might successfully meet some cost-effectiveness criteria while failing others. We will present the formulas in the final report.

Next, we will take cost information from completed annual reports and enter it into the formulas to determine the extent to which programs have successfully met the various cost-effectiveness criteria. We will then look back to the evaluation, regional assessment, and annual report materials to help us better explain the difficulties or successes in meeting the cost-neutrality requirements. We will also talk to HCFA's Medicaid waiver staff to determine how they use the formulas to determine whether a waiver should be renewed or to provide guidance to a state program.

Finally, we will analyze issues of meeting current cost-effectiveness standards in the future based on expected trends in the AIDS population and in treatment methodologies for persons with AIDS. For example, we will look at how the service systems' change from inpatient to outpatient care will effect states' abilities to meet the cost-effectiveness requirement of the Medicaid waiver program.

TABLE 1

STATE POPULATION CHARACTERISTICS

	State Population	Medicaid Eligibility Requirements[a]	Cumulative Number of Persons with AIDS--June 1992	Percent Growth in the Number of Persons with AIDS	
				1989-1990	1991-1992
Alabama					
Alaska					
Arizona					

SOURCE: Current Population Statistics, Census; Medicare and Medicaid Data Book; HIV/AIDS Surveillance Reports, CDC.

NOTE: This table will contain data for all 50 states.

TABLE 2

CHARACTERISTICS OF MEDICAID WAIVERS FOR PERSONS WITH AIDS

State	Waiver ID Number	Waiver Start Date	Status: I (Initial) R (Renewal) E (Expired) P (Pending)	Type of Waiver (Date) Regular or Model	Persons Served (Date)	Population Characteristics	AIDS Specific or Disability Waiver	Number of AIDS Patients (Date)	Rank in Reported Number of AIDS Cases	Proportion of State Population with AIDS	Number of Optional Medicaid Services	FY 1992 FMAP Percentages[a]	Waiver Expenditures per Person Served	Waiver Expenditures
Data Source	Health Care Financing Administration (Duckett)				HCFA (Form HCFA 372's and Waiver Applications)		HCFA (Duckett)	Centers for Disease Control, HIV/AIDS Surveillance Report			Medicare & Medicaid Data Book	CCH Medicare & Medicaid Guide	HCFA (Form HCFA 372)	
California	0183	01/01/89	I[b]	Regular			AIDS					50.00		
Colorado	0211	01/01/91	I	Regular			AIDS					54.79		
Delaware	40149	01/01/91	I	Model			AIDS					50.12		
Florida	0194	11/01/89	I	Regular			AIDS					54.69		
Hawaii	0182	04/01/89	E	Regular			AIDS					52.57		
Hawaii	0182.90	06/01/92	R	Regular			AIDS					52.57		
Illinois	0202	10/01/90	I	Regular			AIDS					50.00		
Illinois	0142	10/01/86	E	Regular			Disability					50.00		
Illinois	0142.90	10/01/89	R	Regular			Disability					50.00		
Illinois	40147	01/01/88	I[b]	Model			Disability					50.00		
Illinois	40147.90	--	P	--			Disability					50.00		
Illinois	40167	--	P	--			Disability					50.00		
Maryland	0197	07/01/91	I[b]	Regular			AIDS					50.00		
North Carolina	40141	07/01/87	E	Model			Disability					66.52		
North Carolina	40140.90	07/01/90	R	Model			Disability					66.52		
New Jersey	0160	03/01/87	E	Regular			AIDS					50.00		
New Jersey	0160.90	03/01/91	R	Regular			AIDS					50.00		
New Mexico	0161	07/01/87	I[b]	Model			AIDS					74.33		
New Mexico	0161.90	--	P	--			AIDS					74.33		
Ohio	0180	01/01/88		Model			AIDS					60.63		

TABLE 2 (continued)

State	Waiver ID Number	Waiver Start Date	Status: I (Initial) R (Renewal) E (Expired) P (Pending)	Type of Waiver (Date) Regular or Model	Persons Served (Date)	Population Characteristics	AIDS Specific or Disability Waiver	Number of AIDS Patients (Date)	Rank in Reported Number of AIDS Cases	Proportion of State Population with AIDS	Number of Optional Medicaid Services	FY 1992 FMAP Percentages[a]	Waiver Expenditures per Person Served	Waiver Expenditures
Ohio	0228	--	P	--			AIDS					60.63		
Pennsylvania	0192	04/01/90	I	Regular			AIDS					56.84		
South Carolina	0186	08/01/88	I[b]	Regular			AIDS					72.66		
South Carolina	0186.90	10/01/91	R	Regular			AIDS					72.66		
Virginia	40160	01/01/91	I	Model			AIDS					50.00		
Washington	0206	07/01/90	I	Model			AIDS					54.98		

[a]FMAP is the Federal Medicaid Assistance Percentage or the proportion of State's Medicaid expenditures that is reimbursed by the Federal government.

[b]Expires in September 1992.

TABLE 3

SERVICES AUTHORIZED IN STATE MEDICAID WAIVERS FOR PERSONS WITH AIDS

			Services Authorized in State Waiver Programs									
State	Waiver ID Number	Waiver Start Date	Case Management	Homemaker	Home Health Aide	Personal Care	Adult Day Care	Habilitation	Day Treatment, Partial Hospitalization, and Other Services for the Chronically Mentally Ill	Respite Care	Psychological Rehabilitation and Clinic Services	Other
California	0183	01/01/89	X	X		X				X	X	X
Colorado	0211	01/01/91	X		X	X	X					X
Delaware	40159	01/01/91	X	X		X			X	X	X	X
Florida	0194	11/01/89	X	X		X			X	X		X
Hawaii	0183	04/01/89	X			X		X	X	X	X	X
Hawaii	0182.90	06/01/92	X			X			X	X	X	X
Illinois	0202	10/01/90	X		X	X				X		X
Illinois	0142	10/01/86		X	X	X	X					
Illinois	0142.90	10/01/89		X	X	X	X					
Illinois	40147	01/01/88			X	X				X		X
Maryland	0197	07/01/91				X						X
North Carolina	40141	07/01/87	X			X				X		X
North Carolina	40141.90	07/01/90	X			X				X		X
New Jersey	0160	03/01/87	X			X			X			X
New Jersey	0160.90	03/01/91	X			X			X			X
New Mexico	0161	07/01/87	X	X		X	X					X
Ohio	0180	01/01/88	X	X		X			X	X	X	X
Pennsylvania	0192	04/01/90		X	X	X						X
South Carolina	0186	08/01/88	X			X					X	X
South Carolina	0186.90	10/01/91	X			X					X	X
Virginia	40160	01/01/91	X			X				X		X
Washington	0206	07/01/90				X			X	X	X	X

