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National AIDS Policy Office
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FOLDER TITLE:

SAMHSA [Substance Abuse and Mental Health Services Administration] [1]

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RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

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- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
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Programs in SAMHSA with HIV-relevant Components

A. Programs with identified funding for AIDS related activities.

1. Center for Substance Abuse Treatment

a. HIV/AIDS Community Outreach - 17 awards, \$10,535,000 estimated for FY 1994. This program funds projects whose purpose is to seek out injecting drug users, other high risk drug abusers and their sexual partners, in order to: 1) encourage them to obtain treatment for drug dependence and obtain medical diagnostic services for HIV/AIDS, STDs and tuberculosis; and 2) provide these individuals with information, skills, and other means to avoid those behaviors which increase the risk of acquiring or transmitting HIV/AIDS, STDs and tuberculosis. This program does not pay for treatment.

b. Linkage Initiative with HRSA - 17 awards, \$7,809,000 for FY 1994. This cooperative program awards grants to substance abuse programs to develop comprehensive care demonstrations that link AIDS programs to the mental health and the primary health care system. The goal of this program is to ensure availability, accessibility, and affordability of comprehensive, high quality treatment for those individuals infected with HIV disease who are in need of primary health care and ADM services. The array of services includes screening and treatment for infectious disease, HIV/AIDS counseling, primary health care, outpatient addiction counseling, and family/collateral counseling.

c. CSAT Linkage Grants - Funded projects offer a comprehensive continuum of care, including screening and treatment for infectious disease, HIV/AIDS counseling, primary health care, outpatient addiction counseling, mental health services, family/collateral counseling, case management and program evaluation.

d. AIDS Training - \$2,812,000 estimated for FY 1994, 10 programs. To provide educational and training organizations grant support for modifying their curricula and strengthening their training effectiveness. Training programs must incorporate CSAT's Comprehensive Care Model, and include education in HIV/AIDS, STDs and TB testing. The goal is to focus on professional training and educational training issues as they relate to the needs of minority populations.

e. Substance Abuse Block Grant HIV Formula Distribution

2. Center for Mental Health Services

a. HIV/AIDS Mental Health Services Demonstrations - 8 awards for \$1,200,000 estimated for 1994.

The Program funds competitive cooperative agreements in collaboration with the Health Resources and Services Administration (HRSA) and the National Institute of Mental Health (NIMH) of the National Institutes of Health (NIH). This program develops new programs or expands existing programs to provide mental health services for individuals, their families, and others who experience serious psychological reactions as a result of testing positive for the HIV/AIDS antibody. The purpose of these cooperative agreements is to provide a range of high quality mental health services to people infected with HIV/AIDS or living with an HIV/AIDS infected individual, evaluate the effectiveness and efficiency of the models used, and determine the outcome of those services on the quality of life of the individuals served. Target populations for service delivery are people at risk for HIV/AIDS, people living with HIV/AIDS, and people affected by HIV/AIDS.

A Data Center serves as the independent technical assistance and evaluation center for the HIV/AIDS services demonstrations awardees. All awardees cooperate fully with the Center to give appropriate feedback on CMHS programs.

b. AIDS Health Care Worker Training - \$2,943,000. Training for traditional mental health care providers and other health care workers who often are first-line providers of mental health services. Specific attention to psychological and neuropsychiatric sequelae of AIDS and HIV infection. This program has developed model curricula.

3. Center for Substance Abuse Prevention

a. HIV/AIDS Supplements in the High Risk Youth Program. \$1,000,000 to supplement up to 20 High Risk Youth grants to include HIV/AIDS outreach and risk reduction activities, and evaluation of these activities. Funding would support skill development, including pre/post HIV test counseling, outreach to resistant populations, and provision of services to those who have experienced loss due to AIDS. CSAP would promote knowledge transfer, including information on the interrelatedness of alcohol, tobacco, and other drug use and the spread of HIV/AIDS, and on the role of gender, age, culture/socioeconomic factors and HIV/AIDS. The extent to which participants have developed increased knowledge about HIV/AIDS will be assessed as will behavioral intentions to change high risk sexual practices. A long term follow up will be conducted to assess differences in the rate of HIV incidence between those exposed to the prevention program and those not exposed.

B. Funded programs that are AIDS relevant, but without specific fiscal obligations for the AIDS component.

1. Center for Substance Abuse Treatment

a. Rural, Remote and Culturally Distinct Populations \$4.0 million for 4 grants in FY 1993. To create culturally sensitive comprehensive community-based programs designed to improve the quality and effectiveness of drug abuse and alcohol treatment services in rural, remote and culturally distinct population areas. Primary objectives include: 1) expansion of ambulatory detoxification services, 2) provision of screening, counseling and treatment for HIV, STDs and TB, 3) provision of case management and treatment services, and 4) expansion of outpatient and pharmacologic maintenance services.

b. Residential Pregnant/Post partum Women, PPW (Sec. 508) 23 grants, \$24,040,000

c. Residential Women and Children, RWC (Sec. 510) 35 grants, \$27,321,000

d. Treatment Improvement Protocols

e. Criminal Justice (Incarcerated and Non-incarcerated) 51 grants, \$30,753,000

f. Critical Populations 63 grants, \$40,214,000.

g. Other - Many other CSAT initiatives specifically identify HIV infection prevention and treatment activities, such as the Capacity Expansion Program and Comprehensive Community Treatment Programs.

2. Center for Mental Health Services

a. Homeless Demonstration Projects

3. Center for Substance Abuse Prevention

- a. High Risk Youth Program - Outreach and support of CBOs for work with a broad range of youth "at risk." HIV/AIDS education, support of general self-esteem enhancement, and empowerment activities. \$57.4 million for grants in FY 1994.
- b. Pregnant and Post-partum Women and Their Infants Demonstration Grant Program. \$40.8 million in FY 1994 grants.
- c. National Prevention Training System - comprehensive training initiative focused on training persons who have access to populations at special risk of alcohol and other drug problems. \$14.5 million appropriated for FY 1994.
- d. Communications program including CSAP National Clearinghouse.
- e. Enhancement of the States development and support of prevention activities funded by the Substance Abuse Block Grant.

TABLE III.1

SERVICES AUTHORIZED IN STATE MEDICAID AIDS WAIVERS

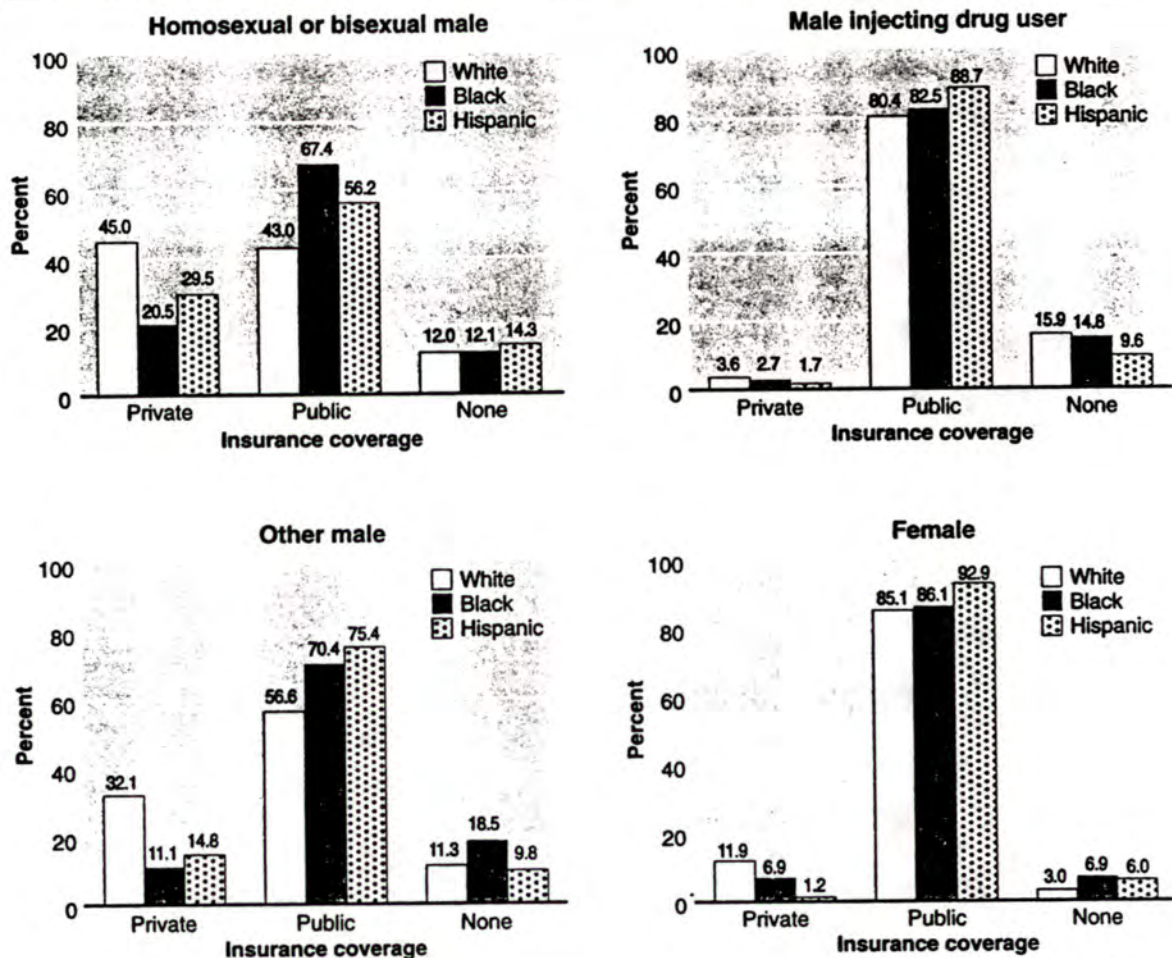
	Basic Home and Community-Based Services								Additional Services						
State	Case Management	Homemaker	Home Health Aide	Personal Care	Adult Day Care	Respite Care	Adult Medical Day Care	Psychosocial Counseling/ Education	Nursing ^a	Minor Home Repair	Foster Care (Supplements or Supervision)	Home-Delivered Meals	Substance Abuse Treatment	Hospice	Other
California	X	X				X		X	X	X	X				Attendant care, transportation
Colorado	X	X	X	X	X				X		X			X	
Delaware	X	X				X	X	X	X		X				
Florida	X	X		X		X	X	X	X	X	X	X	X		Chore services, medical supplies
Hawaii	X			X		X	X	X	X		X	X	X		Emergency home response system, moving assistance, respiratory therapy, transportation
Illinois	X	X	X	X		X				X	X				Emergency home response system
Iowa		X	X			X		X	X						
Missouri				X					X						Supplies, transportation
New Jersey	X			X			X		X		X			X	
New Mexico	X	X		X	X				X						
Ohio	X	X		X		X	X	X				X			Adaptive equipment, medical supplies, nutritional counseling, respiratory therapy, transportation
Pennsylvania		X	X						X						Nutritional supplements, supplies
South Carolina	X			X				X	X		X	X		X	
Virginia	X			X		X			X						Nutritional supplements
Washington				X		X	X	X	X			X			Attendant care, nutrition counseling, transportation

NOTE: None of the current Medicaid AIDS waiver programs offers habilitation care or care for chronically mentally ill people, although both of these services are authorized under the Home and Community-Based Waiver. These two services were not included in this table.

^aIncludes skilled nursing and/or private duty nursing.

1. ***Eligibility Unrelated to HIV Infection.*** Individuals who meet standard categorical eligibility requirements (for example, people who are eligible for AFDC, low-income pregnant women and some children, people with disabilities unrelated to HIV infection who are eligible for SSI) are eligible for Medicaid, regardless of their HIV infection, in all 50 states.
2. ***Eligibility Because of HIV Infection.*** People with AIDS or manifestations of HIV infection that cause them to be so debilitated that they cannot work are considered disabled under the criteria established by the Supplemental Security Income (SSI) program. If their income and assets are below a specified federal standard, they are then eligible for SSI. In 37 states and the District of Columbia, SSI-eligible persons are automatically eligible for Medicaid (in six of these states a separate Medicaid application is required). The remaining 13 states require different, often more restrictive, income and asset limits for Medicaid eligibility.
3. ***Medically Needy Eligibility.*** People who meet the disability requirements but whose income and assets are too high for SSI eligibility may qualify as medically needy in 35 states if their income and assets, minus medical expenditures, are below a specified level.
4. ***Eligibility Under Institutional Higher Income Standard/ Institutional Deeming Rules.*** Some states allow people living in institutions to qualify for Medicaid under a higher income standard, not to exceed 300 percent of the basic SSI benefit (\$1,266 per month in 1992) (Congressional Research Service 1993). In addition, rules to protect family members of persons living in institutions from impoverishment enable people in institutions to qualify for Medicaid based on special institutional deeming rules. In some states, people (including persons infected with HIV) who would require institutional care were it not for the receipt of certain home and community-based services and who, if living in an institution, would be eligible for Medicaid, may also qualify for Medicaid.

Figure 4. Percent distributions of persons 13 years of age and over with AIDS, by health insurance coverage, exposure category, race or ethnicity, and sex: 1991



Note: Persons were classified by stage of illness according to responses to a self-administered questionnaire listing 4 symptoms and 17 conditions related to HIV illness. N = 5,811. Males who reported contracting HIV through sexual contact with an injecting drug user are included in the homosexual or bisexual category.

Source: Agency for Health Care Policy and Research: Data from the Screener Questionnaire, AIDS Cost and Services Utilization Survey.

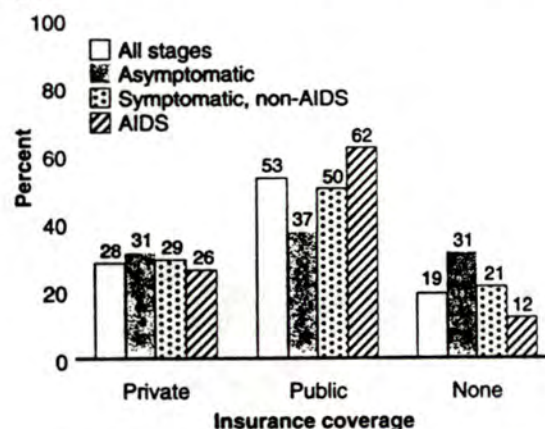
Stage of Illness

For purposes of sample selection, individuals who completed the screener questionnaire were classified by stage of illness according to their responses to a list of symptoms and conditions related to HIV illness. Respondents were asked if they had ever been told by a doctor that they had any of a list of 17 AIDS-defining conditions: candidiasis (thrush), PCP (pneumocystis carinii pneumonia), KS (Kaposi's sarcoma), lymphoma, wasting syndrome, tuberculosis, cryptococcosis, CMV (cytomegalovirus), MAI (mycobacterium avium infection), cryptosporidiosis, dementia, herpes simplex, histoplasmosis, toxoplasmosis, isosporiasis, leukoencephalopathy, and salmonellosis. If they responded yes to any of the conditions, they were classified as having AIDS. One exception was that if they reported only herpes and/or thrush, they were classified as "symptomatic, non-AIDS." Respondents who had none of the conditions were asked if they had experienced any of four symptoms related to HIV infection: swollen glands (lymph nodes), persistent fever, diarrhea, and unintentional weight loss. If they responded yes, they were classified as "symptomatic, non-AIDS." If they had no symptoms or conditions, they were categorized as "asymptomatic." All eligible persons reported that they were HIV positive. According to these responses, 17 percent of the screener population was classified as asymptomatic, 43 percent as symptomatic, non-AIDS, and 40 percent as AIDS. All remaining statistics in this report are presented by stage of illness.

Asymptomatic

Persons in the study population who reported being asymptomatic when they responded to the screener questionnaire were less likely to have public coverage and more likely to have no outside source of payment than the study population as a whole. Of asymptomatic persons, 31 percent had private coverage, 37 percent were covered by Medicaid or some other public source of funding, and 31 percent had no coverage, as shown in Figure 1. As noted previously, this report provides statistics on relationships between variables within the study population. The extent to which these

Figure 1. Percent distributions of HIV-positive persons 13 years of age and over, by health insurance coverage and stage of illness: 1991



Note: Persons were classified by stage of illness according to responses to a self-administered questionnaire listing 4 symptoms and 17 conditions related to HIV illness. N = 5,811.

Source: Agency for Health Care Policy and Research: Data from the Screener Questionnaire, AIDS Cost and Services Utilization Survey.

relationships can be extrapolated to the entire HIV population is unknown.

The likelihood of having some form of private insurance to help defray medical costs for those who reported being asymptomatic increased with age, from 20 percent for persons 13-30 years of age to 39 percent for those 41 years of age and over (Table 1). The reverse pattern was observed for persons without insurance. Only 26 percent of persons 41 years of age and over had no coverage, compared with 37 percent of those ages 13-30. This pattern mirrors the distribution of health insurance coverage in the United States (Short, Monheit, and Beauregard, 1989).

Males were 2½ times as likely to be covered by private insurance as females were but only half as likely to have some form of public coverage. As noted earlier, because of potential Medicaid eligibility through AFDC, females are more likely than males to have this source of public funding available, particularly in early stages of the disease before they are disabled or have been classified as medically needy. White persons were substantially more likely to have private coverage and less likely to be covered by any public funding mechanism than were either black or Hispanic persons. Hispanic persons were more likely than either black or white



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

JUN 23 1994

Office of the Assistant Secretary
for Health
Washington DC 20201

TO: HHS Coordinating Group on HIV/AIDS Principal Members

FROM: Assistant Secretary for Health

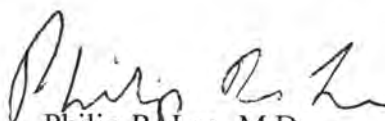
SUBJECT: Establishment of the Research Subgroup of the HHS Coordinating Group on HIV/AIDS and Request for Subgroup Membership Nominations

At the May 11, 1994, meeting of the HHS Coordinating Group on HIV/AIDS (HCG), a consensus was reached that a subgroup to address research issues across the Department should be formed.