TABLE 4

EXPECTED AND ACTUAL NUMBER OF PERSONS SERVED UNDER THE MEDICAID WAIVERS FOR PERSONS WITH AIDS

	Expected Numbers Served		Actual Numbers Served	
	AIDS Waiver	Other Medicaid Services	AIDS Waiver	Other Medicaid Services
California				
Year 1: 1/1/89 to 12/31/89				
Year 2: 1/1/90 to 12/31/90				
Year 3: 1/1/91 to 12/31/91				
Colorado				
Year 1: 1/1/91 to 12/31/91				
Year 2: 1/1/92 to 12/31/92				
Year 3: 1/1/93 to 12/31/93				

SOURCE: Waiver Applications; Form HCFA-372.

NOTE: This table will contain data for all states that have had Medicaid AIDS waivers.

TABLE 5

EXPECTED AND ACTUAL MEDICAID EXPENDITURES OF STATES WITH MEDICAID WAIVERS FOR PERSONS WITH AIDS

	Expected Expenditures		Actual Expenditures	
	AIDS Waiver Services	Other Medicaid Expenditures	AIDS Waiver Services	Other Medicaid Expenditures
California				
Year 1: 1/1/89 to 12/31/89				
Year 2: 1/1/90 to 12/31/90				
Year 3: 1/1/91 to 12/31/91				
Colorado				
Year 1: 1/1/91 to 12/31/91				
Year 2: 1/1/92 to 12/31/92				
Year 3: 1/1/93 to 12/31/93				

SOURCE: Waiver Applications; Form HCFA-372.

NOTE: This table will contain data for all states that have had Medicaid AIDS waivers.

3. Operational Issues

Using the Regional DHHS assessments conducted for states renewing their waiver programs, we will profile any operational successes that appear to deserve wider dissemination and any unanticipated problems that other states should avoid. While the topics covered in this section will depend on those covered in the assessments, possible issues include access to services, quality of care, the role of case managers, recruitment of program participants, perceptions of the program by patients, informal caregivers, and Medicaid staff. If possible, we will also assess concerns and desires of the states towards the management and requirements of the waiver program.

E. DATA SOURCES

The descriptive analysis of the Medicaid waiver programs will draw primarily on data from the states that have had AIDS waiver programs and the regional DHHS assessments of those programs that have applied for renewal. In addition, we may interview individuals from state Medicaid offices or from HCFA's waiver office to discuss issues such as the decision to apply for a waiver, difficulties with the waiver program, and meeting the cost-neutrality requirements.

1. Documentation at HCFA

For each waiver program, HCFA may have as many as four different types of documents: (1) the waiver application and supplementing correspondence, (2) annual reviews (Form HCFA-372), (3) a State program evaluation, and (4) a DHHS regional office program evaluation.

Waiver Application. There is no formal application for a home and community-based waiver. However, states are required to provide HCFA with the following information concerning their waiver program:

- Scope of waivers requested
- Description of waiver participants
- Services to be provided

- Safeguards and evaluations
- Plan of care
- Freedom of choice assurances and documentation
- Cost-effectiveness assurances and documentation

In a recent discussion with Bob Wardwell and his staff of the Division of Policy Coverage at the Medicaid Bureau, we learned that an accepted state application includes the state's initial request plus extensive correspondence between HCFA staff and the state in which the program description and goals are redefined. Thus, in order to use the application materials we will need to review all correspondence between HCFA staff and the state. The extensive revisions and correspondence will make extracting information from state waiver applications a more time consuming task than was previously expected. We will use application materials primarily to document basic program characteristics (target group, expected number of persons served, expected program expenditures, covered services, program management and goals).

Annual Reviews (Form HCFA-372). States are required to submit Form HCFA-372 for each year of waiver program operations. The data collected include the number of waiver recipients and their costs for waiver specific and regular Medicaid services. The data collected in the annual reviews is then used to determine program cost-effectiveness. Thus, by looking at these forms we should be able to determine in what ways cost-effectiveness criteria are met and in what ways actual Medicaid use and costs differed from that expected in the application.

States are supposed to submit their first annual report within six months of the completion of the first year of waiver operations. However, states are often granted an extension for filing these reports. Thus, no form HCFA-372s had been submitted at the time of the RAND study in 1988. Our sense from speaking to Bob Wardwell is that states are often delinquent in submitting these reports so we may find that HCFA has few annual reviews for waiver programs' recent years. In addition, the lag in the time necessary for all Medicaid claims to be counted requires that some states

resubmit an updated annual review at a later date. However, the annual reviews are an important source for determining program cost-effectiveness and thus will be used extensively in this analysis.

State Evaluations. States are required to submit independent evaluations of their waiver programs to HCFA. While these evaluations may allow us to get a better feel for state perceptions of the waiver programs, Bob Wardwell warned us that the evaluations are extremely varied in terms of the level of detail presented (some are three pages; others are quite comprehensive) and topics covered. Thus, we are currently not planning to focus our analysis on these evaluations although they may become of greater use as the process moves forward.

Regional-Office Assessments. Each state applying for a renewal of its waiver program must be evaluated by its Regional Department of Health and Human Services. This assessment of the program is then submitted to both HCFA and the state and plays a role in HCFA's decision whether to renew the waiver. Our impression is that these assessments are the most consistent available source of evaluative information on the state waiver programs. We expect to focus our discussion of operational issues and findings on these assessments rather than the State evaluations because we expect the assessments to be more consistent and to highlight issues in more detail than most of the state evaluations.

2. Other reference materials

While we will not be conducting a full literature review, we will consult current literature to provide use with the necessary background from which to conduct our analysis. Reference materials we expect to use include (1) literature on other waiver programs, (2) data and published information on AIDS including the CDC's AIDS Public Information Data Set, (3) Medicaid data, and (4) state population statistics. In addition, we will use the literature review conducted as part of Study I to help inform our analysis.

3. Other data sources

While this study will focus on the AIDS waiver documentation described above, we will look to other data sources to help us develop a fuller picture of the experiences, use, and cost issues associated with the Medicaid waivers for persons with AIDS. Other data sources we may draw from include: interviews and discussions with HCFA staff working on the Medicaid waivers; interviews of state Medicaid staff for states with waiver programs; and interviews of state Medicaid staff in states with large AIDS populations that have chosen not to apply for Medicaid waivers. In addition, Bob Wardwell and his staff seem to be an excellent resource in helping us interpret our findings or fill gaps in our understanding of the waiver programs.

D. DATA LIMITATIONS

As we have recently learned from Bob Wardwell, the documentation of the waiver programs for persons with AIDS is loosely organized and may lack key data items. Therefore, the number of waiver programs included in the analysis will depend on what data are available at HCFA. In particular, only a few programs are likely to have had regional office assessments so our analysis may be based on a very small sample size. Also Bob Wardwell suggested that lags in claims data may cause some of the data from the Form HCFA-372 to be questionable. We will work with HCFA staff when inconsistencies or questionable data is found.

In addition, we would like to include information on services for persons with AIDS who are covered under the broader based waivers for person with disabilities. However, we will do so only if we find that services and costs of persons with AIDS can be differentiated from all other persons covered in the programs.

Finally, we have left the methods of analysis flexible to the possibility of interviewing State Medicaid staff to gain more information about the decision to apply for a waiver or their experiences serving Medicaid-eligible person with AIDS. In our proposal, we planned to conduct interviews with Medicaid staff from each of the 15 states that have had Medicaid AIDS Waivers in order to

understand state perceptions and plans pertaining to the value of the AIDS waivers. While it would be useful to have this information, we are no longer convinced that this would be the best use of this project's resources. Therefore, as the analysis proceeds, we will evaluate whether these interviews should be conducted or whether we should focus on a more detailed document review than our current plans allow.

E. PRELIMINARY SCHEDULE AND OUTLINE

1. Schedule

The work on this project will be conducted in two phases (see Table 6). The first task, documenting information on the waiver programs for persons with AIDS, will be conducted over the next few months with the initial data collection taking place in March and the analysis and writing being done in April and May. The draft section of the report covering the first phase of the study will be sent to HCFA for review in the end of May. The second task, analyzing cost-effectiveness and operational issues, will begin in September with the draft report being written by the end of November.

2. Preliminary Outline

The documentation of the waiver programs and the analysis of the cost-effectiveness and operational issues will be reported in a single report next November. Table 7 present an outline for the final report profiling the Medicaid AIDS waiver programs.

TABLE 6

WORK SCHEDULE

Task	Date
Design	February 26
Part 1: Descriptive Information on Waiver Programs	
Data Collection	March
Documentation/Writing	April - May
Draft of Part I sent to HCFA for Review	May
Part 2: Evaluations and Indicators of Performance	
Data Collection	September
Documentation/Writing	October-November
Final Report, Draft	November
Revised Report	December

TABLE 7

PROFILE OF MEDICAID WAIVER PROGRAMS FOR PERSONS WITH AIDS

INITIAL WORKING OUTLINE

I. Introduction

II. Background and Prior Research

- A. Overview of the Waiver's Legislation and History
- B. Prior Research
  - 1. Home and Community-Based Care
  - 2. Waiver-Specific Research
  - 3. AIDS Waiver Research

III. Data Sources

IV. Characteristics of the Medicaid Waiver Programs for Persons with AIDS

- A. Population, AIDS Population, and Medicaid Characteristics of All 50 States
- B. Eligibility and Coverage of Waiver Program in 15 States with Waivers
- C. Waiver Program Expenditures
- D. Use of Waiver Program

V. Cost-Effectiveness

- A. HCFAs Cost-Effectiveness Criteria
- B. Current and Past Medicaid AIDS Waivers' Cost-Effectiveness
- C. Trends in AIDS Service System and Population Growth and Their Likely Effect on Cost-Effectiveness

VI. Operational Issues

VII. Conclusions

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PROFILE OF THE CURRENT AIDS SERVICE SYSTEM IN FOUR STATES

STUDY DESIGN

February 26, 1993

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INTRODUCTION

The purpose of this study is to provide the Health Care Financing Administration (HCFA) with information on the impact of Medicaid on the development, funding, coordination, and improvement of the AIDS service delivery system in States in which the epidemic is now beginning to emerge in substantial numbers. These States are regarded as second and third wave States. We expect to provide considerable information on the impact of Medicaid policy, waivers, and program characteristics on a number of broad areas relative to AIDS (e.g., Ryan White CARE Act activity; the service delivery system with particular regard to women and children; utilization of and expenditures for services; State and local planning, organization, cooperation, and coordination of services; access and impediments to services; service provider and practitioner participation; innovative and creative solutions to unique service needs). These data will help HCFA understand more fully the significance of Medicaid policy on the AIDS epidemic in States with emerging caseloads.

SITE SELECTION

The first step in the site selection process is to gather State-specific information about the AIDS population, Medicaid program characteristics, and Ryan White funding. We propose limiting the analysis to the 20 States with the largest reported number of AIDS cases. Selected data for these States are shown in Exhibit 1. Because HCFA's interest is in second and third wave States and not those already studied extensively, we suggest excluding New York, California, New Jersey, Maryland, and Florida.