As agreed at this meeting, the lead agency for the research subgroup will be the Office of AIDS Research (OAR), National Institutes of Health. Dr. William Paul, Director, OAR will chair the subgroup. Representatives from the Health Care Financing Administration, the Office of the Assistant Secretary for Planning and Evaluation, HHS, and each of the Public Health Service agencies will form the subgroup's core membership. Other HHS components wishing to have representation on the subgroup are invited to participate.

The first meeting of the research subgroup is scheduled for **Monday, June 27, 1994, from 2:00 to 4:00 p.m. at the National Institutes of Health, Conference Room 6, Building 31.** I request that you designate a principal and an alternate member.

Please contact Dr. Robert Eisinger, OAR (voice: 301-496-0357 or fax: 301-496-4843) by c.o.b. June 23, 1994, to identify your representative and alternate and to confirm your attendance at the meeting.


Philip R. Lee, M.D.

DRAFT

**Correlates of Medical Service Utilization
among People with HIV Infection***

John A. Fleishman, Ph.D.

David C. Hsia, M.D., J.D., M.P.H.

Fred J. Hellinger, Ph.D.

Division of Cost and Financing

Center for General Health Services Extramural Research

Agency for Health Care Policy and Research

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DRAFT

Correlates of Medical Service Utilization among People with HIV Infection

Objective. To examine factors affecting the utilization of inpatient, outpatient, and emergency room services by people with HIV infection.

Data Sources and Study Setting. Study participants are adults with HIV infection receiving services at major providers of medical care in 10 U.S. cities. Six interviews were conducted over an 18-month period. Analyses use 1600 respondents who completed the second and third interviews. Data on service utilization, personal background characteristics, insurance status, and functional status are based on self-report. Disease stage is based primarily on medical record data.

Study Design. Linear and Poisson regression analyses were conducted to determine the effects of need, enabling, and predisposing factors on the dependent variables of ambulatory visits, emergency room visits, inpatient admissions, and average length of inpatient stay. Independent variables were measured as of the second interview, while dependent variables were measured for the third and fourth interview periods.

Principal Findings. Service utilization was higher among respondents with AIDS than among those at earlier stages of HIV infection. Functional limitations, experienced pain, and negative mood each were associated with increased service use, over and above disease stage. Black respondents reported more hospital admissions and longer lengths of inpatient stays than white respondents. Lack of insurance was related to reduced service use. The effects of disease stage and functional limitations were reduced among people with public, compared to private, insurance.

Conclusions. While disease stage affects use of medical care, the experience of adverse HIV-related conditions, such as pain or functional limitations, has an additional effect on service use. Persistent racial differences in utilization remain to be explained. Lack of insurance impedes use directly and also modifies the effects of disease stage and functioning.

Key Words: HIV Infection, AIDS, service utilization, health insurance, health status.

Correlates of Medical Service Utilization among People with HIV Infection

The epidemic of human immunodeficiency virus (HIV) infection has confronted researchers with a "moving target" (Scitovsky, 1989). Over the past decade, the epidemic has spread from the gay/bisexual population to injection drug users, their sexual partners, and their children. In addition, treatment patterns have changed dramatically. Acquired immune deficiency syndrome (AIDS) was initially viewed as an acute condition requiring inpatient care; currently, HIV infection and AIDS are chronic conditions requiring continual care on an outpatient basis and inpatient care on an intermittent basis.

The rapid changes in treatment patterns and in the sociodemographics of the infected population complicate efforts to understand patterns of health service utilization by people with HIV infection. Prior studies of service utilization are limited in several respects. First, with a few recent exceptions (e.g., Mor et al., 1992; Seage et al., 1993), most research has relied on homogeneous samples, often gay/bisexual men (e.g., Scitovsky, Cline, and Lee, 1984; Bennett et al. 1991) or injection drug users (Bennett et al., 1992; Solomon et al., 1991). Other studies deal exclusively with people covered by a single insurer, typically Medicaid (e.g., Andrews et al., 1991). Second, with few exceptions (Mor et al., 1992; Piette et al., 1993), prior research has used samples collected in only one community. Third, most prior research focuses on people with AIDS and does not provide data on individuals at earlier stages of HIV infection. Fourth, studies based on data collected prior to the approval of zidovudine (ZDV) as an antiretroviral agent in 1987 are outdated. Finally, much of the early effort to describe patterns of medical service utilization and costs focused on inpatient hospital episodes (Seage et al., 1990); more recent research is beginning to provide data on ambulatory care utilization.

The present study examines factors affecting the use of medical services by people with HIV infection. Medical services include inpatient hospital stays, ambulatory visits, and emergency room visits. This study uses data from the AIDS Cost and Service Utilization Study (ACSUS), conducted by the Agency for Health Care

Policy and Research, a component of the U.S Public Health Service. Unlike many prior studies, ACSUS obtained a large, sociodemographically diverse sample, including people at different stages of HIV infection, from 10 communities across the U.S., and the data pertain to utilization patterns as of 1991-1992.

Background

This paper is based on the premise that factors that have been demonstrated to affect use of health services in other populations also influence service use among people with HIV infection. The behavioral model of service utilization (Andersen and Newman, 1973; Aday and Shortell, 1988) provides a conceptual framework that has been used for other populations (e.g., Wolinsky et al., 1983; Wolinsky and Johnson, 1991). This model distinguishes three categories of factors affecting utilization. **Predisposing** factors refer to general propensities to use health services. These factors include sociodemographic variables such as gender, education, or racial/ethnic group. **Enabling** factors reflect those characteristics or resources that facilitate or impede service use. Enabling factors include income, insurance, and the availability of a usual source of care. Finally, **medical need** variables, such as perceived symptoms or health status, comprise the proximal factors that motivate individuals to seek medical care. The present study examines the influence of predisposing, enabling, and medical need factors on utilization of emergency, ambulatory, and inpatient medical services among people with HIV infection. By virtue of its heterogeneous sample, the ACSUS data permit simultaneous consideration of each set of factors.

Previous research has identified several variables related to medical service use among people with AIDS. Compared to nonwhites, whites have been shown to have a lower rate of inpatient admissions and emergency room (ER) use (Mor et al., 1992; Piette et al., 1993; Seage et al., 1990). Patients with a history of injection drug use (IDUs) show a trend toward a greater rate of inpatient utilization than those without such a history (Mor et al., 1992; Seage et al., 1993), as well as longer lengths of inpatient stays (Seage et al., 1993). People without medical insurance, compared to those with insurance, are less likely to be admitted as inpatients (Mor et al., 1992; Fleishman and Mor, 1993; Seage et al., 1990). Finally, indicators of

health status, such as symptoms, functional limitations, or CD4 cell counts, are related to inpatient utilization (Mor et al., 1992; Piette et al., 1993). The present study examines the extent to which these relationships replicate in a new sample of people with HIV infection.

With some exceptions (e.g., Arling, 1985), analyses based on the behavioral model simply assess the relative explanatory power of the three sets of factors, typically by estimating additive multiple regression models. Few studies have closely examined the possibility that the effects of one variable may be conditioned by the value of another variable (i.e., interaction effects are present). Ronis and Harrison (1988) argue that including interaction terms can improve understanding of the process of service utilization.

The notion of an enabling variable suggests the potential for interaction effects. An enabling variable, if present, may increase the magnitude of the relationship between a second variable and utilization; if the enabling variable is absent, the magnitude of this relationship may be reduced. In particular, consider the enabling variable of insurance. If a person has health insurance, fluctuations in need for care may have a relatively strong effect on service use. In contrast, variations in need may have less of an effect among people without insurance. The present study investigates the magnitude of such interaction effects.

Methods

Sample Selection

Sample selection consisted of three stages: selection of geographical areas, selection of medical care providers within each location, and selection of patients within each provider. Selection of locations and of providers was done on a purposive basis; the resulting sample thus cannot be considered to be random.

Communities were selected to obtain diversity in geographical location, in service delivery systems, and in the demographic characteristics of the infected population. In the first stage, 10 communities were chosen from among the 25 cities with the highest reported number of AIDS cases in 1989: Baltimore, Chicago, Houston, Los Angeles, Miami, Newark, New York City, Philadelphia, San Francisco, and Tampa. Other criteria included selecting a community with a moderate prevalence of HIV

infection (Tampa), a community from a state with a Medicaid waiver (Newark, Miami), a community from a state with restrictive Medicaid policies (Houston), communities from states with relatively liberal Medicaid policies (Los Angeles, San Francisco, New York), and four communities that would enable a sufficiently large pediatric sample to be selected (e.g., New York, Newark, Baltimore, Chicago, Los Angeles).

In the second stage, providers treating the largest numbers of HIV-infected patients in each community were identified. A total of 32 providers was selected, of which 26 consented to participate. Of the 26 providers, 3 were office-based private physician practices; 3 were county-operated clinics serving primarily an uninsured clientele; and the remainder were public and private hospitals treating substantial numbers of HIV-infected patients. At least two separate providers were selected in each community.

In the third stage, a probability sample of patients was selected within each provider. Over a 2-4 month recruitment period, on-site coordinators distributed a self-administered screening questionnaire to all patients using a specific service (e.g., an infectious disease clinic) at each provider. Patients indicated on the questionnaire whether they had ever had a positive HIV test, whether they had experienced each of four HIV-related symptoms (i.e., swollen glands, persistent fever, diarrhea, weight loss) in the past five years, and whether, for each of 17 AIDS-defining conditions (e.g., PCP, CMV, Toxoplasmosis), a doctor had diagnosed them as having the condition in the past five years. In addition, the questionnaire obtained information on gender, HIV exposure route (sex with bisexual/homosexual male, injection drugs, sex with injection drug user, or other), and racial/ethnic background [white (not Hispanic), black (not Hispanic), Hispanic, Asian, American Indian, or other].

After the screening questionnaire was completed, the coordinator determined whether the patient was eligible to participate in the study. Only patients with HIV infection were eligible for the study. Self-reported data on symptoms and conditions were used to create three strata of illness stage: asymptomatic, symptomatic non-AIDS, and AIDS. In addition to illness stage, patients were stratified by gender and HIV exposure group (male gay/bisexual, male IDU, female),

and gay/bisexual men were further stratified by insurance status (private, public, none). A systematic random sample was obtained from each stratum, with oversampling of women and pediatric cases. Berk et al. (1993) provide a detailed description of the ACSUS sampling design.

Overall, 6122 HIV-positive patients completed the screening questionnaire; of these, 2487 were sampled. After reviewing the questionnaire and determining if the patient was in the sample, the site coordinator reapproached the patient to initiate formal recruitment. Of those sampled, 2197 (88%) agreed to participate. Recruitment rates showed little variability across different sampling strata. Of those agreeing to participate, 2090 persons (95%) completed the initial interview, of whom 141 were pediatric patients. The analyses in this paper are restricted to respondents over age 13.

Interview Content

ACSUS obtained information on health service utilization for an 18-month observation period, beginning March 1, 1991 and ending on August 31, 1992. Respondents were scheduled to be interviewed six times over this period. Each interview pertained to the period since the prior interview. The time period covered in each interview thus averaged three months.

Measures of Utilization. In-person interviews obtained self-reported data on the number of inpatient admissions and the length of stay for each admission; the number of ambulatory care visits to hospital clinics, other clinics, or private physicians' offices; and the number of visits to a hospital emergency room. Visits to hospital clinics, other clinics, and community physicians were summed to create an overall measure of frequency of ambulatory care. An average length of stay (ALOS) variable was derived by dividing the total number of inpatient admissions into the total number of inpatient days.

Independent Variables. The predisposing variables of race/ethnicity, gender, and HIV transmission group were measured by the screening questionnaire. Respondents who were neither white nor black nor Hispanic or who were missing data on race/ethnicity were removed from the analysis ($n = 36$). For purposes of analysis, HIV transmission category was coded as IDU or nonIDU; respondents who

noted multiple transmission behaviors were coded as IDU if any injection drug use was indicated. Level of education was dichotomized as high school graduate or less versus at least some college in order to focus on a relatively highly educated group.

With respect to enabling factors, respondents provided detailed information on medical insurance coverage. Respondents were categorized as having private insurance, public insurance (primarily Medicaid, but also including Veterans' Administration and Medicare), or no insurance¹. Respondents also indicated whether their usual source of medical care was a private physician, a hospital clinic, or if they had no usual source of care. Self-reported income was dichotomized at \$9000 per year. Finally, respondents were classified as whether they lived alone or with others. Data from the second interview were used to measure each of these four enabling variables.

The second interview also obtained data on physical functioning, pain, and mood. To measure physical functioning, respondents indicated for each of six activities whether their health had limited them for more than three months, for three months or less, or not at all. The first two responses received scores of 1, and the latter response was scored 0. The activities were (1) vigorous activities like lifting heavy objects or running, (2) moderate activities like moving a table or carrying groceries, (3) walking uphill or climbing a few flights of stairs, (4) bending, lifting or stooping, (5) walking one block, and (6) eating, dressing, bathing, or using the toilet. Responses were summed, resulting in a scale ranging from 0 to 6 ($\alpha = .88$).

A set of eight items (e.g., "I have unbearable pain," "I'm in pain when I walk") measured pain. Respondents indicated whether or not each item was true for them "most of the time." Responses were summed to create an overall pain scale ($\alpha = .90$).

Five items measured current mood. Respondents were asked how often in the past month they had (1) been a very nervous person, (2) felt calm and peaceful, (3) felt downhearted and blue, (4) been a happy person, (5) felt so down in the dumps that nothing could cheer you up. Respondents answered on a 6-point Likert scale

ranging from "all of the time" to "none of the time." After reversing the scores for the second and fourth items, scores were summed to create a mood scale ($\alpha = .84$), with higher scores indicating more distress.

Stage of HIV infection was categorized as either asymptomatic, symptomatic, non-AIDS, or AIDS. Respondents were staged on the basis of data from inpatient and ambulatory medical records obtained from the respondent's usual source of care. For each inpatient admission, up to 10 discharge diagnoses were recorded. Dates of notification of HIV infection and of AIDS diagnosis were also recorded if mentioned in the record. Abstractors recorded any mention of 75 HIV-related conditions and symptoms in outpatient records. Respondents were deemed to have AIDS if any of the indicator diagnoses, using the 1987 CDC definition, were noted in the medical records. If the records indicated HIV-related symptoms but no AIDS-defining diagnoses, respondents were classified as symptomatic; respondents with no symptoms or AIDS-defining diagnoses in the medical records were classified as asymptomatic.

Illness stage was determined as of the time of the second interview. For 408 respondents, staging information from medical records was unavailable at the second interview. For 122 of these respondents, illness stage was determined based on medical record data as of the time of the first interview. For the remaining 286 respondents, illness stage was based on HIV-related symptoms and AIDS-defining diagnoses as reported in the self-administered questionnaire.

Analysis

Because physical functioning, pain, and mood were not measured in the first interview, the 98 respondents who attrited after the first interview were excluded from the analysis. To take advantage of the longitudinal nature of the survey, data from the second interview were used to predict utilization in the third and fourth interview periods. Two interview periods were analyzed in order to provide a sufficient time for utilization events to occur. A total of 123 respondents attrited after the second interview and consequently provided no utilization data for periods three and four.

Analyses were limited to those with no missing data on the independent variables and to those with an observation period longer than 30 days. A total of

128 respondents were dropped due to missing data or a short observation period, resulting in an analytic sample of 1600 respondents. Table 1 compares respondents who attrited, who were eliminated due to missing data, and who constituted the final sample. The three groups did not differ significantly in terms of gender, ethnicity, or education. Respondents with a history of injection drug use were more likely to attrit than those with no injection drug use. Respondents with AIDS were more likely to attrit than those at less severe disease stages, primarily as a result of death. In general, with the exception of race/ethnicity, having missing data was unrelated to sociodemographic characteristics.

To examine factors influencing service utilization, regression analyses were conducted for each dependent variable--ambulatory visits, inpatient admissions, emergency room (ER) visits, and average length of inpatient stays. The latter variable was defined only for those with one or more inpatient admissions. To reduce skewness, a logarithmic transformation was applied to the number of ambulatory visits and to the average length of stay. Given the discrete nature of the number of inpatient admissions and the number of ER visits, Poisson regression was performed for these variables; ordinary least squares regression was conducted for the remaining dependent variables.

The regression models included the predisposing, enabling, and need variables described above. Because utilization might be affected by geographic variations in practice patterns and resource availability, and because those with longer observation periods would be likely to report more utilization events, all analyses controlled for the city of data collection and for the number of days in the observation period. The mean length of the observation period for respondents in the analytic sample was 185 days (median = 189), with a range from 32 to 297 days.

To assess interactions between need variables and insurance, appropriate product terms were computed. Each interaction was tested separately by entering the variables representing it into the regression equations after all other variables had been entered.

Results

Sample Description

Table 2 presents descriptive data on the analytic sample. The sample was diverse in sociodemographic characteristics, containing substantial proportions of women (19%), injection drug users (24%), Blacks (30%), and Hispanics (27%). Over half the sample (53%) had at most a high school education, and 56% reported incomes of at most \$9000 per year.

The majority of the sample (76%) used a clinic as their usual source of care, and only one third had private health insurance. Nearly half the sample (49%) were symptomatic but did not have AIDS, while over a third had AIDS.

Service Utilization

Tables 3 and 4 present summary statistics showing utilization of each type of service within categories of disease stage. Virtually all respondents had one or more ambulatory care visits in the six months following the second interview; the likelihood of any ambulatory visit did not vary across disease stages. (This high rate of outpatient utilization is not surprising in view of the fact that the sample was recruited primarily from outpatient clinics.) Half of the respondents with AIDS had an inpatient admission during the observation period; inpatient use was lower among the symptomatic and lowest among the asymptomatic. A similar pattern was observed for emergency room visits, with the highest proportion observed among those with AIDS.

Table 4 presents mean and median utilization frequencies for each disease stage. Because the length of the observation period is not constant, an annualized mean was also calculated by multiplying each person's frequency of use of a particular service by 365 and dividing by the length of his or her observation period; the resulting quantities were then averaged across respondents.

For each type of medical service, persons with AIDS reported more frequent utilization, while utilization was lowest among the asymptomatic group. People with AIDS averaged 21 ambulatory visits per year; asymptomatic respondents averaged 12 outpatient visits per year. Respondents with AIDS had two inpatient admissions and emergency room visits per year. Corresponding rates for symptomatics and

asymptomatics were half as great and were closer in value to each other than to the rates for people with AIDS.

Multivariate Analyses

Ambulatory Visits. Results of regression analyses appear in Table 5; to conserve space, the effects of geographical location (city) and of observation period are not presented. For (logged) number of ambulatory visits, respondents with a history of injection drug use had significantly fewer visits than those without drug use. Blacks and Hispanics tended to have fewer visits than whites, but this trend approached significance only for blacks ($p = .06$). Those with at most a high school education used outpatient care less frequently than those with some college experience. Respondents without a usual source of care had fewer visits than those with a clinic as their usual care source; this effect was significant even after insurance status was controlled. The enabling variable of insurance had strong effects; respondents with public insurance had fewer visits than those with private insurance, and those with no insurance had even fewer visits.

Greater need was consistently associated with more frequent use of ambulatory care. Despite controls for predisposing and enabling factors, respondents with AIDS or those with symptoms averaged more visits than asymptomatic respondents. People who were taking zidovudine had more visits than those who were not. Moreover, greater levels of functional impairment and of pain each were associated with increased outpatient utilization, net of disease stage.

Inpatient Admissions. Insurance and need factors emerged as the most important predictors of the rate of inpatient admissions. Predisposing factors of gender, IDU history, and race/ethnicity had nonsignificant effects, with the exception that black respondents had more admissions than whites. Respondents with no health insurance had significantly lower rate of admissions than those with private insurance; those with public insurance had slightly fewer admissions than those with private insurance, but this difference was minimal. In contrast to ambulatory care use, having no usual source of care did not significantly affect the rate of inpatient admissions.

Not surprisingly, respondents with AIDS had a higher rate of admission than

asymptomatic respondents. The difference between asymptomatic and symptomatic respondents, in contrast, was not significant. In addition, greater functional impairment and more prevalent pain each were related to more frequent admissions. Negative mood also raised the rate of admission.

Emergency Room Use. Analysis of emergency room use revealed a pattern generally similar to that for inpatient admissions. Among the predisposing and enabling factors, education had the strongest effect on the likelihood of ER use. Respondents with no college had a higher rate of ER use than the college educated. In addition, blacks used the ER slightly more frequently than whites ($p = .06$). Those with no insurance used the ER more often than the privately insured.

People with AIDS had a higher rate of ER use than asymptomatics, while symptomatics did not differ significantly from asymptomatics. Controlling for disease stage, functional impairment, pain, and negative mood each increased the rate of visiting the emergency room.

Average Length of Inpatient Stay. Analyses of (logged) average length of inpatient stay (ALOS) were conducted for the 460 respondents with at least one inpatient episode. Black respondents reported significantly longer ALOS than whites. Gender and IDU status were nonsignificant when other variables were controlled. Respondents with public or no insurance had longer ALOS than those with private insurance; the difference between no insurance and private insurance was significant ($p = .04$). In addition, respondents with a private physician as their usual source of care tended to have longer lengths of stay than those with a clinic as their usual care source.

In contrast to ambulatory visits and inpatient admissions, average length of stay was unaffected by functional impairment, pain and mood. People with AIDS, however, had longer stays than asymptomatic respondents. Symptomatic and asymptomatic respondents did not differ in their ALOS.

Interactions between Insurance and Need

Table 6 presents the results of adding terms to each regression equation that represent the interaction between insurance status and need variables. Separate analyses were conducted for each need variable and for each utilization variable,

resulting in 16 analyses. For example, to represent the interaction between insurance and disease stage, four product terms were computed and added to the regression model for each dependent variable. The coefficients for these terms appear in the last two columns of Table 6.

The predominant sign of the coefficients is negative. With private insurance as the reference category, negative coefficients imply that the magnitude of the relationship between a need variable and utilization is reduced for people with no insurance or with public insurance, as hypothesized.

Statistically significant effects occur for ambulatory visits and for inpatient admissions. Particularly noteworthy are interactions involving disease stage. Table 7 illustrates the pattern of results for combinations of disease stage and insurance status. Entries in each cell were calculated by summing the products of the coefficients and their corresponding dummy variables, ignoring all other variables in the equation. For respondents with private insurance, the number of ambulatory visits rises as disease stage becomes more severe. For respondents with no insurance, in contrast, the magnitude of the increase in ambulatory visits is not as great. For respondents with public insurance, the relationship shows a slight trend in the opposite direction. A similar pattern occurs for the number of inpatient admissions (not shown). Thus, having public or no insurance dampens the magnitude of the relationship between disease stage and utilization of ambulatory and inpatient care.

Functional limitations also interact with insurance status to affect ambulatory visits and inpatient admissions. The relationships between functioning and utilization of these services are significantly reduced among respondents with public insurance, compared to the privately insured. Similarly, having public insurance moderates the effects of pain and of mood. Surprisingly, interactions between functioning and no insurance are not significant.

In general, significant interaction effects are less frequent for ALOS and ER use than for inpatient and outpatient care. Length of inpatient stay may depend more on physicians' than patient's decisions and may be responsive to specific clinical manifestations, rather than general stage of HIV infection or physical

functioning. In contrast, emergency room visits may be under a patient's control to a greater extent than length of inpatient stay, yet significant interaction effects did not appear for ER visits. ER visits may primarily occur in periods of crisis, when considerations of insurance coverage are perhaps not of primary importance to the patient.

Discussion

Because the ACSUS sample is not a strict probability sample, the results cannot be generalized with a known level of confidence to a specific target population. However, the sample is the largest and most heterogeneous of any study reported to date. ACSUS findings that are replicated in other well-conducted research can be viewed as particularly robust.

The correlates of health service utilization among people with HIV infection are similar to those identified in studies of other populations. Research using the behavioral model has consistently found that need variables are the strongest predictors of utilization (Aday and Shortell, 1988; Wolinsky et al., 1983). The same pattern emerged here. Reflecting their more impaired health status, persons with AIDS had greater utilization of ambulatory, inpatient, and emergency room services than either asymptomatic persons or symptomatic persons who had not progressed to AIDS. Utilization rates for the latter two groups were not significantly different from each other, with the exception of ambulatory visits. Evolving practice standards for the treatment of HIV infection suggest more frequent periodic monitoring for symptomatic than for asymptomatic individuals, which will produce a differential rate of ambulatory care utilization.

The interpretation of effects of disease stage must be qualified by the fact that the analysis did not account for changes in disease stage over the observation period. Unfortunately, medical record data for periods 3 and 4 of the survey were currently unavailable for a large proportion of the sample. It is likely that some respondents progressed from asymptomatic to symptomatic, or from symptomatic to AIDS, subsequent to their staging as of the second interview. In fact, progression in disease stage accounts for at least 10 of the 30 asymptomatic respondents who subsequently reported an inpatient admission. (Another 6 were hospitalized for

conditions unrelated to HIV, e.g., myocardial infarction, substance abuse. Information was unavailable for the remainder.) Treating disease stage as constant probably produces a conservative bias, slightly narrowing the differences between the three disease stage groups.

The three categories of disease stage do not fully account for all variation in clinical condition. Recent studies show that variations in the number of CD4 cells is related to utilization (Piette et al., 1993; Zucconi et al., in press). Measures of CD4 cells were currently unavailable for the ACSUS sample. In addition, other research (Mor et al., 1992) has shown that intensity of HIV-related symptoms is positively related to use of ambulatory, emergency, and inpatient services among people with AIDS. Respondents in ACSUS were not asked about their HIV-related symptoms. It is possible that introducing controls for CD4 cells and HIV-related symptoms might modify the present findings. However, Piette et al. (1993) found that racial differences in utilization persisted after controlling for CD4 count, and Mor et al (1992) found effects of race and insurance status after symptoms were controlled.

Controlling for disease stage, limitations in physical functioning, negative mood, and experienced pain each significantly affected use of medical care. These findings are consistent with studies of the elderly, which find that measures of functional limitations generally predict health service use (e.g., Wolinsky and Arnold, 1988; Wolinsky and Johnson, 1991). The study by Mor and colleagues (1992) also showed significant effects of functional limitations on medical service use, controlling for symptoms and disease stage. The present findings reinforce the conclusion that the patient's personal experience of adverse health states resulting from HIV infection influences health service utilization, over and above disease stage.

The effects of negative mood deserve special comment. Prior research has shown that people seek medical attention when experiencing psychological distress (Arling, 1988; Manning and Wells, 1992). Much of this research has been conducted using samples of the general population; it might be expected that the impact of distress would be muted in a sample of people with a chronic condition who were

already in the health care system. Nevertheless, negative mood had a significant effect on ER visits and inpatient admissions. These results are especially notable because the effects of mood emerged after disease stage, functional limitations, and a number of other predisposing and enabling variables were controlled in the analyses. One interpretation of the effects of mood is that this variable is acting as a proxy for HIV-related symptoms. In other words, symptoms such as night sweats or weight loss may both create psychological distress and motivate seeking medical attention, especially by using the emergency room. Nevertheless, in view of prior findings showing a direct effect of psychological distress on health care use, future studies should examine the combined effects of mood and symptoms on health care utilization among people with HIV infection.

The effects of adverse health states, such as pain, functional limitations, and symptoms, can be interpreted as motivating patients to seek medical attention. The effects of such variables would be strongest for utilization that is patient-initiated, such as ER visits. Conversely, for utilization that is primarily determined by physician decisions, such as lengths of inpatient stays, effects of these variables are minimal. These findings reinforce the need to distinguish patient-based from provider-based determinants of health care utilization. Especially for a chronic condition such as HIV infection, a great deal of utilization may result from provider decisions, which should be explicitly incorporated into a comprehensive model of the utilization process.

Studies of health care utilization often find that predisposing factors have relatively little influence, compared to need factors (e.g., Wolinsky et al., 1983). This was true for the ACSUS data as well. In particular, gender did not significantly affect use of inpatient, outpatient, or ER services. Other studies have also found nonsignificant gender differences in hospitalization rates among people with AIDS (Mor et al., 1992; Seage et al., 1990; Seage et al., 1993).²

Respondents with a history of injection drug use had fewer outpatient visits than nonIDUs. This finding is consistent with those of Mor et al. (1992). However, in contrast to other findings (Mor et al., 1992; Seage et al., 1990; Seage et al., 1993), IDU status was not related to inpatient or ER utilization. It should

be noted, however, that 14% of respondents indicated a mode of HIV transmission other than sex with another man, injection drug use, or heterosexual relations. Since it is unlikely that the ACSUS sample contained an unusually large number of hemophiliacs or recipients of tainted blood products, information about mode of HIV transmission reported in the ACSUS screening questionnaire may be inaccurate.

Black respondents had significantly more inpatient admissions than white respondents, and they tended to have more ER visits but fewer ambulatory visits. In addition, the average length of stay was significantly longer for blacks than for whites. In contrast, differences between whites and Hispanics were smaller. Previous studies (Mor et al., 1992) also have found that nonwhites with AIDS were less likely than whites to use outpatient services and more likely to have an inpatient admission and an ER visit; these differences persisted when CD4 cell counts were controlled (Piette et al., 1993). Racial differences often can be explained as products of differences in income, education, or substance abuse. However, racial differences persisted in this study despite controls for such variables and a host of other predisposing, enabling, and need variables. Studies of health care use in other populations have also found persistent racial differences (Blendon et al., 1989; Aday and Shortell, 1988; Yergan et al., 1987). Future research should examine more closely factors that might explain these racial differences, such as attitudes toward the health care system, differential access barriers, or delays in presenting for treatment.

Among enabling factors, insurance status had the strongest effects. Compared to those with private insurance, respondents with no insurance consistently had lower rates of medical care use. Those with public insurance had fewer outpatient visits than those with private insurance, but differences in inpatient admissions and ER visits were less pronounced. These results are quite similar to those reported by Fleishman and Mor (1993), who found that PWAs with no insurance had significantly fewer outpatient visits and inpatient admissions than PWAs with private insurance. As in the present study, Fleishman and Mor found that although PWAs with public insurance had fewer inpatient admissions, this difference was not significant. Research in other populations (e.g., Spillman, 1993), as well as

studies of people with AIDS (e.g., Seage et al., 1990; Solomon et al., 1991; Kass et al., 1991) have reported similar utilization differentials as a function of insurance status.

Lengths of inpatient stay presented a different pattern. Average lengths of stay were longer among those with no insurance or with public insurance than among those with private insurance. Longer lengths of stay may be related to fewer outpatient visits. Without periodic outpatient monitoring, patients' conditions may deteriorate to such an extent that they are sicker upon admission and require extended periods of inpatient care. Future research should examine more closely the relationships between inpatient and outpatient utilization.

The statistical interactions between insurance status and need variables are significant for both theory and policy. As others have suggested (e.g., Rundall, 1979; Ronis and Harrison, 1988), the behavioral model can be interpreted as implying that the combination of need and enabling factors affects utilization, over and above their separate effects. Relatively few studies using the behavioral model have examined interaction effects. Future research should determine whether such interaction effects are significant in other populations.

The nature of the interactions implies that the impacts of disease stage and functional status on inpatient and ambulatory medical care are reduced in magnitude among people with public insurance, compared to those with private insurance. In other words, lack of insurance is not only a barrier to care in itself, but it also weakens the link between medical need and receipt of care. As the HIV epidemic spreads among members of disadvantaged communities, who often lack the resources to purchase private insurance, existing tendencies for a dualistic system of care to develop--one system for the privately insured and another for those without private insurance--may intensify. In the current climate of health care reform, evidence that lack of insurance creates utilization differentials among the most needy may help sustain efforts to alleviate this inequity.

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Footnotes

1. Respondents who reported insurance coverage both by private sources and by Medicaid or Medicare were classified as having private insurance.
2. Other analyses of data from ACSUS (Hellinger, in press) have reported that symptomatic HIV-infected women are more likely to receive outpatient care and less likely to be hospitalized than men. One reason for this discrepancy is different choices of reference group in the analysis. The present study contrasted women with all men, while Hellinger's study compared women to men with an "other" HIV transmission route (i.e., neither homosexual/bisexual nor IDU). In addition, Hellinger included emergency room visits with non-emergent outpatient visits, while the present analysis separated ER from ambulatory visits. The specification of the regression model also differed.

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Table 1
Correlates of Interview Status

	Interview Status		
	Attrited	Missing Data	In Analysis
Injection Drug User*			
No	9.9%	6.0%	84.1%
Yes	15.1	7.0	73.9
Gender			
Female	10.3	6.4	83.3
Male	11.6	6.6	81.8
Race/ethnicity			
White	10.3	3.7	86.0
Black	12.0	5.0	83.1
Hispanic	12.9	6.4	80.7
Illness Stage*			
AIDS	19.0	6.4	74.6
Symptomatic	6.8	6.3	86.9
Asymptomatic	6.0	7.6	86.4
Education			
No college	12.4	7.1	80.5
Some College	10.0	5.7	84.2
N	221	128	1600

* -- Significant differences in interview status, $p < .05$.

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Table 2

Characteristics of Analytic Sample

Variable		N	proportion
Gender	male	1301	81.3
	female	299	18.7
Race/ Ethnicity	white	695	43.4
	black	479	29.9
	Hispanic	426	26.6
IDU	no	1209	75.6
	yes	391	24.4
Illness Stage	AIDS	558	34.9
	Symptomatic	782	48.9
	Asymptomatic	260	16.3
Insurance	Private	542	33.9
	Public	678	42.4
	None	380	23.8
Income	< \$9000	889	55.6
	> \$9000	711	44.4
Education	< 12	851	53.2
	> 12	749	46.8
Usual Source of Care	None	95	5.9
	Clinic	1212	75.8
	Private M.D.	293	18.3

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Table 3

Proportion Using Each Service by Disease Stage

Service	Overall	AIDS	Symptomatic	Asymptomatic
Inpatient Admission*	30%	50%	21%	12%
Emergency Room*	36%	50%	30%	22%
Ambulatory Care	95%	93%	97%	93%

* -- Effect of disease stage statistically significant, $p < .05$.