The selection criteria we propose require 1) a substantial number of reported AIDS cases per State, 2) a significant rate of reported AIDS cases per 1,000 population, 3) a notable rate of growth of cumulative cases between 1991 and 1992, and 4) a meaningful number of cases of women with AIDS. We suggest the following inclusion criteria: a minimum number of cases per State (i.e., 2,000); a minimum rate of AIDS per 1,000 population (i.e., 0.5); a minimum cumulative total 1991-to-1992 growth rate (i.e., equal to or greater than 25 percent); and a minimum number of reported cases

EXHIBIT 1

POPULATION, MEDICAID, AND RYAN WHITE TITLE I CHARACTERISTICS
FOR THE 20 STATES WITH THE LARGEST POPULATION OF PERSONS WITH AIDS

	Population Characteristics					Medicaid Program Features				State-Only AIDS Funds		Ryan White Title I Funds		
State	Cumulative Number of AIDS Patients (June 1992)	Rank in Reported Number of AIDS Cases	Aprox. Rate of AIDS in State (per 1,000 persons)	Growth Rate 1991-1992	Reported Cases of Women with Aids 1992	Total Medicaid Expenditures 1990 (mil. dol.)	Optional Services 10/1/91	Change in Optional Services	Medicaid AIDS Waiver	Change in State-Only AIDS Funds FY1990 to FY1991	Rank in State-Only AIDS Funds FY1991	Number of Cities Receiving Title I Funds	Formula Grant Amount for FY 1993	First Year State Received Title I Funds
California	42755	2	1.41	24.71%	1748	6517	30	4	AIDS	0.21%	2	5	$23,198,407	1991
Colorado	2260	20	0.67	23.77%	105	516	18	1	AIDS	-3.45%	41			
Connecticut	2628	18	0.80	22.35%	531	1205	24	0		32.20%	13			
DC	3819	11	6.39	26.21%	334	246	23	1		19.79%	15	1	$3,313,635	1991
Florida	22097	3	1.66	30.64%	3637	2361	24	5	AIDS	8.03%	3	3	$7,804,533	1991
Georgia	6476	7	0.98	33.55%	587	2076	14	0		20.46%	14	1	$2,445,365	1991
Illinois	7153	6	0.62	33.98%	555	2424	25	0	Disabled and AIDS	22.36%	8	1	$2,707,310	1991
Louisiana	3460	12	0.81	31.46%	264	1315	14	0		153.03%	9	1	$1,104,782	1993
Maryland	4675	10	0.96	28.50%	747	1090	22	1		10.46%	10	1	$1,312,875	1992
Massachusetts	4736	9	0.79	22.16%	628	2730	27	-3		-1.49%	4	1	$1,663,443	1991
Michigan	3064	15	0.33	35.16%	370	2195	26	-2		14.58%	5	1	$955,066	1993
Missouri	2831	17	0.55	33.41%	151	897	17	0	AIDS	6.26%	24			
New Jersey	13786	5	1.78	19.10%	3124	2298	26	0	AIDS	-6.61%	7	2	$5,181,454	1991
New York	46608	1	2.58	20.94%	7689	11877	26	0		31.96%	1	2	$29,618,956	1991
North Carolina	2582	19	0.38	34.13%	379	1426	23	2	Disabled	0.00%	30			
Ohio	3296	13	0.30	29.61%	216	3132	23	-1	AIDS	10.67%	17			
Pennsylvania	6351	8	0.53	27.53%	643	2883	19	3	AIDS	5.59%	16	1	$2,194,694	1991
Texas	15929	4	0.92	24.71%	773	2781	20	0	AIDS	60.10%	6	2	$5,420,546	1991
Virginia	3061	16	0.49	28.02%	305	985	21	-5	AIDS	16.29%	11			
Washington	3080	14	0.61	22.66%	117	952	28	1	AIDS	15.53%	12	1	$1,091,801	1993

EXHIBIT 1 (continued)

DISTRIBUTION OF MEANS OF TRANSMISSION WITHIN THE 20 STATES WITH THE LARGEST POPULATIONS OF PERSONS WITH AIDS

	Adult/adolescent Exposure to HIV								Pediatric Exposure to HIV			
State	Men Who Have Sex With Men	Injecting Drug Use (Female and Heterosexual Male)	Men Who Have Sex With Men and Inject Drugs	Hemophilia/ Coagulation Disorder	Heterosexual Contact With High Risk HIV	Born Pattern-II Country	Receipt of Transfusion, Blood Components, or Tissue	Other/ Undetermined	Hemophilia/ Coagulation Disorder	Mother With, or at Risk for, HIV Infection	Receipt of Transfusion of Blood, Blood Components, or Tissue	Other/ Undetermined
California	77%	6%	8%	1%	2%	0%	2%	3%	0%	0%	0%	0%
Colorado	75%	6%	9%	2%	3%	0%	2%	2%	0%	0%	0%	0%
Connecticut	35%	41%	4%	1%	9%	1%	1%	5%	0%	3%	0%	0%
District of Columbia	68%	16%	6%	0%	3%	0%	1%	4%	0%	1%	0%	0%
Florida	50%	20%	6%	0%	10%	6%	2%	3%	0%	2%	0%	0%
Georgia	63%	16%	6%	1%	6%	0%	2%	5%	0%	1%	0%	0%
Illinois	77%	2%	5%	1%	5%	1%	3%	4%	0%	1%	0%	0%
Louisiana	65%	10%	9%	1%	4%	0%	4%	7%	0%	1%	0%	0%
Maryland	49%	28%	5%	1%	6%	1%	4%	5%	0%	2%	0%	0%
Massachusetts	54%	24%	4%	1%	4%	5%	2%	3%	0%	2%	0%	0%
Michigan	56%	23%	5%	2%	4%	0%	2%	6%	0%	1%	0%	0%
Missouri	75%	7%	7%	3%	3%	0%	2%	2%	0%	1%	0%	0%
New Jersey	26%	52%	3%	1%	9%	1%	2%	2%	0%	3%	0%	0%
New York	41%	41%	4%	0%	4%	2%	1%	5%	0%	2%	0%	0%
North Carolina	47%	22%	6%	2%	9%	0%	3%	9%	0%	2%	0%	0%
Ohio	72%	8%	6%	2%	3%	0%	2%	4%	0%	1%	0%	0%
Pennsylvania	30%	34%	12%	3%	8%	0%	4%	5%	0%	3%	0%	0%
Texas	71%	8%	10%	1%	2%	0%	2%	5%	0%	1%	0%	0%
Virginia	66%	13%	4%	1%	5%	0%	4%	5%	0%	2%	0%	0%
Washington	76%	5%	11%	1%	2%	0%	2%	2%	0%	0%	0%	0%

of AIDS in women (i.e., 300). We also propose including selected Medicaid program services as part of our selection criteria. For example, we suggest including States with and without waiver programs, and we would like to include States with good data systems and readily available data.

We will want to examine Medicaid program characteristics. They may include items such as optional services; eligibility criteria and coverage rules; enrollment procedures; reimbursement policy for institutional, physician, and outpatient services and prescription drugs; and alternative delivery and payment systems such as waivers or managed care programs. We will also plan to gather data on the availability of and reimbursement for selected provider types that are particularly germane to the delivery of services through alternative means or through optional services. For example, what is the availability of and Medicaid reimbursement rate for those services most relevant to beneficiaries with AIDS--private duty nursing, personal care service providers, case management, hospice care, respiratory care, and so forth.