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Table 4
Service Utilization by Stage of HIV Infection

Service Type	Stage	N	mean	std.	std	median
				mean	dev.	
Ambulatory Visits	AIDS	558	11.0	23.0	11.5	8
	SYMPT	782	8.3	16.1	9.2	6
	ASYMPT	260	6.4	12.2	8.6	5
Inpatient Admits	AIDS	558	0.9	2.1	1.1	0.5
	SYMPT	782	0.3	0.7	0.7	0
	ASYMPT	260	0.2	0.4	0.6	0
Inpatient ALOS	AIDS	270	12.5	---	12.0	9.0
	SYMPT	160	9.1	---	9.9	6.3
	ASYMPT	30	9.4	---	13.5	5.0
Inpatient Nights (among those with an admission)	AIDS	270	21.7	52.6	22.3	14
	SYMPT	160	13.7	31.4	17.3	7
	ASYMPT	30	15.6	35.9	20.3	5.5
Inpatient Nights (entire sample)	AIDS	549	10.7	25.9	19.0	0
	SYMPT	776	2.8	6.5	9.6	0
	ASYMPT	258	1.8	4.2	8.5	0
ER Visits	AIDS	556	1.0	2.2	1.5	1
	SYMPT	782	0.5	1.1	1.1	0
	ASYMPT	260	0.3	0.6	0.7	0

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Table 5

Regression Analyses of Correlates of Service Utilization

Independent Variable	Dependent Variable		
	Ambulatory Visits ^a	Inpatient Admissions ^b	ER Visits ^b
Black	-.09+	.22*	.15+
Hispanic	-.03	-.02	-.02
IDU	-.13*	.13	.03
Male	.03	.05	.02
No College	-.11*	.14+	.26*
Usual Source of Care			
none	-.19*	.10	.05
private MD	.10+	.12	.01
Taking AZT (T1)	.09*	.08	.03
Income > 9000	-.02	-.19*	-.22*
No insurance	-.30*	-.65*	-.31*
Public insurance	-.13*	-.04	.18+
Lives Alone	.01	-.12	-.11+
Functioning	.06*	.11*	.06*
Pain	.02*	.05*	.04*
Negative Mood	.01	.02*	.02*
AIDS	.29*	1.00*	.71*
Symptomatic	.18*	.24	.25

Note: Entries are unstandardized regression coefficients. All analyses include dummy variables representing geographical location and a variable reflecting the number of days in the study (results not shown).

a -- Dependent variable transformed to natural logarithm.

b -- Poisson regression used for analysis.

* -- $p < .05$

+ -- $p < .10$

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Table 5 (continued)
Regression Analyses of Correlates of Service Utilization
Dependent Variable

Independent Variable	ALOS ^a
Black	.29*
Hispanic	.15
IDU	-.06
Male	.11
No College	-.01
Usual Source of Care	
none	-.21
private MD	.23+
Taking AZT (T1)	-.04
Income > 9000	.07
No insurance	.31*
Public insurance	.15
Lives Alone	.12
Functioning	.02
Pain	.01
Negative Mood	-.01
AIDS	.40*
Symptomatic	.14

Note: Entries are unstandardized regression coefficients. All analyses include dummy variables representing geographical location and a variable reflecting the number of days in the study (results not shown).

a -- Dependent variable transformed to natural logarithm.

* -- p < .05

+ -- p < .10

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Table 6

Tests of Interactions between Insurance and Need

Dependent Variable	Insurance	Need Indicator				
		Functioning	Pain	Mood	Aids	Sympt.
Ambulatory Visits	none	-.018	.011	-.003	-.364*	.010
	public	-.076*	-.042+	-.017*	-.730*	-.223+
ER Visits	none	-.034	-.009	-.009	-.598+	-.504
	public	-.062	-.009	-.014	-.053	.034
Inpatient Admissions	none	.010	-.062	-.052*	-.744+	-1.297*
	public	-.122*	-.093*	-.042*	-1.189*	-1.013*
ALOS	none	.021	.052	-.033+	-.363	-.112
	public	-.044	.006	-.012	-.248	-.081

Note: Entries are coefficients from regression analyses in which interaction terms were added after all variables listed in Table 5 have been included. Interaction terms for AIDS by insurance and for symptomatic by insurance were included together in the model. Ambulatory visits and ALOS were logarithmically transformed. Poisson regression was used to analyze number of admissions and number of ER visits.

* -- $p < .05$.

+ -- $p < .10$.

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Table 7
Pattern of Interaction between Insurance and Disease Stage
(for Ambulatory Visits)*

Insurance	Stage		
	ASYMPTOMATIC	SYMPTOMATIC	AIDS
PRIVATE	.423	.636	1.062
PUBLIC	.723	.713	.632
NONE	.243	.517	.446

a -- Entries are sums of coefficients times their respective dummy variables. For example, the entry for AIDS and public insurance equals .423 (the constant) + .300 (coefficient for public insurance) + .639 (coefficient for AIDS) - .730 (coefficient for interaction term). Since other variables in the regression model have not been included in these calculations, the entries are not predicted values.

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Results of the AIDS Cost and Services Utilization Survey for Pediatric AIDS Patients

Utilization of Services, Functional Status, and Social Severity

Marianne C. Fahs, PhD, MPH*
Douglas Waite, MD**
Marilyn Sesholtz, MD*
Charlotte Muller, PhD*
Elizabeth A. Hintz, MA, MHSA***
Carla Maffeo, PhD***
Peter Arno, PhD****
Charles Bennett, MD*****

* Departments of Community Medicine, Geriatrics and the International Leadership Center on Longevity and Society (US), and ** Pediatrics, Mount Sinai Medical Center, City University of New York, NYC, NY; *** WESTAT, Bethesda, MD; **** Department of Social Medicine, Montefiore Medical Center, New York, NY; ***** Department of Health Services Research & Development, VA Medical Center, Durham, NC

Please address correspondence to:

Marianne C. Fahs, PhD; Director & Associate Professor
Division of Health Economics, Mount Sinai Medical Center
One Gustave Levy Place, Box 1043, New York, NY 10029
(212) 241-3184, (212) 360-6965 (fax)

ABSTRACT

The increased incidence of HIV infection and AIDS among women has been accompanied by a rise in perinatal transmission of the virus. AIDS now ranks among the top five causes of death for children. This is the first study to examine hospital and community-based service utilization patterns of pediatric patients in five metropolitan regions of the United States. Data reported in this study are from the AIDS Cost of Services and Utilization Survey (ACSUS) and cover the six-month period beginning March 1991 (n=135). Personal interviews were conducted with patients' primary caregivers. Medical and social support service usage patterns are analyzed with respect to patient demographic characteristics, clinical trial participation, functional/developmental status and social environment. A weighted ten point social severity scale was developed to assess family/household stability.

The sample is comprised of 62% Black, 25% Hispanic and 10% White patients. Medicaid is the primary payor for 92%. Within the six-month period, approximately one-third of the sample (29.6%) was hospitalized. Mean length of stay is 16.0 days. Clinical trial participation is positively related to mean number of hospital clinic visits and receipt of formal (paid) home care. There are no differences in usage of emergency room, community clinic, mental health, and inpatient facilities by clinical trial status. Participation in clinical trials is positively related to income and inversely related to social severity.

Further study of the relationship between the social environment and utilization patterns over the 18 month study period is recommended. Policy implications such as using increased participation in clinical trials as an entry to expanded health care services are discussed.

INTRODUCTION

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Pediatric AIDS cases constitute approximately 2 percent of total AIDS cases in the United States, but already AIDS ranks among the top five causes of death for children. By the end of 1992, the CDC had reported 4,249 children with AIDS; of these, 1,962 were still alive. (CDC, 1992b). Eighteen percent all pediatric AIDS cases and 23 % of all cases among women were reported during the single year ending December, 1992 (CDC, 1992b). Presently, we are able to accurately study only the immediate plight of children with AIDS, or HIV symptomatic illness, a six-month perspective which barely hints at prospects ahead for the estimated 1,500 to 2,100 newborns who are born HIV-positive each year as a result of perinatal transmission (Gwinn et al., 1990; Institute of Medicine, 1991).

Complex economic and social forces sustain the AIDS epidemic. Homelessness, poverty, and oppressive social conditions often confound attempts at slowing the failing course of this disease (National Commission on AIDS, 1991; Birn, Santelli, Burwell, 1990). Among children with perinatally-acquired AIDS, fifty-two percent have been born to women with a history of intravenous drug use, and the mothers of another 20% became infected through sexual intercourse with injecting drug users (CDC, 1992b).

Increasingly, HIV is affecting entire families, especially those of minority and low socioeconomic classes. Fifty-four percent of the reported children with AIDS have been of African-American descent, although only about 14% of all the nation's children are black. In addition, 24% of the children with AIDS have been of Hispanic or Latino origin, although these ethnicities contribute only about 11% of the nation's children. Medical management of HIV in

children is often complicated by the loss of one or both parents through AIDS and/or drug use, with death, disability, and absence all playing a part in this loss (Muller, Fahs, Mulak, et al, 1992). Thus in many ways, health care delivery to children with AIDS mirrors and magnifies current problems with medical care delivery to disadvantaged children in our society (Hegarty, 1993).

No research to date has examined the influence of low socioeconomic status upon health care utilization patterns for pediatric AIDS patients. In an attempt to characterize and measure concurrent social and economic factors that influence the use of medical and support services by children with AIDS, we designed an index of social severity. We analyze utilization patterns for inpatient, outpatient, community-based and informal care services for pediatric AIDS patients from five cities in the United States, paying particular attention to clinical trial participation.

METHODS

Data for this study come from the first six months of the AIDS Cost and Service Utilization Survey (ACSUS), an 18-month, federally funded study conducted by the Agency for Health Care Policy and Research. Information was provided by the person accompanying the child to a hospital clinic visit, usually the parent, in two interviews after an initial screening to select HIV-positive patients with at least one HIV-related symptom or condition. Pediatric patients were sampled at seven hospitals in five different urban metropolitan areas, each with

specific clinics serving HIV positive children.

Utilization measures are standardized to a six-month period beginning March 1, 1991 and extending to the date of the second interview. Per capita income is measured using reported total household income from all sources for the past month. Monthly income has been annualized and average annual per capita income estimated based on household size. For respondents reporting SSI and/or AFDC payments, incomes are calculated inclusive (maximum estimate of real income) and exclusive (minimum estimate of cash income) of average annual estimated payments of \$4,600 and \$3,650, respectively (Social Security Bulletin, 1991).

Functional status is assessed using a series of age-appropriate questions on motor and social development from the National Health Interview Survey conducted by the US Department of Health and Human Services, Public Health Service, National Center for Health Statistics. A social severity scale was developed based on prior work by two of the authors with the Mount Sinai Medical Center department of social work services to assess problems of family functioning for pediatric AIDS patients (Muller, Fahs, Mulak, et al, 1992). The algorithm in this study is shaped to use the categories of information provided by this data base, and therefore is different in details, although similar in concept, from the one used in the previous study. The social severity scale developed for this report provides a composite measure for three dimensions of the child's social environment: family structure, economic security, and informal personal network.

Family structure consists of household composition, presence or absence of HIV seropositive persons in the household, and language. The maximum score for this section is four, which is assigned as follows:

Household Composition: 1 = Two parents or two other kin living in household
0 = Other

A score of 1 indicates some degree of family ties implying continuous responsibility for and interest in the child.

HIV + persons in household: 2 = No HIV + persons in household
1 = No HIV + relative or foster parent
0 = One or more HIV + relatives or foster parents

Scores other than 2 indicated that the family support structure is, or will be, compromised by serious illness of one or more household members.

Language: 1 = English
0 = Spanish

Command of English improves one's ability to deal with a variety of social systems that may be called upon to arrange services for the child or the family.

Economic security is comprised of stability of housing and annual income. The maximum score is three and values are assigned as follows:

Housing: 1 = Caregiver owns or holds lease on house or apartment
0 = Other

Security of tenure is provided by deeds or leases, whose absence signifies a current or likely housing problem.

Annual Income: 2 = \$20,000 or more excluding public programs (i.e., AFDC, SSI)
1 = \$20,000 or more including public programs
0 = Less than \$20,000

Annual income is a measure of resources available to meet all needs for health care, food, and shelter. Independence from public assistance maintenance programs signifies greater stability.

Informal personal network is defined as help from family or friends (other than household members) and has a maximum value of two:

- 2 = 20 or more hours of help per week
- 1 = 10-19 hours of help per week
- 0 = Less than 10 hours of help per week

Help from family or friends augments the potential caregiving resource of members of the household.

The social severity score is based on a weighted ten point scale with a score of zero representing the least favorable circumstances and nine the most favorable. These scores are converted to percents (9 = 100%). Percent scores for households with missing data are computed using the score for known items taken as a percentage of the total possible score for non-missing items for that household.

RESULTS

Demographic Characteristics

The total pediatric sample consisted of 141 children, six of whom were lost to follow-up, leaving 135 children at the end of 6 months. Demographic characteristics are presented in Table 1. Fifty-two percent are male and 48% are female, and this ratio is consistently found in the five sample cities. More than half (54%) of the national sample consists of children aged 48 months or more and almost four-fifths (79%) are 22 months old and over. Only 9 children (7%) are aged 12 months or younger and 19 (14%) are between 13 and 21 months of age. Age distributions were also stable across cities, and resemble city-specific age distributions for pediatric AIDS cases reported to the CDC (CDC, 1992c).

Consistent with CDC surveillance reports, Black and Hispanics are proportionally over-represented compared to their numbers in the general population. The sample is 62% Black, 25% Hispanic, and 10% White (92% speak English). The ethnic/racial mix varies widely by city; from 23% to 97% for Blacks, from 8% to 68% for Hispanics, and from 3% and 38% for Whites.

Over 90% of all respondents receive Medicaid, with only 9 children (7%) having private insurance. Sixty-one percent of children live with a caregiver who either owns, or holds a lease to, a residence.

Thirty-one percent of respondents reported a total annual income of less than \$5,000. Approximately 58% have total incomes under \$10,000, compared with 15% nationally (US Bureau of Census, 1992a). Three-quarters have incomes under \$20,000 and only 20% report

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incomes of \$20,000 and above, compared with over 50% nationally (five percent of respondents did not report household income).

The mean number of people per household is 4.3. The estimated maximum mean per capita income for the total sample, including annualized estimates of AFDC/SSI benefits, is \$3,440. The minimum estimate of mean per capita income (exclusive of AFDC/SSI benefits) is \$2,815. These figures are much lower than mean per capita income for the US of \$11,923 (US Bureau of the Census, 1992b). For the 75% of respondents with total incomes less than \$20,000, mean per capita annual income (inclusive of AFDC/SSI benefits) is \$1,983 and ranges from \$312 to \$7,500, and from \$0 to \$7,500 exclusive of these payments, with a mean of \$1,278. Based on the estimates that include AFDC/SSI benefits, 56% of the sample report per capita incomes of \$2,500 or below and 27% are living on less than \$1,000 per capita per year.

Table 2 describes the distribution of public assistance for the sample households. The percentages of households receiving AFDC, SSI, and WIC are 41%, 30%, and 31% respectively. Less than 3% of the sample receive all three benefits in combination, but almost two-thirds receive one or more forms of public assistance. Of the 42 respondents receiving WIC, only 23 also received AFDC.

Utilization

By study definition, all respondents visited a hospital clinic during the six-month period. Table 3 presents a summary of standardized utilization measures. The mean number of hospital outpatient visits is 7.34 (± 0.94 , 95% confidence interval). The range is wide, from 1.45 to 45.98, with the modal number of unadjusted clinic visits being six, reflecting a once-a-month clinic visit schedule.

Fifty-two percent of the sample visited the emergency room, for a mean emergency room visit rate of 1.27 (± 0.34 , 95% confidence interval) per child. Children used the services an average of 1.16 (± 0.10 , 95% confidence interval) unique emergency facilities. The 70 children who used the emergency room returned for an average of 2.5 visits per user.

During the six-month period, 40 children were hospitalized for a total of 614 hospital days or 4.55 days per child. The mean admission rate was 0.47 (± 0.16 , 95% confidence interval). The range of admissions was 0 to 5.8. The average length of stay was 16.03 days (± 4.61 , 95% confidence interval).

Few children received community-based services (clinical and social services outside the hospital). Twenty-one percent visited private physicians and 13% visited community clinics. Less than one-half of the children (42%) received formal home care services. For children seven years old and over, less than a third (32%) received mental health services. This is much greater than rates of 2%-4% found for normal children from a community-based sample, but consistent with rates of less than 30% found for children with severe mental illness (Hogwith, 1993).

One-half of the sample was tested for HIV seropositivity before the age of one year. Little variation in HIV testing by age group was found across the five different urban settings,

most testing took place in the youngest age group. However, in one city, one-fourth of the children were not tested until they had reached 4 years of age or more.

Respondents were shown a list of HIV-related medications* and asked if the child being cared for had taken any of the specified medications. Eighty percent of the sample had, at some time, received medication specific to the treatment of HIV infection. Percentages were generally high across geographic sites. The lowest rate of HIV medication (71%) was found in the same city in which lower rates of early HIV testing occurred. Table 4 presents these results.

Clinical Trial Analysis

Clinical trial participants visited hospital clinics more often than did non-participants (mean number of outpatient visits: participants 8.48 ± 1.79 versus non-participants 6.50 ± 0.95 , 95% confidence interval, $p=.05$). Non-participants made somewhat greater use of private physicians' services (mean number of visits: participants 0.25 ± 0.24 versus non-participants 0.93 ± 0.51 , 95% confidence interval, $p=.04$). Participation in clinical trials is also associated with the use of formal (paid) home care services (proportion receiving formal home care: participants 52.63% versus non-participants 34.62%, $p=.04$). These results are presented in Table 3.

No differences related to clinical trials were found in mean utilization rates or mean visit rates for emergency room, community clinic and mental health services or for inpatient

* HIV-related Medicines: AZT, Zovirax (Acyclovir), Ganciclovir (DHPG), Amphotericin B, Dextran Sulfate, IVIG (Intravenous Gamma Globulin), Nebupent (Aerosol Pentamidine), Pentam (Pentamidine, IM, IV), Bactrim, Septra, Sulfadiazine, Pyrimethamine, Nystatin, Ampicillin, Amoxicillin, Isoniazid (INH), Fluconazole (Diflucan), Foscarnet, Ketoconazole (Nizoril), Rifampin (Rifadin), Ciprofloxacin (Cipro).

hospitalizations or mean number of days spent in the hospital. The mean number of unique emergency rooms and hospitals used showed no difference as well.

When hospital and community-based service utilization rates were analyzed by clinical trial participation across cities, there were few differences in most service use patterns. Emergency room utilization is an exception. Emergency room utilization varied widely across cities, with rates consistently lower for clinical trial participants than for non-participants in four of the five cities.

Since clinical trial participation is associated with patterns of care that may indicate differences in quality or follow-up, access to clinical trials is a concern. Patient demographic characteristics associated with clinical trial participation were analyzed. Household income is positively related to clinical trial participation ($p=.05$) as shown in Table 3. No other patient demographic characteristic was found to be associated with clinical trial participation. Clinical trial participation also correlated with higher social severity scores ($p=0.006$). Clinical trial participants have a mean value of 4.56 (± 0.57 , 95% confidence interval, and non-participants have a mean value of 3.58 ± 0.44 , 95% confidence interval).

Functional Status

Respondents were asked about age-specific childhood developmental milestones and school attendance. The total sample is grouped by age: 0-21 months, 22-47 months, and 48 months and older. No differences were found in the mean number of items achieved within age groups when analyzed by sex, race, income level, and clinical trial participation.

The youngest age group (0-21 months) is comprised of 28 children (21%), each of whom

is evaluated on 14 developmental skills. The mean number successfully completed is 7.5 (± 1.43 , 95% confidence interval). There are 34 children (25%) aged 22-47 months. Sixteen age-specific developmental abilities are assessed. The mean number of items achieved is 9.4 (± 1.47 , 95% confidence interval).

Caregivers of children 4 years of age and older are asked questions regarding attendance at school, days missed, and days in bed inclusive and exclusive of hospitalization. There is a total of 73 children (54%) in this oldest age category. Fifty-seven of the 73 (78%) attended school at some point during the study period. Twenty children (35% of those enrolled in school) missed school due to illness or injury. The mean number of school days reported missed is 11.2. Analysis by sex, age and clinical trial participation showed no differences.

For the 62 children aged 0-47 months, an aggregate mean proportion of developmental criteria achieved is estimated. Children met just over one-half (0.55 ± 0.07 , 95% confidence interval) of age-appropriate developmental criteria. This proportion did not vary by race. However, trends suggest a possible association between functional status and clinical trial participation. Sixty-eight percent of participants have scores at the sample median or above, compared with 51% of non-participants ($p = .19$).

Table 6 presents the results of analyses of the relationship of functional status and utilization. Children with functional status levels below the median receive the same amount of informal home care from families and friends outside the household as do children with higher functional status. Only 29% of children aged 0-47 months receive 20 hours or more of home care from family and friends. Similarly, for children aged 4 years and over, more hours of informal household help do not appear to be associated with children experiencing the higher

home care needs, as measured by days spent in bed at home. The average number of days spent at home in bed is 5.1.

Functional status is related to hospital utilization, though not all children with low functional status scores are hospitalized during the six-month period. For children aged 0-47 months with scores below the median, 54% are hospitalized for an average of 10.9 days per child, compared with 22% with scores at the median or higher for an average of 1.2 days per child ($p=.01$). There were no differences in emergency room use. Sicker children (as measured by functional status) did have more hospital outpatient visits (9.1 ± 3.56 , 95% confidence interval, versus 6.0 ± 0.86 , 95% confidence interval).

Children's use of community-based clinics did not vary by functional status but there is a trend for children of higher functional status to have higher visit rates with private physicians (0.25 versus 1.21, $p=.10$). Formal home care is also related to functional status ($p=.05$), although the data suggest possible disparities between formal home care use and need. Over one-third of children with functional status scores below the median receive no formal home care services. Informal home care services do not vary by functional status. 60% of children receive less than 10 hours of non-paid home help per week.

Social Severity

The impact of pediatric AIDS on families is indicated by the mean social severity score of 4.0 (± 0.36 , 95% confidence interval) with a modal value of three, which is far below the maximum of 9. Table 5 presents the mean and distribution of social severity scores. Social severity does not vary by race.

Little variation in patterns of utilization was found between patients with high and low social severity scores (Table 7). The only exception is an association of higher social severity scores (scores between 4-9) with a higher rate of emergency room use ($p=.01$). However, visit rates per user were lower than for those children who had lower social severity scores. Non significant trends showed slightly higher percentages of formal home care and markedly higher mental health care use for children from the more stable social environments.

For the 28 children aged seven and over, trends suggest that use of mental health services increases with increased levels of informal home care support ($p=.14$). The data show that among this age group, only 23% of children in disadvantaged home care support situations (less than 10 hours of informal home care available from family and friends), receive mental health support services. The mean number of mental health visits is 1.4 (± 1.74 , 95% confidence interval) for this disadvantaged group ($n=17$). By contrast, children with 10-19 hours of informal home care available, and over 20 hours available, average 13.3 (± 26.6 , 95% confidence interval) and 11.8 (± 15.3 , 95% confidence interval), respectively.

Clinical trial participation is related to higher social severity scores ($p=.006$) (Table 5). shows. Clinical trial participants have a mean value of 4.56 (± 0.57 , 95% confidence interval), and non-participants have a mean value of 3.58 (± 0.44 , 95% confidence interval). Forty-nine percent of children with social severity scores above the median were in clinical trials, compared with 34% of children with social severity scores below the median ($p=.07$).

The analysis presented in this report suggests substantial areas for improvement to policy-makers concerned with resource administration for the growing pediatric AIDS population. Participation in clinical trials, already singled out by community providers as services in limited supply (Harvey, Boland, and Burr, 1992), is even more limited to those who by our measure of social severity, need the services provided by trial participation the most. By design, clinical trial studies serve as a gateway to medical and social services that provide continuity of care and outreach to children and their families to insure follow-up, and hence trial completion. This study, however, suggests that access to clinical trials, and thereby to supportive services, may be limited for the majority of disadvantaged children with AIDS.

What is the barrier to clinical trials? Given limited funding, rationing of trial participation is inevitable. While forty-two percent of children in this study were enrolled in AIDS clinical trials, national rates of clinical trial participation for children with cancer run over 80%. More unsettling however, is that while clinical trial participation correlates with higher income, it is negatively correlated with social severity. In other words, children who live in poverty and in the most severe socially disadvantaged environments are least likely to be enrolled in clinical trials. While ideally services should not be rationed to any child with AIDS, this study suggests an inequality among this population, with children from the most stable social environments receiving more formal home care services, the very children who may relatively need them the least.

This study suggests that increased funding for clinical trials alone may improve access

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to social services for children from more severe social environments. Mean utilization rates for hospital clinics varied little by social severity score, implying that caretakers of children with low social severity scores are capable of the long-term follow-up required for the medical care of their sick children. Barriers to care seem to exist for only some services, namely the supportive services often provided to those in clinical trials. While social severity in itself does not hinder access to care, social severity correlates with clinical trial participation which is associated with higher rates of hospital clinic visits and formal home care. Mental health care service utilization also displayed a positive (although nonsignificant) trend with clinical trial participation.

Inevitably one must question whether clinical trial participants are simply sicker children, and therefore more worthy of these supportive services. However, in analyzing functional status as measured by age-specific developmental milestones and school attendance, we found no significant difference between clinical trial participants and non-participants, suggesting neither population is more medically infirm than the other. Functional status in general is compromised. On average, children met only one-half of the age-specific developmental criteria. They tended to perform better on simple motor and verbal tasks, but appeared to do less well on complex ones, which may require concentrated adult input and teaching.

Families in our study appear to under-utilize income support services, an unexpected finding not generally discussed or anticipated in the literature. Despite per capita incomes at the bottom of the income scale, almost one-third of these children receive no public income assistance. Fifty-six percent of the sample report annual per capita incomes of 2,500 or below, while only 68% receive some form of public assistance (either AFDC, SSI, or WIC), with only

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3% receiving all three forms of assistance. These children may be revealing the effects of national trends in the deterioration of material conditions for disadvantaged children during the 1980s in the United States (Fuchs and Reklis, 1992).

Because by definition, our study population has already accessed health care services in a hospital clinic, this study probably underestimates barriers to health care and support services for many of HIV positive children in the United States. Indeed, other researchers have found that the proportion of children from families at or below the poverty threshold covered by Medicaid dropped from 50.3% in 1977, to 37.6% in 1987 (Cunningham, Moneheit, 1990). While 90% of children in this sample have Medicaid coverage, this high rate would be expected, given that the children are already patients in an outpatient clinic of a major urban hospital. Would a broader population, one not recruited in hospital clinics, reveal disparities in patterns of utilization that might be lost in our select clinic population? In addition, because study selection required HIV symptomatology, our study population ignores the larger, asymptomatic group of HIV-positive children.

Although a six-month time period is too short to measure such effects with reliable precision, increased clinical trial participation may contribute to increased home care services and continuity of care, and improved social and economic outcomes, such as reduced hospital costs. The need for such social support services has been well described. In a study of inpatient AIDS cases at Harlem Hospital between 1981 and 1986, Heagarty found that one-third of the total inpatient days, and over 20% of the cost resulted from social rather than medical factors (Heagarty, Abrams, Hutchinson, et al, 1988). Boarder babies (ie., homeless children) had a mean length of stay nearly four times longer than those with homes. Kemper and Forsyth (1988)

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found that for the 34 HIV+ pediatric patients hospitalized at Yale through 1987, 58% of their hospital days were medically unnecessary, due largely to inadequate outpatient services. Lifetime inpatient expenditure estimates for pediatric AIDS patients range from \$45,080 to \$90,347 (Andrews, Keyes, Fanning, et al, 1991; Heagarty, Abrams, Hutchinson, et al, 1988) with Medicaid being the expected primary payer (Andrulis, Wslowski, Hintz, et al, 1990; Andrews, Keyes, Fanning, et al, 1991; Ball and Thaul, 1992). To better understand the effects of clinical trial participation on utilization patterns, as well as on measures of outcome, analyses over the full 18-month study period are warranted. Future analyses might examine changes in social severity over time associated with clinical trial participation and service utilization rates.

The families of children in our study mirror the 40% of our nation's children who not only live in poverty, but chronically remain there (Wright, 1993). Further study of health care delivery to children with AIDS can thus highlight barriers to medical and social services to the greater population of disadvantaged children in our society who live in the persistent cycle of poverty and poor health.

CONCLUSION

Inadequate support services for pediatric AIDS cases are a national problem (National Commission on AIDS, 1991). Most HIV-infected children come from disadvantaged families who depend on public health and social service systems, but the various services that would provide alternatives to hospital care or otherwise reduce hospital use are over-burdened in many communities. However, the results of this preliminary investigation of factors related to hospital and community-based utilization among pediatric AIDS patients indicate several areas where quality of care might be increased and where the expense of costly hospitalizations due to social rather than medical factors might be reduced.

Socioeconomic status, as measured by social severity score, is not in itself associated with significant variations in health care utilization. However, social severity score correlates with clinical trial participation, which in this study, was associated with higher rates of hospital clinic visits, and formal home care. Only 42% of children in the sample are enrolled in clinical trials, compared with rates of over 80% for children with cancer. The analysis suggests that access to clinical trials is limited to a large number of children with AIDS, who in many ways might benefit the most from the services provided through clinical trial research. Expanding clinical trial participation to include these children would serve to emphasize the importance of outreach programs from urban academic health centers to families who, whether because of parental illness, drug addiction, or simply chaotic home environments represent the very reason the AIDS epidemic has flourished among the most disadvantaged population in our society. It is possible for concerted efforts among policy-makers and providers in our disadvantaged communities to substantially improve the difficult situation faced by children with AIDS and their families.

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Table 1
Demographic Characteristics

	Total Sample <u>n=135</u> %
Sex	
Male	51.85
Female	48.15
Age	
0 - 12 months	6.67
13 - 31 months	14.07
22 - 47 months	25.19
48+ months	54.07
Race	
White	10.37
Black	62.22
Hispanic	25.19
Other/No Answer	2.22
Primary Language	
English	91.85
Spanish	8.15
Housing	
Caretaker Owns/Holds Lease	60.74
Caretaker Pays Rent/Does not hold Lease	37.04
Other Living Arrangement	2.22
Health Insurance	
Medicaid	91.85
No Medicaid	8.15
Private Insurance/ % Total Private Insurance	100.00
Income	
< 5,000	31.1
5,000 - 9,999	26.7
10,000 - 19,999	16.3
20,000 - 39,999	11.9
40,000 +	8.1
Unknown	5.9

Table 2**DRAFT****Utilization of Public Assistance by Type of Public Assistance**

	Total Sample <u>n=135</u> %
Receive AFDC/WIC/SSI	68.15
Total Receiving AFDC	41.48
AFDC Only	13.33
Total Receiving WIC	31.11
WIC Only	10.37
Total Receiving SSI	30.37
SSI Only	12.59
Multiple Forms of Government Aid	31.85
AFDC + SSI + WIC	2.96
AFDC + SSI	11.11
AFDC + WIC	14.07
SSI + WIC	3.70
Do Not Receive AFDC/WIC/SSI	31.85

Table 3

DRAFT

**Percentages of Children Utilizing Medical Services
and Mean Visits by Clinical Trial Participation**

	Total Sample n=135 %	Clinical Trial Participant n=57 %	Non- Participant n=78 %	P Value
<u>Medical Service</u>				
Hospital Clinic Users	100.00	100.00	100.00	
Mean Outpatient Visits	7.34	8.47	6.50	.05
Emergency Room Users	51.85	57.89	47.44	-
Mean ER Visits	1.27	1.36	1.21	
Mean Unique Providers	1.16	1.06	1.24	
Formal Home Care Users	42.22	52.63	34.62	.04
Inpatient Hospitalization Users	29.63	26.32	32.05	-
Mean Admissions	.47	.42	.51	
Mean Hospital Days	4.55	5.35	3.97	
Unique Hospital Providers	1.15	1.13	1.16	
Private Physician Users	20.74	12.28	26.92	.04
Mean Visits	.64	.25	.93	.02
Community Clinic Users	13.33	10.53	15.38	-
Mean Visits	.23	.26	.20	
Non-Medical/Social Services	62.22	59.65	64.10	
Mean Number Services	1.27	1.18	1.35	
	Total Sample 7 years old + n=28 %	CTP n=11 %	Non-P n=17 %	
Mental Health Services Users	32.14	36.36	29.41	-
Mean Visits (n = 28)	5.64	10.82	2.29	

Table 4

DRAFT

Clinical Trial Participation by Income and Language

<u>Patient Characteristic</u>	<u>Proportion Admitted to Clinical Trial</u> %
Total Sample	42.2
Income Level *	
0 - 6,000	24.5
6,001 - 9,000	42.1
9,001 - 15,600	54.5
15,601 - 21,000	22.2
21,001 - 36,000	66.7
36,001 and over	71.4
Language	
English	42.2
Spanish	42.9

* p = .05

Table 5

DRAFT

**Severity Score Distribution and
Total Social Severity Score by Clinical Trial Participation**

	Total Sample <u>n=135</u> %	Clinical Trial Participant <u>n=57</u> %	Non- Participant <u>n=78</u> %	<u>P Value</u>
Total Social Severity Score				
0 (most severe)	-	-	-	
1	13.33	7.02	17.95	
2	12.59	10.53	14.10	
3	20.00	19.30	20.51	
4	14.81	12.28	16.67	
5	15.56	17.54	14.10	
6	11.85	15.79	8.97	
7	5.19	7.02	3.85	
8	3.70	5.26	2.56	
9 (least severe)	2.96	5.26	1.28	
Mean Total Social Severity Score	3.99	4.56	3.58	.006

Table 6

Proportions of Children Aged 0-47 Months Receiving Services, by Functional Status

	Functional Status Score			<u>p Value</u>
	<u>Total</u> <u>n=62</u> %	<u>Median</u> <u>and Above</u> <u>n=36</u> %	<u>Below</u> <u>Median</u> <u>n=26</u> %	
Clinical Trial Participant	40.32	47.22	30.77	-
Medical Services				
Hospital Outpatient Clinic	100.00	100.00	100.00	-
Emergency Room	58.06	58.33	57.69	-
Formal Home Care	46.77	36.11	61.54	.05
Inpatient Hospitalization	35.48	22.22	53.85	.01
Private Physician	20.97	25.00	15.38	.10
Community Clinic	16.13	19.44	11.54	-
Non-Medical Services	72.58	75.00	69.23	
	<u>Total</u> <u>n=59</u> %	<u>Median</u> <u>and Above</u> <u>n=34</u> %	<u>Below</u> <u>Median</u> <u>n=25</u> %	
Home Help				
20 hours or more	28.81	26.47	32.00	-
10-19 hours	11.86	17.65	4.00	-
Less than 10 hours	59.32	55.88	64.00	-

DRAFT

Table 7

**Percentage of Children Utilizing Medical Services
and Mean Visits by Social Severity Score**

	Total Sample n=135	Social Severity Score 0-3 n=62	Social Severity Score 4-9 n=73	p Value
<u>Medical Service</u>				
Hospital Clinic Users	100.00%	100.00%	100.00%	
Mean Outpatient Visits	7.34	6.78	7.81	
Emergency Room Users	51.85%	40.32%	61.64%	0.01
Mean ER Visits	2.45	2.89	2.21	
Mean Unique Providers	1.16	1.24	1.11	
Formal Home Care Users	42.22%	38.71%	45.21%	
Inpatient Hospitalization Users	29.63%	27.42%	31.51%	
Mean Admissions	1.59	1.42	1.72	
Mean Length of Stay	16.03	11.41	19.38	
Unique Hospital Providers	1.15	1.12	1.17	
Private Physician Users	20.74%	20.97%	20.55%	
Mean Visits	3.09	3.36	2.87	
Community Clinic Users	13.33%	14.52%	12.33%	
Mean Visits	1.70	1.53	1.87	
Non-Medical/Social Services	62.22%	64.52%	60.27%	
Mean Number Services	2.05	2.25	1.86	
	Total Sample 7+ years old n=28	Social Severity Score 0-3 n=13	Social Severity Score 4-9 n=15	
Mental Health Services Users	32.14%	15.38%	46.67%	
Mean Visits	17.56	2.00	22.00	

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. form	re: Grant for HIV Cost and Services Utilization Study (HCSUS); [Personally Identifiable Information] [Partial] (5 pages)	00/00/0000	b(6)

COLLECTION:

Clinton Presidential Records
National AIDS Policy Office
Kristine Gebbe
OA/Box Number: 8299

FOLDER TITLE:

SAMHSA [Substance Abuse and Mental Health Services Administration] [1]

2018-0756-F
jp4870

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
- P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
- P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

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- b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
- b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
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- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

DEPARTMENT OF HEALTH AND HUMAN
HEALTH SERVICE



422304

APPLICATION

Type in the unsh.
y must be 10 c.p.l.