We want to examine Medicaid's involvement with the group(s) responsible for Ryan White Title I funding and planning. Therefore, we suggest including States with Ryan White funding. To more fully understand the interactions between Medicaid and Ryan White funds, we suggest that funding should be available for at least one complete year (i.e., 1992 or earlier) to be eligible for inclusion in a site visit. Our effort will build and expand upon the information already available (e.g., article published by Bowen et. al in the September-October 1992 *Public Health Reports* and other sources).

Based on all of these criteria, we recommend that the case study include the District of Columbia, Georgia, Illinois, and Pennsylvania as the four study states. Including these four states will provide substantial information on Medicaid and its role in the continuing evolution of the AIDS service delivery system in States with emerging caseloads. These States will also provide information on both rural and urban issues as well as issues related to different geographic areas (i.e., midwest, south, and east).

While these States have some Medicaid program characteristics in common, the States also differ in many ways. A summary of some of the similarities and differences in Medicaid program characteristics are shown in Exhibit 2. The case study will provide much data on the impact of differing Medicaid programs on both beneficiaries with AIDS and the AIDS service delivery system (e.g., service system planning, implementation, and coordination; eligibility and enrollment issues as they impact beneficiaries overall and by different risk groups; reimbursement policies and the impact on provider and practitioner participation and the delivery of care; Medicaid shortfalls; prescription drug coverage; access to services; gaps in services; waivers and other innovative alternative delivery systems; interactions with other funding organizations, etc.).

Through this case study, we will attempt to identify and quantify successes, inadequacies, and gaps in policies and the service delivery system with particular emphasis on issues related to women and children. These data can then be used to prepare for the growing demands that the AIDS epidemic will likely place on the Medicaid program.

To gather data in preparation for site selection, we will conduct a literature review of published material and we will contact selected individuals who and organizations that have published relevant material or been involved in funding studies. These individuals may include but will not be limited to Anthony Pascal of RAND; Peter Arno and Jesse Green who are co-authors of the "Medicaidization of AIDS"; Stephen Bowen of BHRD (HRSA); Julia Hidalgo of Maryland; Fred Hellinger and Karen Rudzinski of AHCPR; Robert Buchanan of the University of Illinois, who is completing a survey of state Medicaid Policies for AIDS-related care; Stephen Bowen, Katherine Marconi, Sally Kohn, and Dorothy Bailey of HRSA; and David Greenberg, Penny Pine, Bob Wordwell, and John Klemm of HCFA.

SITE VISIT

A number of steps will be taken prior to actually visiting the selected sites. With the help of HCFA staff, we will identify a key person in each State who can provide us with copies of documents

EXHIBIT 2

Selected Medicaid Program Characteristics*	Recommended Case Study States			
	DC	GA	IL	PA
• Medicaid payments per beneficiary (FY91)	$4,456	$2,411	$2,387	$2,690
• Average annual rate of change in Medicaid payments (FY85-91)	7.0%	15.5%	19.6%	11.4%
• AFDC (Jan 1992) (IL/PA-figures shown is for area with highest benefit as there are state differentials)				
- 185% of "need" standard	$1,317	$ 784	$1,561	$1,136
- 100% of "need" standard	$ 712	$ 424	$ 844	$ 614
- Payment standard	$ 409	$ 424	$ 367	$ 421
- Maximum benefit	$ 409	$ 280	$ 36	$ 421
• Poverty level coverage for pregnant women (% of poverty) (Jan 1992)	185%	133%	133%	133%
• Medically needy program characteristics (March 1992)				
- Presence of	Yes	Yes	Yes	Yes
- Age limit for children	21	18	NA	21
- Optional coverage				
caretaker	Yes	No	NA	Yes
disabled	Yes	Yes	NA	Yes
• Medically needy resource standards level (Jan 1992)				

Selected Medicaid Program Characteristics*	Recommended Case Study States			
	DC	GA	IL	PA
- Family of 1	$2,600	$2,000	$2,000	$2,400
- Family of 4	$3,200	$4,200	$3,100	$3,800
• Monthly income eligibility levels (Jan 1992)				
- Payment standard	$ 409	$ 424	$ 367	$ 421
- Eligibility levels for persons with income				
Months 1-4	$ 734	$ 756	$ 671	$ 752
Months 8-12	$ 529	$ 544	$ 487	$ 541
Months > 12	$ 499	$ 514	$ 455	$ 511
- Medically needy levels	$ 545	$ 375	$ 492	$ 467
- Poverty level coverage				
Pregnant women and infants	$ 1,784	$ 1,282	$ 1,282	$ 1,282
Children under 6 years	$ 1,282	$ 1,282	$ 1,282	$ 1,282
Children born after 9/30/83	$ 964	$ 964	$ 964	$ 964
• Qualified Medicare beneficiaries (Oct 1992)				
Part A QMBs	495	10,971	2,385	14,301
Part B buy-ins	12,937	140,895	109,601	137,002
Part B QMBs only	51	34,259	83,315	114,502
• Prescription drugs (July 1991)				
- Limit/month	None	6 drug/Mo.	None	None

Selected Medicaid Program Characteristics*	Recommended Case Study States			
	DC	GA	IL	PA
- Refill limit	3 drug/Mo.	None	2 refill	5 refill
- Quantity limit	30-34 day supply or 100 units	30-34 day supply or 100 units	30-34 day supply or 100 units	30-34 day supply or 100 units
- Limit on over-the-counter	Few reimb.	Few reimb.	Few reimb.	Most reimb.
- Prior authorization	Yes	Yes	Yes	No
• Co-payment (Jan 1991)				
- Prescription drugs	50 cents[1,2]	-----	-----	50 cents
- Inpatient hospital	-----	-----	varies[3]	$31/day
- Non-emergency service in hospital	-----	-----	-----	varies
- Emergency room	-----	-----	-----	varies
- All other allowable services	-----	-----	-----	varies
• Medicaid inpatient hospital (Jan 1991)				
- Prospective cost to trend limit	Yes	-----	-----	-----
- Prospective hospital level	-----	Yes	-----	-----
- Hospital level with peer group	-----	-----	Yes	-----