NAME: SHAPIRO, MARTIN F
APPL NO: U01 HS08578-01

ADUS/LAI
COUN DATE: 05/94
RCVD: 03-01-94

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1. TITLE OF PROJECT (Do not exceed 56 typewriter spaces.)

2a. RESPONSE TO SPECIFIC REQUEST FOR APPLICATIONS OR PROGRAM ANNOUNCEMENT ☐ NO ☒ YES (If "YES," state number and title)
Number: HS-94-003 Title: HIV COST AND SERVICES UTILIZATION STUDY (HCSUS)

2b. TYPE OF GRANT PROGRAM U01

3a. NAME (Last, first, middle)
SHAPIRO, MARTIN

3. PRINCIPAL INVESTIGATOR/PROGRAM DIRECTOR

3b. DEGREE(S)
MD

(b)(6)

3d. POSITION TITLE
Natural Scientist Sr.

3e. MAILING ADDRESS (Street, city, state, zip code)

RAND
1700 Main Street
P.O. Box 2138
Santa Monica, CA 90407-2138

310 206 8067

3f. DEPARTMENT, SERVICE, LABORATORY, OR EQUIVALENT
Social Policy

3g. MAJOR SUBDIVISION
Domestic Research Division

3h. TELEPHONE AND FAX (Area code, number and extension)

TEL: 310-393-0411 x7280

FAX: 310-451-6921

BITNET/INTERNET ADDRESS Martin.Shapiro@rand.org

4. HUMAN SUBJECTS

If "Yes,"
exemption no. or

IRB
approval
date

4b. Assurance of
compliance no.

5. VERTEBRATE ANIMALS If "Yes,"
IACUC approval date

5b. Animal welfare
assurance no.

4a. ☐ NO ☒ YES

PENDING

M1031

X 5a. ☐ NO ☐ YES

6. DATES OF ENTIRE PROPOSED PROJECT PERIOD

From (MMDDYY)

Through (MMDDYY)

070194

063098

7. COSTS REQUESTED FOR INITIAL BUDGET PERIOD

7a. Direct Costs (\$)

7b. Total Costs (\$)

8. COSTS REQUESTED FOR ENTIRE PROPOSED PROJECT PERIOD

8a. Direct Costs (\$)

8b. Total Costs (\$)

\$13,401,021

\$15,000,000

9. PERFORMANCE SITES (Organizations and addresses)

RAND
1700 Main Street
Santa Monica, CA 90401

Various Sites across USA

10. INVENTIONS AND PATENTS (Competing continuation application only)

☐ NO ☐ YES If "YES," ☐ Previously reported ☐ Not previously reported

11. NAME OF APPLICANT ORGANIZATION

RAND
ADDRESS 1700 Main Street
P.O. Box 2138
Santa Monica, CA 90407-2138

[001]

12. TYPE OF ORGANIZATION

☐ Public: Specify ☐ Federal ☐ State ☐ Local

☒ Private Nonprofit Research Organization

☐ Forprofit (General) ☐ Forprofit (Small Business)

13. ENTITY IDENTIFICATION NUMBER

Congressional District

1951958142A1

27

14. BIOMEDICAL RESEARCH SUPPORT GRANT CREDIT

Code: 60 Identification Other Research Organization

15. NAME OF ADMINISTRATIVE OFFICIAL TO BE NOTIFIED IF AWARD IS MADE

Shirley Hall
TELEPHONE 310-393-0411 x6291
FAX 310-453-6990
TITLE Contract/Grant Administrator
ADDRESS RAND
1700 Main Street
P.O. Box 2138
Santa Monica, CA 90407-2138

16. NAME OF OFFICIAL SIGNING FOR APPLICANT ORGANIZATION

Richard L. Wright
TELEPHONE 310-393-0411 x6901
FAX 310-453-6990
TITLE Director, Contract & Grant Services
ADDRESS RAND
1700 Main Street
P.O. Box 2138
Santa Monica, CA 90407-2138

BITNET/INTERNET ADDRESS Shirley.Hall@rand.org

BITNET/INTERNET ADDRESS Richard.Wright@rand.org

17. PRINCIPAL INVESTIGATOR PROGRAM DIRECTOR ASSURANCE: I agree to accept responsibility for the scientific conduct of the project and to provide the required progress reports if a grant is awarded as a result of this application. Willful provision of false information is a criminal offense (U.S. Code Title 18, Section 1001). I am aware that any false, fictitious, or fraudulent statement may, in addition to other remedies available to the Government, subject me to civil penalties under the Program Fraud Civil Remedies Act of 1986 (45 CFR 79).

SIGNATURE OF PERSON NAMED IN 3a
(In ink. "Per" signature not acceptable)

DATE

Martin Shapiro

03/05/94

18. CERTIFICATION AND ACCEPTANCE: I certify that the statements herein are true and complete to the best of my knowledge, and accept the obligation to comply with Public Health Service terms and conditions if a grant is awarded as a result of this application. A willfully false certification is a criminal offense (U.S. Code Title 18, Section 1001). I am aware that any false, fictitious, or fraudulent statement may, in addition to other remedies available to the Government, subject me to civil penalties under the Program Fraud Civil Remedies Act of 1986 (45 CFR 79).

SIGNATURE OF PERSON NAMED IN 16
(In ink. "Per" signature not acceptable)

DATE

[Signature]

03/05/94

DESCRIPTION: State the application's broad, long-term objectives and specific aims, making reference to the health relatedness of the project. Describe concisely the research design and methods for achieving these goals. Avoid summaries of past accomplishments and the use of the first person. This abstract is meant to serve as a succinct and accurate description of the proposed work when separated from the application. DO NOT EXCEED THE SPACE PROVIDED.

HIV/AIDS is increasingly a disease of the disadvantaged; care is moving out of the major epicenters and treatment centers into dispersed communities and practice settings. Policymakers, health care providers, and HIV patients need accurate information that is relevant to these trends on the delivery of care, sources of financing, and patient outcomes. Unbiased estimates at the national level, necessary for statistical inferences to the population of interest, currently are lacking. Therefore, we propose to cooperate with AHCPR in collecting data on a national probability sample of persons with HIV/AIDS and their providers. The study will enroll 4000 randomly-selected subjects receiving care in 18 states and the District of Columbia from about 60 major and 120 smaller providers in 30 randomly-selected locales and from 3 purposefully-selected supplemental rural sites. Data collection will consist of a baseline interview, follow-up interviews at 6, 12 and 18 months, and medical (on 1 or 2 occasions) and billing record abstraction for data on utilization, costs and severity.

The research team includes: investigators from RAND, NORC, Project HOPE, Harvard, Brown, Miami and Boston Universities, Jefferson, Mt. Sinai and Charles Drew Medical Colleges, UCLA, UCSD, San Francisco Department of Public Health, Kaiser-Permanente of Northern California, and other institutions, as well as leading HIV/AIDS providers in the communities sampled who will facilitate execution of the study and participate in scholarly work. Members of the HIV community will have a strong role in the project. To facilitate cooperation with AHCPR, all major meetings of the study team, and meetings of the community and scientific advisory panels, will be held in Washington.

This project will examine use and costs of medical and nonmedical services and how they vary geographically, across health care systems and patient clinical and demographic characteristics; examine variations in access to care, unmet needs for services, health-related quality of life, social support, quality of care, clinical epidemiology, satisfaction with care and knowledge about HIV/AIDS; validate measures of severity and staging; evaluate transitions in principal provider of care, and conduct special studies on HIV infection among women (to be sampled at twice the rate of men) and children (n=400), in rural areas (n=400), on mental health and dental care, and on formal and informal caregivers. We will estimate lifetimes costs of HIV treatment and the impact of health reform and therapeutic advances, as well as analyze ACSUS data to provide continuity with previous work. These data will provide national estimates of the impact of HIV that can answer a broad range of questions and will allow analyses of how care varies across sites, including those at the frontiers of the epidemic. The data will be made available for public use, and the project's investigators will respond rapidly to policy-related requests for data and additional studies.

PERSONNEL ENGAGED ON PROJECT, INCLUDING CONSULTANTS/COLLABORATORS. Use continuation pages as needed to provide the required information in the format shown below on all individuals participating in the project.

RAND

Name	Martin Shapiro	Degree(s)	M.D.	Social Security No.	(b)(6)
Position Title	Prof. of Medicine/Sr. Scientist	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	Principal Investigator
Organization	University of California Los Angeles RAND			Department	Medicine
Name	Samuel A. Bozzette	Degree(s)	M.D.	Social Security No.	(b)(6)
Position Title	Associate Professor (7/94)	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	Co-Prin. Inv.
Organization	University of California San Diego RAND			Department	Medicine
Name	Sandra Berry	Degree(s)	M.A.	Social Security No.	(b)(6)
Position Title	Dir., Survey Research Group	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	Survey Designer
Organization	RAND			Department	Social Policy
Name	Naihua Duan	Degree(s)	Ph.D.	Social Security No.	(b)(6)
Position Title	Senior Statistician	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	Statistician
Organization	RAND			Department	Human Capital
Name	Dana Goldman	Degree(s)	Ph.D.	Social Security No.	(b)(6)
Position Title	Associate Economist	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	Investigator
Organization	RAND			Department	Social Policy
Name	Ron Hays	Degree(s)	Ph.D.	Social Security No.	(b)(6)
Position Title	Senior Social Policy Analyst	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	Psychometrician
Organization	RAND			Department	Social Policy

Name	<u>David Kanouse</u>	Degree(s)	<u>Ph.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Senior Behavioral Scientist</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>RAND</u>			Department	<u>Social Policy</u>
Name	<u>Joan Keesey</u>	Degree(s)	<u>B.A.</u>	Social Security No.	(b)(6)
Position Title	<u>Senior Programmer Analyst</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>RAND</u>			Department	<u>Information Resources</u>
Name	<u>Arleen Leibowitz</u>	Degree(s)	<u>Ph.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Senior Economist</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>RAND</u>			Department	<u>Social Policy</u>
Name	<u>Judy Perlman</u>	Degree(s)	<u>M.A.</u>	Social Security No.	(b)(6)
Position Title	<u>Associate Survey Analyst</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Survey Staff</u>
Organization	<u>RAND</u>			Department	<u>Social Policy</u>
Name	<u>Mark Schuster</u>	Degree(s)	<u>M.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Natural Scientist</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>RAND</u>			Department	<u>Social Policy</u>
Name	<u>Walt Senterfitt</u>	Degree(s)	<u>MPH</u>	Social Security No.	(b)(6)
Position Title	<u>Director</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>Being Alive</u>			Department	<u>NA</u>
Name	<u>Cathy Sherbourne</u>	Degree(s)	<u>Ph.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Behavioral Scientist</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>RAND</u>			Department	<u>Social Policy</u>
Name	<u>Beverly Weidmer</u>	Degree(s)	<u>M.A.</u>	Social Security No.	(b)(6)
Position Title	<u>Survey Analyst</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>RAND</u>			Department	<u>Social Policy</u>

National Opinion Research Center

Name	<u>Carol-Ann Emmons</u>	Degree(s)	<u>Ph.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Senior Survey Director</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Project Director</u>
Organization	<u>NORC</u>			Department	<u>NA</u>
Name	<u>Martin R. Frankel</u>	Degree(s)	<u>Ph.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Senior Statistical Scientist</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>NORC</u>			Department	<u>NA</u>
Name	<u>Jeanette Daugherty Hill</u>	Degree(s)	<u>MA</u>	Social Security No.	(b)(6)
Position Title	<u>Survey Director</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>NORC</u>			Department	<u>NA</u>
Name	<u>Kay Malloy</u>	Degree(s)	<u>NA</u>	Social Security No.	(b)(5)
Position Title	<u>Divisional Field Manager</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Field Manager</u>
Organization	<u>NORC</u>			Department	<u>NA</u>
Name	<u>Natalie Suter</u>	Degree(s)	<u>BA</u>	Social Security No.	(b)(6)
Position Title	<u>Survey Director</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Assoc Project Director</u>
Organization	<u>NORC</u>			Department	<u>NA</u>
Name	<u>Kristine Talley</u>	Degree(s)	<u>MBA</u>	Social Security No.	(b)(6)
Position Title	<u>Divisional Field Manager</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Field Manager</u>
Organization	<u>NORC</u>			Department	<u>NA</u>
Name	<u>Mark Wojcik</u>	Degree(s)	<u>BA</u>	Social Security No.	(b)(6)
Position Title	<u>Survey Director</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>NORC</u>			Department	<u>NA</u>
Name	<u>Pearl Zinner</u>	Degree(s)	<u>BA</u>	Social Security No.	(b)(6)
Position Title	<u>Special Assistant to President</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Senior Advisor</u>
Organization	<u>NORC</u>			Department	<u>NA</u>

Boston

Name	<u>Paul Cleary</u>	Degree(s)	<u>Ph.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Professor</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>Harvard University</u>			Department	<u>Medicine</u>
Name	<u>Kenneth Freedberg</u>	Degree(s)	<u>M.D., M.Sc.</u>	Social Security No.	(b)(6)
Position Title	<u>Asst Professor of Medicine</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>Boston University</u>			Department	<u>Medicine</u>
Name	<u>Helen Losina</u>	Degree(s)	<u>M.S.</u>	Social Security No.	(b)(6)
Position Title	<u>Data Analyst</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>Boston University</u>			Department	<u>Medicine</u>
Name	<u>George R. Seage, III</u>	Degree(s)	<u>D.Sc., MPH</u>	Social Security No.	(b)(6)
Position Title	<u>Chief Epidemiologist</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>Institute for Urban Health Research and Policy</u>			Department	<u>Public Health</u>

Jefferson

Name	<u>Leona Markson</u>	Degree(s)	<u>Sc.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Associate Director</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>Jefferson Medical College</u>			Department	<u>N/A</u>
Name	<u>Barbara Turner</u>	Degree(s)	<u>MD, M.S.Ed., FACP</u>	Social Security No.	(b)(6)
Position Title	<u>Director, Ctr Res. in Med Edu.</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>Jefferson Medical College</u>			Department	

Charles R. Drew University of Medicine and Science

Name	<u>Eric Bing</u>	Degree(s)	<u>M.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Faculty Scholar</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>UCLA</u>			Department	<u>Neuropsychiatric Inst.</u>

Other Key Investigators

Name	<u>Marianne Cullen Fahs</u>	Degree(s)	<u>Ph.D., M.P.H.</u>	Social Security No.	(b)(6)
Position Title	<u>Associate Professor/Director</u>	Date of Birth (MM/DD/YY)		Role on Project	<u>Investigator</u>
Organization	<u>Mount Sinai Medical Center</u>			Department	<u>Community Medicine</u>
Name	<u>Margaret Fischl</u>	Degree(s)	<u>M.D.</u>	Social Security No.	
Position Title	<u>Professor</u>	Date of Birth (MM/DD/YY)		Role on Project	<u>Investigator</u>
Organization	<u>University of Miami</u>			Department	<u>Medicine</u>
Name	<u>Robert Hiatt</u>	Degree(s)	<u>M.D.</u>	Social Security No.	
Position Title	<u>Assistant Director of Research</u>	Date of Birth (MM/DD/YY)		Role on Project	<u>Investigator</u>
Organization	<u>Kaiser Permanente, Northern California</u>			Department	<u>N/A</u>
Name	<u>Mitchell H. Katz</u>	Degree(s)	<u>M.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Director, AIDS Office</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>City/County of San Francisco</u>			Department	<u>Public Health</u>
Name	<u>Vincent Mor</u>	Degree(s)	(b)(6)	Social Security No.	(b)(6)
Position Title	<u>Professor</u>	Date of Birth (MM/DD/YY)		Role on Project	<u>Investigator</u>
Organization	<u>Brown University</u>			Department	<u>Community Health</u>
Name	<u>Rachel M. Schwartz</u>	Degree(s)	<u>M.P.H.</u>	Social Security No.	
Position Title	<u>Director of Research</u>	Date of Birth (MM/DD/YY)		Role on Project	<u>Investigator</u>
Organization	<u>National Perinatal Information Center</u>			Department	<u>N/A</u>
Name	<u>Anne A. Scitovsky</u>	Degree(s)	<u>MA</u>	Social Security No.	(b)(6)
Position Title	<u>Senior Staff Scientist</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>Palo Alto Medical Foundation</u>			Department	<u>Health Economics</u>
Name	<u>Gwen Scott</u>	Degree(s)	<u>M.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Professor</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>

Name	<u>Susan Hunt</u>	Degree(s)	<u>M.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Medical Director</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>PACT, Pittsburgh, PA</u>			Department	<u>NA</u>
Name	<u>Lisa G. Kaplowitz</u>	Degree(s)	<u>M.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Director, HIV Center</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>Virginia Commonwealth University</u>			Department	<u>Medicine</u>
Name	<u>George Karam</u>	Degree(s)	<u>M.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Chief, Department of Medicine</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>Earl K. Long Hospital, Baton Rouge, LA</u>			Department	<u>Medicine</u>
Name	<u>Peggy Keen</u>	Degree(s)	<u>Ph.D.</u>	Social Security No.	
Position Title	<u>Program Director</u>	Date of Birth (MM/DD/YY)		Role on Project	<u>Investigator</u>
Organization	<u>Grady Health System, Atlanta, GA</u>			Department	<u>N/A</u>
Name	<u>Rob Roy MacGregor</u>	Degree(s)	<u>MD</u>	Social Security No.	(b)(6)
Position Title	<u>Professor</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>University of Pennsylvania</u>			Department	<u>Medicine</u>
Name	<u>Susan Miller</u>	Degree(s)	<u>M.D., M.P.H.</u>	Social Security No.	
Position Title	<u>Medical Director</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>Thomas Street Clinic, Houston, TX</u>			Department	<u>NA</u>
Name	<u>Frank Palella</u>	Degree(s)	<u>M.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Instructor, Clinical Medicine</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>Northwestern University</u>			Department	<u>Medicine</u>
Name	<u>George Perez</u>	Degree(s)	<u>M.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Attending Physician</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>Peter Ito Clinic, Newark, NJ</u>			Department	<u>N/A</u>
Name	<u>John P. Phair</u>	Degree(s)	<u>M.D.</u>	Social Security No.	
Position Title	<u>Professor</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>Northwestern University</u>			Department	<u>Medicine</u>
Name	<u>William Powderly</u>	Degree(s)	<u>M.D.</u>	Social Security No.	
Position Title	<u>Associate Professor</u>	Date of Birth (MM/DD/YY)		Role on Project	<u>Investigator</u>
Organization	<u>Washington University</u>			Department	<u>Medicine</u>
Name	<u>Cornelis Arthur Maria Rietmeijer</u>	Degree(s)	<u>M.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Med. Dir., Denver AIDS Prev.</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>Denver Disease Control Service</u>			Department	
Name	<u>Henry Sacks</u>	Degree(s)	<u>Ph.D., M.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Professor</u>	Date of Birth (MM/DD/YY)		Role on Project	<u>Investigator</u>
Organization	<u>Mount Sinai Medical School</u>			Department	<u>Community Medicine</u>
Name	<u>Susan Strong</u>	Degree(s)		Social Security No.	(b)(6)
Position Title	<u>Executive Director</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>CARES Clinic, UC Davis</u>			Department	<u>N/A</u>
Name	<u>Sumner Thompson</u>	Degree(s)	<u>M.D.</u>	Social Security No.	
Position Title	<u>Executive Director</u>	Date of Birth (MM/DD/YY)		Role on Project	<u>Investigator</u>
Organization	<u>Grady Health System, Atlanta, GA</u>			Department	<u>N/A</u>
Name	<u>Larry VonBehren</u>	Degree(s)	<u>M.D.</u>	Social Security No.	(b)(6)
Position Title	<u>Director, HIV Clinic</u>	Date of Birth (MM/DD/YY)	(b)(6)	Role on Project	<u>Investigator</u>
Organization	<u>Southern Illinois University</u>			Department	<u>Medicine</u>

CONSULTANTS

Name	<u>Peter Arno</u>	Degree(s)	<u>Ph.D.</u>	Social Security No.	
Position Title	<u>Professor</u>	Date of Birth (MM/DD/YY)		Role on Project	<u>Investigator</u>
Organization	<u>Montefiore</u>			Department	<u>Medicine</u>

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES
ADMINISTRATION (SAMHSA)

STRATEGIC PLAN FOR HIV/AIDS

Submitted by Elaine M. Johnson, Ph.D.
Acting Administrator
Substance Abuse and Mental Health Services Administration

U.S. Public Health Service
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I. INTRODUCTION

"Strong positive leadership is needed to overcome entrenched ignorance and fear, as well as to rectify the serious flaws and deficits in care and prevention strategies. We are witnessing an expanding national disaster, and there is greater urgency than ever to mobilize against the scourge of AIDS."

AIDS: An Expanding Tragedy
Final Report of the National Commission on AIDS
June, 1993

The Substance Abuse and Mental Health Services Administration (SAMHSA) plays a critical role in providing federal leadership in the response to the HIV epidemic. Following the establishment of SAMHSA in the fall of 1992, the agency recognized that HIV/AIDS would be a priority issue because of its significant impact on populations targeted for prevention efforts and services supported by SAMHSA. An agency-wide strategic planning process for addressing HIV/AIDS was initiated with the formation of SAMHSA. On January 6, 1993, SAMHSA issued an interim report on the development of the strategic plan. This report outlined SAMHSA's history, programs and issues relevant to the development of the plan. This report had the benefit of input from a significant number of groups involved with the national response to the HIV/AIDS epidemic. The report set forth the timeline and the process for developing the final plan. This document is a product of that process.

SAMHSA recognizes that the high risk populations they serve are not only in need of individual treatment services, but also an array of preventive interventions and other actions. The epidemic has disproportionately affected individuals with or at risk for developing mental illness and addictive problems. In addition to these populations, SAMHSA provides services to Gay and lesbian individuals, adolescents, and criminal justice populations. These are populations not only disproportionately affected by HIV/AIDS, they have unique issues regarding access to services as well as prevention programs. Accordingly, SAMHSA recognizes a special responsibility to address forthrightly and comprehensively the needs for HIV prevention and treatment activities in its current programs and to delineate plans for the future based on need and evolving knowledge.

This plan examines the trajectory of the HIV/AIDS epidemic in relation to key target populations served by SAMHSA. It describes SAMHSA's organizational and programmatic responses to the epidemic and articulates nine principles which guide SAMHSA's

ongoing HIV-related efforts. Conclusions are made concerning the epidemic and SAMHSA's role in leading the response to the epidemic.

II. THE TRAJECTORY OF THE AIDS EPIDEMIC

HIV will continue to spread in the foreseeable future. Every year an additional 40,000 to 80,000 people become infected with the HIV. It is projected that by January 1995 120,000 people will be living with AIDS. The total number of AIDS cases reported to the CDC as of March 31, 1993 was 289,320 (CDC, 1993b). By the end of 1994 the number of cases may reach 390,000. Approximately 1 million individuals are carrying the AIDS virus. Of that 1 million, only about one half are aware that they are carrying the virus.

Geographically, the epidemic is becoming more diffuse. While cities on both coasts continue to have the highest number of AIDS cases, there is an increasing number of cases in the central region of the country.

Gay and Bisexual Men

- AIDS continues to affect Gay and bisexual men more than any other group. Approximately 62% of the AIDS cases reported since the beginning of the epidemic are among men who have sex with men. While HIV transmission among older Gay men has dropped sharply, a great number of younger Gay men are not taking precautions to decrease chances of transmission.

Injecting Drug Users

- The second largest infected group are individuals who are IV drug users or who have sex with IV drug users. This group accounts for approximately 32% of the cases.

Non-Injecting Drug Users

- While injecting drug use has always been associated with HIV transmission, other drug and alcohol use is playing an increasingly important role. Use of crack cocaine, cocaine, opiates and alcohol are linked with high risk sexual behavior for many populations. Thus, exchanging sex for drugs, and impairment of judgment resulting from alcohol and drug use may result in HIV transmission.

Racial and Ethnic Minority Populations

- AIDS continues to affect racial and ethnic minority populations disproportionately. Approximately half of all reported AIDS cases are in racial and ethnic minority populations. While African Americans comprise about 12% of the population, they represent about 30% of AIDS cases (CDC, 1993). Hispanics comprise about 9% of the population, but about 16% of AIDS cases (CDC, 1993b). Other racial and ethnic minority populations, including Asian Americans,

Native Americans and Alaskan Natives include a significant number of AIDS cases.

Women, Adolescents, and Children

- The second decade of the epidemic is characterized by an increasing number of infected women, African Americans, children and adolescents. Heterosexual transmission will be on the rise. CDC projects that the percentage of infected cases who are African-Americans will increase from 30% to 43%; that the percentage who are women will rise from 10% to 17%; and that the percentage who are teens will rise from 1% to 3%. The heterosexual transmission of AIDS cases has already increased dramatically -- by 17% in 1992 alone (CDC, 1993b).

Costs

- The economic cost of the HIV epidemic to society is significant and will likely become much greater. The societal cost of HIV/AIDS was estimated to be \$66.5 billion in 1991. While that cost is lower than many other diseases (e.g. cancer cost \$72.5 billion in 1985; injuries cost \$157.6 billion in 1985), it is significant both in magnitude of expenditure and continuing escalation (Farnham, P.G. 1992). Of the \$66.5 billion, 83.6% (\$55.6 billion) comprise indirect costs and its programs address the needs associated with the indirect costs of HIV/AIDS. Indirect costs are likely to continue to comprise a disproportionate amount of the total HIV/AIDS costs.

Support

- People with AIDS are living longer. Consequently, AIDS is assuming the character of a chronic illness. The need for support for people living with AIDS as a chronic illness, will present an ongoing challenge to the substance abuse and mental health systems. There is a critical need to develop and strengthen infrastructures that will support psychological and social programs for people infected with and affected by HIV/AIDS. Substance abuse and mental health treatment services must be further integrated within the generic health care and public health systems. SAMHSA advocates innovative programs to maximize the continued functioning of individuals living with HIV/AIDS, whether they be children, adolescents, young adults, or older individuals.

A. Gay and Bisexual Populations

SAMHSA programs address the needs of Gay and bisexual men.

Gay and bisexual men have been and continue to be the group most affected by the AIDS crisis. Men who have sex with men constitute about 62% of all AIDS cases reported to date. While studies of Gay men in urban centers indicate that the rate of infection has consistently decreased in recent years, this is not the case for all Gay men. Young Gay men appear to be at considerable risk as they are reported to continue to engage in high risk behavior. The statistics on Gay and bisexual populations include those on people of color. Substance abusing Gay and bisexual men are one of the groups at highest risk for HIV infection. The use of alcohol and other drugs contribute significantly to high risk behaviors among Gay men and bisexuals.

B. Injecting Drug Users

SAMHSA is the primary federal agency supporting services for injecting drug users. It funds a significant number of drug use prevention and HIV prevention programs for drug users.

Approximately 32 percent of all adult/adolescent AIDS cases are related to injecting drug use (National Commission on AIDS, July 1991). As of March 31, 1993 (CDC, 1993b), the number of reported AIDS cases where the mode of transmission was either drug injecting behavior or men having sex with men who inject drugs was 83,819. There are additional cases of transmission related to IV drug use not included in this calculation, e.g. women who become infected through sex with IV drug using men and transmission to infants from HIV positive drug using mothers.

There are about one million IV drug users in the United States. Of these, anywhere from 70% to 90% share injection equipment (NIDA, 1991). Seroprevalence studies of injecting drug users yield significant differences of HIV infection in different geographical areas. The rates of HIV infection are highest (typically 50% or greater) in the New York City area; intermediate (15-35%) in other urban areas such as Baltimore and San Francisco; and low (5% or less) in some western cities (e.g. Los Angeles) (National Research Council, 1989)

There is evidence that in recent years HIV seroprevalence has stabilized in some communities where injecting drug use is widespread, such as New York City and San Francisco, and increased in other areas, such as Louisiana and Maryland (National Research Council 1990). The disproportionate impact of AIDS on minorities remains unabated. Of all males reporting injecting drug use as their only risk factor for HIV transmission, 47.6 % are African American and 32 % are Hispanic

(National Research Council, 1990). As of 1988, African-Americans were 2.8 times as likely to contract AIDS as whites; and Hispanics were 2.7 times as likely to contract AIDS as whites (Friedman et.al., 1992).

In recent years it has become apparent that drugs other than intravenous drugs play a significant role in HIV transmission. In particular, the use of crack cocaine has become a risk factor. People under its influence are more likely to engage in unsafe sexual practices. Crack is reported to have the effect of heightening sexual pleasure for males and is often marketed by promoting this claim. Some females who use crack report exchanging sexual favors for the drug (National Research Council, 1990). Surveys have identified individuals with HIV whose only high risk behavior appeared to be sexual activity associated with crack (National Research Council, 1990). Alcohol use may also lead to diminished self control, which may result in high risk sexual behavior that might not occur otherwise.

Many drug users are reported to be poly-drug users rather than single drug users. Drugs such as smokable methamphetamine ("ice"), benzodiazepines, amphetamines, alcohol and marijuana are associated with HIV transmission. Injecting anabolic steroids and growth hormones, as is sometimes done by body builders, athletes and adolescents, may involve the sharing of needles, which places users at risk for HIV transmission.

Injecting drug use is the predominant risk factor associated with 70% of pediatric AIDS cases. In these cases the mothers are injecting drug users themselves or they have sex with injecting drug users (National Commission on AIDS, July 1991).

C. Women

Women receive unprecedented emphasis in both treatment and preventive programming through SAMHSA's Residential Program for Women and the Pregnant and Post-partum Women and Their Infants Programs.

The HIV epidemic is spreading faster among women than any other group. While they represented 8% of all AIDS cases in February 1989, women represented 11% of the cases in March 1993 (CDC, 1993b). The increase of women with AIDS between 1991 and 1992 was an extraordinary 17%, compared to 4% for men (CDC, 1993b).

While the primary mode of transmission for women continues to be injecting drug use, (71% of the cases, National Commission on AIDS, July, 1992), sexual contact with an injecting drug user has increasingly become a mode of transmission (21% of cases) (CDC, 1993b). Women are at higher risk than men of having sex with HIV infected heterosexual partners because most IV drug users are

men; almost all hemophiliacs are men and some HIV-infected men are bisexual. In addition, transmission from males to females is more likely than transmission from females to males. One study found that women were 17.5 times more likely to become infected by having sex with an HIV positive male partner than men were by having sex with a HIV positive female partner (Johnson, 1992).

Seventy-three percent of women with AIDS are African-American or Hispanic and live in large metropolitan areas on the Atlantic coast. The average age of diagnosis for AIDS is between 30 and 34 years old. Most are between the ages of 15 and 44, the childbearing years. Of the one million persons infected with HIV in the United States, it is estimated that about 80,000 are women in the childbearing years. Pediatric AIDS is closely linked to women with AIDS. Approximately 25%-35% of HIV positive women transmit the virus to their children during pregnancy or delivery.

In 1990, AIDS became the sixth leading cause of death for women in the U.S. in the childbearing years. For African-American women, HIV infection was the leading cause of death in five out of thirty states. For young Hispanic women, HIV infection was the leading cause of death in two of 12 states (Selik, R.M., Chu, S.Y., Buehler, J.W., 1993).

In AIDS research, as in other areas of health research, women have been significantly under-represented. As a result, less is known about the progression of HIV infection in women and the manner in which HIV-related drugs affect them. A number of initiatives have been developed by the Public Health Service to ameliorate this situation. The revised CDC definition of AIDS is more sensitive to the presentation of HIV infection and AIDS in women and includes cervical cancer. Increased efforts to include women in clinical trials, and a heightening of general awareness about women's issues through the establishment of several panels, study groups and conferences, has already taken place.

D. Children

SAMHSA, through its support of the CSAP and its High Risk Youth program, offers unique access to many high risk children and youth for HIV prevention initiatives.

As of March 31, 1993, 4,480 children under the age of 13 have been reported as having AIDS (CDC, 1993). As the prevalence of HIV infection rises in women, it will likely rise in infants. In 1990 it was estimated that 80% of pediatric AIDS cases were attributable to maternal transmission. Of infants with AIDS, 60% were born to injecting drug using mothers and 14% were born to mothers who had sex with injecting drug users (U.S. Public Health Service, 1992). It is estimated that between 1,500 and 2,100 HIV infected babies will be born annually.

E. Adolescents

SAMHSA's programs that address the needs of adolescents are broad in scope, ranging from prevention efforts for high risk youth to treatment programs targeted to adolescents including incarcerated and non-incarcerated juvenile offenders.

Adolescents account for less than 1% of reported AIDS cases (a total of 1,167 as of March 31, 1993); however the number of cases is rising rapidly. Between 1991 and 1992, AIDS cases among teens ages 13 to 19 transmitted heterosexually increased by 65% (CDC, 1993a). The number of adolescents infected with the virus is unknown. About 20% of AIDS cases fall into the 20-29 year old age group. With an average 10 year incubation period, the majority of these individuals was likely infected during their teenage years. Thus, it is imperative that teenagers be targeted with aggressive prevention initiatives.

A substantial percentage of cases among adolescent boys and young men are related to homosexual contact. Of male teen cases, 37% were related to homosexual contact. Of the 20-24 year old cases 68% were related to homosexual contact. The highest risk category for male adolescents is exposure to contaminated blood and blood products, accounting for 44% of the cases among 13-19 year olds. This high rate of cases is explained somewhat by hemophilia, which is almost exclusively seen in males (National Research Council, 1990).

Teenagers typically engage in sexual behavior that puts them at risk for HIV infection. Survey data from 1988 indicates that 86% of adolescent males and 77% of adolescent females have had sexual intercourse by the age of 20 (National Center for Health Statistics, 1988). In some communities, the average age may be as low as 12 years old.

Despite increases in condom use among teens, a considerable proportion of sexually active teens still do not use condoms at all, or do not use them consistently. Furthermore, a significant number of sexually active teens have multiple partners (National Research Council, 1990).

Another high risk behavior commonly found among adolescents is the use of alcohol and other drugs. The 1992 survey of high school seniors indicates that about 41% of all seniors had used illicit drugs at least once; 1.2% had used heroin; and 6.1% had used cocaine (OSAP, 1991). Needle sharing, when injecting drugs, is a high risk behavior for HIV transmission. Use of alcohol and non-injection drugs reduces inhibitions and may lead to unprotected sexual behaviors, which may thereby place adolescents at risk for HIV transmission.