[1]Pregnant women for non-pregnancy services

[2]Age > 20 years

[3]$2 per diem of $275 to $325; $3 per diem > $325

Selected Medicaid Program Characteristics*	Recommended Case Study States			
	DC	GA	IL	PA
- Diagnosis - specific	-----	-----	Yes	-----
- DRG (1992)	-----	-----	-----	Yes
• Medicaid payment as of % of Medicaid Cost (1990)	69.5%	86.1%	56.8%	65.6%
- Percent change from 1989 to 1990	-14.7%	+16.4%	+7.2%	-3.8%
- Medicaid estimated hospital expenses (1990)	11.9%	11.0%	13.3%	9.4%
- Medicaid estimated shortfall (1990)	3.6%	1.5%	5.7%	3.2%
• Physician payment (1989)				
- Methodology	fee schedule	fee schedule	fee schedule	fee schedule
- Fee schedule source and base year	charges	charges	charges	charges
- Ratio of Medicaid rates to FY89				
Average of all states (based on bundle of 18 services)	0.97	1.64	0.82	0.77
Medicare allowed change	0.57	1.14	0.56	0.54
Medicare fee schedule	0.58	1.07	0.51	0.49
• Medicaid Hospital Outpatient (1989)				
- (P)rospective/(R)etrospective	R	P	-----	-----
- Fee schedule	-----	-----	Yes	Yes
- Negotiated rates	-----	-----	-----	-----
• Waiver programs				
- Disabled (includes children)	-----	-----	Yes	-----

Selected Medicaid Program Characteristics*	Recommended Case Study States			
	DC	GA	IL	PA
- AIDS	-----	-----	Yes	Yes
• State Medicaid Agency				
- Health-Social Services	Yes	-----	-----	
- Medicaid	-----	Yes	-----	
- Social Services	-----	-----	Yes	Yes
• Streamlined Medicaid eligibility for pregnant women and children (Jan 1992)				
- Presumptive eligibility	Yes	-----	Yes	Yes
- Outstanding eligibility workers (1991)	-----	Yes	-----	-----
- Shortened application	-----	Yes	Yes	-----
- Expedited eligibility	-----	Yes	-----	-----
• Claims processing (Apr 1991)				
- Inpatient hospital	FI[4]	FI	S[5]	S
- Physician services	FI	FI	S	S
- Dental services	FI	FI	S	S
- Prescription drugs	FI	FI	S	S
- LTC	FI	FI	S	S

[4]FI = fiscal intermediary

[5]S = state

Selected Medicaid Program Characteristics*	Recommended Case Study States			
	DC	GA	IL	PA
• Medicaid financing (FY91)				
- Medical assistance proportions by				
State	49.9%	38.4%	49.8%	43.2%
Federal	50.1%	61.6%	50.2%	56.8%
- Administrative				
State	42.4%	41.3%	43.4%	46.7%
Federal	57.6%	58.7%	56.6%	53.3%
• Medicaid spending as a proportion of state funds (projected FY91)	NA	7.9%	8.2%	10.9%
• Eligibility status (FY91)				
- Categorically needy				
With cash assistance	79%	72%	68%	64%
Without cash assistance	9%	6%	6%	17%
- Medically needy	7%	<1	16%	10%
- Other	5%	22%	10%	9%
• Medicaid payments by eligibility status (FY91)				
- Categorically needy				
With cash assistance	$3,239	$1,982	$1,814	$2,001
Without cash assistance	$6,830	$ 957	$ 833	$5,780
- Medically needy	$16,233	$1,279	$6,002	$2,520

Selected Medicaid Program Characteristics*	Recommended Case Study States			
	DC	GA	IL	PA
• Medicaid beneficiaries by age group (FY91)				
- Children 0-5	27%	25%	26%	23%
- Children 6-20	27%	26%	29%	29%
- Adults 21-44	25%	24%	27%	27%
- Adults 45-64	8%	7%	8%	8%
• Medicaid payments per beneficiary by age group (FY91)				
- Children 0-5	$1,731	$1,130	$1,084	$ 781
- Children 6-20	$1,101	$1,164	$ 843	$1,097
- Adults 21-44	$4,087	$2,870	$2,718	$3,198
- Adults 45-64	$9,247	$4,560	$5,562	$5,579
• Medicaid beneficiaries by race (FY91)				
- White	2%	38%	42%	60%
- Black	95%	56%	46%	31%
- Hispanic	0	<1%	11%	7%
• Medicaid hospital payment (FY91)				
- Percent inpatient	82%	77%	89%	89%
- Percent outpatient	18%	23%	11%	11%
• Percent population below poverty (1991)[6]**	21.1%	15.8%	13.7%	11.0%

[6]U.S. Bureau of the Census, 1991

Selected Medicaid Program Characteristics*	Recommended Case Study States			
	DC	GA	IL	PA
• Percent receiving Medicaid (1991)[7]**	15.4%	10.0%	9.3%	9.9%
• Federal matching rates (FY92)[8]**	50.0%	61.8%	50.0%	56.8%

*Source: Medicaid Source Book: Background Data and Analysis (A1993 Update), Congressional Research Service, January 1993.
**Source: Report of the Kaiser Commission on the Future of Medicaid, November 1992.

[7]Prospective Payment Assessment Commission, 1991

[8]HCFA, 1992

useful in understanding the AIDS service delivery system and funding mechanisms. This contact will be made early in the study period and will include both a telephone call and an introductory letter, a draft of which is shown in Exhibit 3. It will be important to make this contact as early as possible so that documents can be requested, received, and reviewed prior to our site visits. Based on document review and conversations with the key contact in each state, we will identify the names, addresses, and telephone numbers of contacts in the AIDS service delivery systems, special interest groups particularly as they relate to women and AIDS, and within the state's Medicaid offices.

Once the sites have been selected, we will develop a site visit schedule. That is, we will identify a week in which to visit the State. Thereafter, we will solicit names of important participants in the AIDS service delivery system and special interest groups (e.g., organizations that provide and help find services for women and children). We will seek the names of Medicaid staff who handle service, program, and reimbursement data and issues. We will also need the names and phone numbers of other important participants. We can either contact these people individually, or we can request the key person in each State to make the initial contact. In similar situations in the past, we have carried out this activity both ways.

To reduce any undue burden on State staff, we suggest a two-tiered approach. That is, first we will draft a letter of introduction that will be reviewed by HCFA project staff and the key person in the state. Modifications will be made as necessary. To facilitate cooperation with the case study data collection, these letters will be mailed or telefaxed prior to our initial phone contact with potential interviewees. These letters will include a short introduction to the study and project staff, the general types of documents in which we are interested, and the general types of questions we will attempt to answer. Providing a copy of the site visit protocol to each person who will potentially be interviewed may also be helpful in facilitating cooperation and promoting an understanding of the case study objectives. It will be helpful if the state's key contact co-signs this letter implying that they are both aware of the activity and support it. We expect this approach will encourage the

Exhibit 3

DRAFT LETTER OF INTRODUCTION

DATE

MR/MS XXXXXXXXXX
XXXXXXXXXXXXXXX
XXXXXXXXXXXXXXX
XXXXXXXXXXXXXXX

Dear:

We have been contracted by the Health Care Financing Administration to perform a study of Medicaid and the role it plays in the AIDS service delivery system in your State and three others (A,B,C). To complete this study we will need to review relevant documents and conduct in-person interviews with appropriate personnel within the Medicaid agency and others involved in the service delivery system. For your convenience, a copy of the interview guide has been enclosed.

To complete our contracted scope of work, within one week of receiving this letter, we will contact you by phone to arrange a 30-60 minute phone conference. The purpose of the call is to answer any questions you may have regarding this study and to gather additional information from you prior to our site visit so that we can minimize our imposition on you and others whom we will contact and interview. During the phone call, we will request that you 1) identify relevant documents that should be part of our study, and 2) identify and provide phone numbers of appropriate personnel within your organization and elsewhere who are pivotal in the AIDS service delivery system, particularly as it relates to Medicaid. We will also schedule our in-person interview with you during this phone call.

To improve our understanding of the AIDS delivery system and Medicaid policy vis a vis AIDS in your State, it would be most helpful to have copies of the relevant documents prior to our visit. In this way, we can more effectively conduct our in-person interviews, and we can minimize our intrusion on your time.

Once we complete our document review and site visits, we will be preparing a report for HCFA. You and other key informants will receive a copy of the draft report at the same time that it is provided to HCFA. We request that you review the sections pertaining to your State and we welcome any feedback you wish to provide. Where appropriate, this feedback will be incorporated into the final report.

In advance, we look forward to speaking with you and beginning this meaningful study. Should you have any questions, please feel free to call me at the following number (202) 244-1610.

Sincerely,

Margaret A. Keyes
Associate Director
Health Policy Center (DC)

enclosure

cooperation of all potential interviewees. These letters will be sent seven days prior to our initial phone call to these contacts. Thus, the potential interviewees will be generally familiar with our names and the study objectives.

Phone contact will be used to identify and request key documents in preparation for the site visit and to establish an exact day and time for in-person interviews. To minimize the burden on participants, these interviews will be limited to two or less hours per interviewee. We will expect to receive requested documents sufficiently in advance of the visit to review them and properly prepare for the site visit. Review of documents prior to the site visit will enable us to more efficiently conduct the interview and to probe in important areas.

Within each State, we expect to visit the State capital and the city with the largest AIDS population or a city that has developed and implemented an interesting or innovative approach to funding or the delivery of services to people with AIDS. We expect to complete personal interviews with 10 to 15 people in each State. As mentioned previously, each interview will be limited to two or less hours. This is sufficient time to collect a substantial amount of information but not long enough to generally cause interviewees to refuse an interview. To collect information on rural areas, we will rely on telephone calls.

SITE VISIT PROTOCOL

The site visit protocol will be considered an interview guide that is designed to gather as much information as possible on the topics and issues that are of the foci of this study. The site visit protocol will be modeled after one that we used in a previous project with modifications to reflect current activities of interest and changes in the impact of the epidemic during recent years. We will focus our examination on the following areas:

- Impact of Medicaid
  - Administration and management

- -- Who administers programs vis a vis AIDS
- -- What involvement is there with other organizations (e.g., service delivery, funding, community based, etc.)
- -- Who does the planning and coordinating

- Policy/procedures

  - -- Eligibility criteria
  - -- Enrollment (easy or difficult, impediments, etc.)
  - -- Reimbursement policy for participating providers and practitioners
  - -- Medicaid shortfalls,
  - -- Availability and participation of providers and practitioners

- Program characteristics

  - -- Mandatory and optional services by category of eligibility

- Waivers

  - -- Covered services
  - -- Beneficiary eligibility
  - -- Availability of service providers
  - -- Reimbursement policies

- Beneficiary characteristics

  - -- By eligibility group
  - -- By risk group
  - -- By gender
  - -- By age

• Ryan White CARE Act activities

- Medicaid involvement in planning council

  - -- Who is involved
  - -- What role is played in council
  - -- How and when is information shared
  - -- Where in the State organization is this representative located

- Medicaid relationship with agency administering CARE award

  - -- Level of involvement, planning, cooperation, coordination, information sharing, etc.

• Service delivery system

- Services

  - -- Availability [acute; outpatient (clinic, fee-for-service); home health (nursing, personal, and physician support); long term care (SNF)
  - -- Access, gaps and unmet needs (by risk group with special emphasis on both women and children and constraints imposed by Medicaid policy) for example, psychological and mental health services, substance abuse treatment, child care, foster care, transportation, dental care, in-home administration of IV treatment or aerosolized medication, private duty nursing, housekeeping, meal preparation, rehabilitative services, financial, housing/shelter, personal care, specialty and general medical care,
  - -- Provider willingness to treat
  - -- Payment disincentives

- Continuity of care
- Case management

  - -- Who provides the service(s) organizationally and individually and what is the background/training of the individual case managers
  - -- Caseload per manager
  - -- Centralized or decentralized system
  - -- What types of services are case managed (medical, social service, etc.)

- Data systems

  - Do they exist
  - What data elements are captured
  - How accessible are they
  - How reliable are they

- Utilization and expenditures of services reimbursed by Medicaid

- Successes and failures of plans, programs, and services and impediments to service improvement

- Planning and coordination of services

  - Who is involved
  - What agencies and groups are involved
  - What interferences occur
  - What dissension exist

- Innovative and creative solutions within funding sources and the service delivery system with particular emphasis on Medicaid

The protocol will be designed to cluster information that will be easily transferable to the final report.

That is, we will identify themes and group together questions relative to that theme.

The protocol design will reflect both a structured and open-ended interview guide approach. That is, we will expect all questions to be answered either through review of documents or through the interview process. While we will attempt to develop a comprehensive guide, there may be some issues that were overlooked during the development of the protocol and those issues must be pursued even though the questionnaire may not address them. To take advantage of the "lessons learned" from each site visit, we will stagger the site visits. Thus, where appropriate, we will use the "lessons learned" from one site visit to improve the protocol for subsequent site visits. If pertinent issues arise in the last site visits, we will also re-contact key individuals in site visits completed earlier. As a result of the review of site-specific documents, we may also identify issues that appear to be pertinent to only one site. These issues will also be pursued. We will also be particularly attentive to those issues for which we get conflicting information and we will be prepared to probe these issues to address the discrepancies.

Shortly after a site visit is completed, we will write up our notes. It will be important to complete this task quickly so that we do not lose the context of responses. This effort will be intended to fill in blanks, flesh-out responses, write out the meanings of abbreviations, and identify any conflicting information that may not have been readily apparent while on site. We will also send a brief note of thanks to each interviewee. When necessary (e.g., for clarification), we will re-contact site personnel by phone.

REPORT

As part of our preparation for the site visit, we will draft a report outline that will be submitted for review and approval. The outline, in addition to the literature review and the previously developed protocol will help us focus effectively on critical elements in this case study. In further preparation for writing the report, we will hold a one-day meeting in the MPR offices in Princeton, New Jersey. This meeting will be attended by the Project Director, Craig Thornton, and the two project staff (i.e., Valerie Cheh and Marge Keyes) completing the site visits. The purpose of this

meeting will be to discuss our findings, identify common themes and issues, and to finalize the report format.

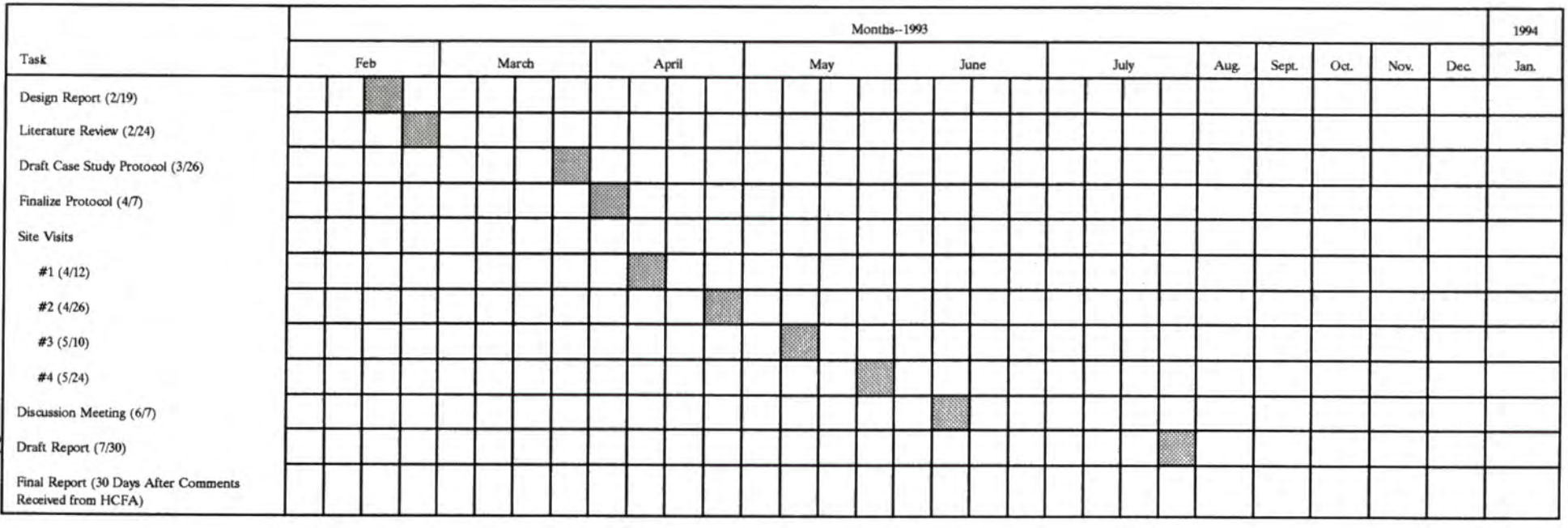
The report will begin with a brief review of the literature, particularly national trends in the AIDS epidemic, trends in the AIDS-related health care, and trends in the costs and financing of such care. The report will then include short summary sections on each of the States. The remaining sections of the report will focus on themes across States. For example, we will have a section on policy that will include issues such as the role of Medicaid in the current service system (e.g., program characteristics) with particular emphasis on relevant optional services such as private duty nursing, clinic services, dental services, prescribed drugs, personal care services; hospice care, outpatient care, hospital care, housing support, child/family care, special reimbursement rates for HIV/AIDS services, and so forth. Another section will summarize our findings on the impact of home and community-based waivers with emphasis on the availability of formal (i.e., community) and informal (i.e., family) support systems; availability of a network of paid caregivers to support in-home care; and so forth. Another section will describe population characteristics in each state, including similarities and differences in risk group composition and the impact this has on the need for and provision of services. Another section will be devoted to describing expenditure and utilization trends within the last few years across the populations served by Medicaid as well as by risk group within populations. Another section will focus on Ryan White CARE Act activities and the interaction with Medicaid. Another section will characterize access to services with particular emphasis on those risk groups experiencing impediments to or limitations on access.

Schedule

The case study schedule is attached as Exhibit 4. Although the project has an end date of January, 1994, we will expect to complete the vast majority of the work by the end of July, 1993. We will draft and finalize a site visit interview guide by the end of March. We will complete site visits during April and May. We will discuss study findings in early March, and a draft report will be

EXHIBIT 4

CASE STUDY TIMELINE



written during June and July. We anticipate completing the draft report by the end of July. We will expect the final report to be completed within 30 days of our receipt of comments from HCFA but no later than January 1994.

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