Some research indicates that teens who use drugs are more likely to engage in sexual activity than those who do not. The reverse also appears to be true. One study indicated that teens are more likely to initiate drug or alcohol use prior to sexual behavior rather than sexual behavior prior to drug use (National Research Council, 1990).

Some sub-populations of teens are at particularly high risk for HIV infection. Among these groups are runaway and homeless youth and delinquent and incarcerated youth. Many runaway and homeless youth consider themselves to be Gay or lesbian. Of the one million teenagers that run away from home each year, about 187,500 are involved in illegal behaviors that are related to high risk behaviors for HIV infection. These behaviors include drug use, and prostitution. Anonymous HIV testing at one runaway home in New York City revealed a seroprevalence rate of 7% (OSAP, 1991).

Teenagers involved with the criminal justice system appear more likely than others to be sexually active, involved with drugs and aware of HIV infection. In one study, among 417 incarcerated youth, ages 15 to 17, 90 percent were sexually active -- many with multiple partners and few with condom use. In another study of 113 teenagers in detention, 13% reported drug injection, compared with four percent of high school students (OSAP, 1991).

As with other subgroups of the population, adolescents of color are disproportionately affected by the AIDS epidemic. While African Americans make up only 15.3 percent of the teenage population, they represent 36 percent of AIDS cases. Hispanics represent 10 percent of the teenage population and 18% of the AIDS cases (National Research Council, 1990).

F. The Seriously Mentally Ill

SAMHSA's Center for Mental Health Services is responsible for the funding and guidance of virtually all federal programs addressing the needs of people with serious mental illness.

Research is presently addressing issues related to HIV and serious mental illness. Serious mental illness may increase the risk of HIV infection by contributing to indiscriminate sexual behavior and drug use during times of decompensation (Empfield et.al., 1993). Psychiatric diagnosis and substance abuse are reported to be related (Cournos et.al. 1991). The HIV seroprevalence rate for people with serious mental illness is estimated to be between 5% and 7%, which is significantly higher than the seroprevalence rate for people without mental illness (Meyer et.al. 1992). A survey of 85 state and county mental hospitals from 37 states revealed that most have some in-patients

with HIV infection (Harvey 1989). Seriously mentally ill women and men appear to have about the same rate of infection.

People with mental illness may be particularly hard to reach to provide prevention and treatment services for many reasons. They may be homeless, unaffected from social services and they may have no contact with any medical or health service system. Because of their mental illness, they may have difficulty accessing support systems.

G. Racial and Ethnic Minority Populations

SAMHSA-funded programs are tailored to meet the needs of the racial and ethnic minority populations they serve.

Although African-Americans and Hispanics make up about 21% of the population, they account for about half of all AIDS cases to date (CDC, 1993b). Similarly, a disproportionate representation of minorities is evident among women infected with the virus, children and teenagers. CDC projects that over-representation of minority populations will continue to rise in coming years (Newsweek, June 21, 1993).

H. AIDS as a Chronic Illness

As a services agency, SAMHSA is dedicated to the long term support of individuals with substance abuse and mental illness, including those infected and affected by HIV.

The time from infection to diagnosis with AIDS is quite variable. An average length of time is reported to be 10 years, but for drug abusers an earlier onset due to the existence of co-morbid diseases and a general non-HIV compromise of the immune system is reported. As treatments continue to be available for various opportunistic infections and as prophylaxis, the life expectancy for a person with HIV -- will likely grow. There will be an increasing number of individuals in America living with HIV and AIDS in years to come.

Some commentators have noted that, as we enter the second decade of the epidemic, we enter a decade in which AIDS will be viewed as a chronic condition, rather than as a time-limited epidemic (Fee & Fox 1992). People living with HIV or AIDS will seek to live their lives in as routine a manner as possible with, accommodations to their needs and to the ups and downs of the disease. While the emphasis on scientific research and medical treatment will continue, attention to facilitating the continuation of routine daily life, such as holding a job and continuing a social life, will grow.

The majority of AIDS cases occur among people who are in the midst of their most productive working years -- age 25 to 44. Employees with HIV/AIDS are in the workplace as never before. About two-thirds of large businesses and one in 10 small businesses have employees with HIV/AIDS (National Leadership Coalition on AIDS, 1993). Developing accommodations and supports for people living with HIV and AIDS will be a priority in the second decade of the disease.

III. SAMHSA RESPONDS TO AIDS

A. Office on AIDS

In the fall of 1992, shortly after the Substance Abuse and Mental Health Services Administration was established, the position of Associate Administrator for AIDS and the Office on AIDS were created. This position is located in the Office of the SAMHSA Administrator.

The Office on AIDS is responsible for coordination, advocacy, planning and policy functions within SAMHSA. The Office will formulate policy recommendations concerning HIV/AIDS in the areas of substance abuse and mental health on an ongoing basis. This policy development is done in concert with the Department of Health and Human Services and with the President's AIDS Coordinator. The Associate Administrator works with the three Center Offices on AIDS (see below) to ensure that HIV/AIDS concerns are appropriately addressed in all of SAMHSA's efforts. In addition, the Office serves as a liaison with the SAMHSA Women's Committee and other Federal and non-Federal agencies on programs and issues of mutual concern.

SAMHSA's Office on AIDS, in conjunction with the Center AIDS Offices, is engaged in an ongoing process to further develop HIV-related programs within SAMHSA through:

- o A comprehensive and continuing assessment of unmet HIV-related needs of the populations targeted for the Agency's services. These populations include alcohol and other drug abusers, those at risk for alcohol and other drug abuse, those with mental health needs, and the seriously mentally ill.
- o Analysis of those unmet needs.
- o Recommendations for program development and enhancement of SAMHSA programs.

During the course of developing this strategic plan for HIV/AIDS, SAMHSA's Office on AIDS examined several areas of knowledge and practice related to HIV/AIDS. The Office, with outside consultation, reviewed the literature and the knowledge base in several areas relevant to HIV/AIDS services for SAMHSA programs. One area of examination stood out as being in particular need of continued examination: successful strategies and models for services integration. The literature appears to lag considerably behind practice, and yet this is an area where information dissemination will be critical for effective service delivery in future years.

Services integration is an ongoing challenge in virtually every area of health and human services today. It is particularly challenging for individuals with multiple, complex needs, such as many persons living with HIV/AIDS (e.g., injecting drug users with HIV, people with serious mental illness and HIV). In addition, many people targeted for SAMHSA's services have little ongoing access to any kind of health delivery system. Providing multiple services through one point of entry into the system is of great importance for those with multiple needs who are not part of the system. Interaction with a substance abuse or mental health treatment program may be an individual's only health care related contact. It is important to take advantage of that contact as a way to initiate services to address other needs of the individual.

The linkages initiative of the Center for Substance Abuse Treatment (CSAT) has funded programs to link up a range of health and health related services (e.g. substance abuse treatment, HIV/AIDS counseling and testing, primary health care, mental health services, family counseling and case management.) While many of these programs are reported to be exemplary, little information appears about them in the literature. The SAMHSA Office on AIDS and CSAT will commission a paper on exemplary strategies and models for services integration. This work will be an important contribution to the knowledge base and the field as efforts to integrate services continue.

B. Center Offices on AIDS

Each of the three Centers that comprise SAMHSA has an Office on AIDS and an AIDS Director/Coordinator who meet regularly with the SAMHSA Associate Administrator on AIDS. These Directors/Coordinators and their offices in the respective Centers have the following functions: 1) ensure that HIV/AIDS issues are addressed in all of their funded programs; 2) ensure integration of HIV-related activities among programs within the Center and with those of other Centers, as well as with other Federal and private organizations; and 3) work with SAMHSA's Office on AIDS to share information, coordinate initiatives and make recommendations for improvements to policies and programs.

C. SAMHSA AIDS Work Group

SAMHSA will have an AIDS Work Group that will function under the aegis of the SAMHSA National Advisory Council and will be composed of selected representatives from this Council and from the three Center Councils. It will be the forum for discussion of HIV/AIDS planning and implementation efforts of SAMHSA and its Centers. The SAMHSA Committee for Women's Services will be represented. Representatives will have HIV/AIDS experience in at

least one of the following areas: prevention, training of health care personnel, delivery of treatment services to persons with HIV/AIDS and advocacy for the needs of persons with HIV/AIDS. Consultants to the SAMHSA AIDS Work Group will be chosen on an ad hoc basis by the Work Group members to provide expertise on particular issues as they arise. The Associate Administrator for the SAMHSA Office on AIDS will serve as the Executive Secretary of the Work Group. The AIDS Director/Coordinator from each Center will serve as an ex-officio member of the Work Group.

D. Interagency Collaboration

Through the Office on AIDS, SAMHSA coordinates its efforts with other Federal agencies and with non-Federal agencies. SAMHSA has worked with NIH, NIDA, OAR, HRSA, NIDA, NIAAA, NIMH, SSA, AHCPR and HUD to share information and coordinate initiatives. SAMHSA works in conjunction with the Public Health Service and the Health and Human Services offices to coordinate agency-wide efforts. SAMHSA will participate with any future mechanisms developed which are intended to coordinate and improve the Federal response to HIV/AIDS.

E. Public/Private Partnerships

SAMHSA is actively developing public/private partnerships in several areas. All SAMHSA grants require the grantees to collaborate and coordinate with public and private entities as a part of the grant program and/or as a condition of grant award.

The Center for Substance Abuse Prevention (CSAP) has a project entitled "Partnerships for Permanent Resources" in which they are facilitating partnerships with private, public and philanthropic agencies at the national, state and local levels. The project is developing a conceptual framework, a resource inventory, a demonstration resource partnership project and expansions of existing communication, education, training and technical assistance networks. A September 1992 meeting was followed by the development of ongoing relationships with the many Foundations that participated. A continuing dialogue is focusing on potential initiatives in the areas of prenatal care, substance abuse treatment for women, and primary, secondary, and tertiary prevention of HIV/AIDS.

Many foundations have already initiated HIV/AIDS programs. Others utilize the CSAP initiative as a means of forming linkages and filling gaps as well as a way to identify areas for public-private joint sponsorship of specific programs. CSAP is currently designing a program with a private health foundation and another HHS agency to address the needs of children in communities with high seroprevalence of HIV/AIDS.

IV. SAMHSA PROGRAM GOALS

The Substance Abuse and Mental Health Services Administration has a unique responsibility to effectively address the HIV/AIDS epidemic in the most stigmatized and least accessible populations. It recognizes a responsibility to provide a broad range of interventions to those living with HIV/AIDS and those affected by HIV/AIDS who have no other resources to support their mental health and well being. The program goals for SAMHSA are responsive to these mandates.

SAMHSA is seeking to set goals that are measurable and consistent with the standards set for Healthy People 2000. To achieve this end, SAMHSA is committed to working with other Federal agencies in a supportive and complementary fashion. The demonstration and communication programs supported by SAMHSA are a crucial link in knowledge development and transfer of findings from research into practice. In the area of substance abuse and mental health prevention and treatment services SAMHSA accepts the challenge to lead.

SAMHSA HIV/AIDS programming is an integral part of many ongoing programs, as cited in this report. However, only three programs are recognized in SAMHSA's formal budget as identified AIDS related programs. These programs are the CMHS AIDS Training Program, and CSAT's Outreach and Linkage Programs. While many of the goals outlined below can be achieved incrementally in the context of ongoing program activities, significant additional funds will be needed to accelerate the ultimate achievement of the goals that are enumerated.

SAMHSA HIV/AIDS Program Goals are as follows:

1. Increase the effectiveness and responsiveness of the substance abuse and mental health treatment community to HIV/AIDS.

Staff working with people who abuse alcohol and other drugs, people with mental health problems and people with serious mental illness will receive training in HIV/AIDS.

SAMHSA's programs target people who use and are at risk for using alcohol and other drugs as well as those with mental health needs. As a whole, this population is at greater risk for HIV infection than the population at large. Staff that work with these individuals -- substance abuse counselors, social workers, psychologists, physicians including psychiatrists, and nurses -- need training to recognize and address HIV/AIDS. Staff training to understand HIV and AIDS in order to provide prevention and treatment services as well as risk reduction information and support for behavioral changes is an ongoing priority for SAMHSA.

o By 1995 every substance abuse provider should have available state of the art training materials that are culturally appropriate, readily understood, and provide the broad scope of knowledge to allow the effective utilization of the range of resources needed to help injecting and non-injecting drug users with or at risk for HIV/AIDS. These materials will be complemented by technical assistance.

Program Activities:

The Center for Substance Abuse Treatment (CSAT) funds training programs for substance abuse counselors, other health care professionals and primary care providers to meet the demand for knowledgeable, skilled and competent treatment personnel to deliver HIV/AIDS, TB and substance abuse services through entry level training, professional training, and primary care training.

All CSAT Treatment Improvement Protocols (TIPs) stress the importance of screening and treatment for HIV/AIDS, TB, STDs and other infectious diseases. A CSAT TIP that focuses exclusively on screening and treatment of infectious disease among substance abusers is soon to be published.

CSAP's National Training System, which reaches a broad range of providers, trainees and trainers has a track record of effective educational programs. The National Training System now provides for HIV/AIDS prevention training in its network. CSAP's Perinatal Resource Center's Community Team Training has included HIV/AIDS in their initial community assessment, and the Center training programs have addressed how to approach the epidemic in their communities. Technical assistance is provided to help accomplish the plans. Similar training has been provided on a State-wide level.

o By 1995 ensure that there is a core of adequately trained and supported mental health providers to meet the needs of those with HIV/AIDS and those affected by HIV/AIDS.

Program Activities:

The Center for Mental Health Services (CMHS) is supporting 12 grants and 2 contracts for the education of mental health care providers to address the neuropsychiatric and the psychosocial aspects of HIV/AIDS. Two contracts are in the second year and 4 of the 12 grants are in the third year of the three year project periods. The other 8 grants were awarded September 30, 1992 for a 3 year period. Trainees

include the traditional mental health care provider groups, psychiatrists, psychiatric nurses, psychiatric social workers, psychologists, and marriage and family counselors, as well as medical students, primary care providers, and non-traditional mental health care provider groups, such as clergy, police and alternative health care site providers. The CMHS program is the mental health training equivalent of the HRSA Education and Training Centers program for primary care physicians, nurses, dentists, and pharmacists.

2. Increase access to HIV/AIDS treatment for substance abusers.

Alcohol and other drug treatment will include HIV/AIDS services.

Injecting drug users and their sex partners are at high risk for becoming HIV infected. Non-injecting drug users are also at risk due to the sexual behavior that is more likely to occur under the influence of AOD, or as the result of trading sex for drugs. Those who are infected need to be able to access medical treatment and learn how to manage their infection. Those who think they might be infected need to be tested. Those who are not infected need to know how to protect themselves from infection.

o By 1995 the Federally supported treatment capacity for injecting drug users should reach 90% of need and by the Year 2000 drug treatment on demand should be a reality for all.

Program Activities:

CSAT, through the AIDS Outreach for Substance Abusers Program, funds community outreach programs that seek out injecting drug users, other high risk drug abusers and their sexual partners in order to: 1) encourage them to obtain treatment for drug addiction and obtain medical diagnostic services for HIV/AIDS, STDs and tuberculosis; and 2) provide these individuals with information, skills, and other means to avoid those behaviors which increase the risk of acquiring or transmitting HIV/AIDS, STDs and tuberculosis.

The Substance Abuse Prevention and Treatment (SAPT) Block Grant statutorily mandates the provision of HIV/AIDS related services in states where the reported incidence of AIDS is greater than 10/100,000.

All CSAT programs are especially relevant to those with and at risk for HIV infection. These include special populations in identified programs for the Rural and Culturally Distinct, the Residential Treatment of

Pregnant/Postpartum Women, the Residential Treatment of Women and Children Program, and Critical Populations.

All CSAT programs have specific HIV/AIDS components, including the Capacity Expansion Program, Comprehensive Treatment Programs, and technical assistance programs.

3. Limit the spread of HIV/AIDS in vulnerable populations.

Outreach services will be expanded to reduce the risk for HIV infection among people who are substance abusers and people who have mental illness who are not currently in treatment or not seeking treatment for substance abuse or mental illness.

It is unlikely that there will be enough drug treatment slots for those who need them any time in the foreseeable future. Currently, only about 10%-25% of injecting drug users are in drug treatment at any one time. It is not uncommon for drug users who go through treatment to relapse, continuing drug use for a period of time until they go back into treatment again. Thus, for both the injecting drug users who are not in treatment and those who are, outreach to prevent HIV infection is critical. Currently, there are far too few outreach workers to even come close to reaching the estimated 850,000 injecting drug users not in treatment.

The need for outreach services to educate non-injecting and injecting drug users (and their sex partners) about HIV infection and provide training and reinforcement in risk reduction behaviors is ongoing. Outreach services must also be provided to families of injecting drug users.

Through outreach activities not specifically related to entrance into treatment, CSAT, CMHS and CSAP can provide essential clinical services and prevention messages to populations not otherwise reached by current programs. These programs will seek individuals where they are and offer sustained involvement. CSAT will maintain its outreach activities that have entrance to treatment as a goal.

Priority will be given in prevention initiatives to women and adolescents.

Women and adolescents are two high risk groups for HIV infection. In recent years the HIV infection rate has increased notably in women. Women are most at risk of becoming infected with the HIV from heterosexual intercourse. The rate of HIV infection in women is closely related to the rate of HIV infection in newborns.

Adolescence is a period of exploration that often involves sexual activity and drug and alcohol use -- behaviors that may increase

the risk of HIV transmission. Adolescents who are runaways or involved with the juvenile justice system are at an increasingly high risk. Prevention initiatives targeted toward these distinctive groups will be a priority for SAMHSA.

Strategies must be developed to allow at risk populations to help define their own messages and vehicles for dissemination of these messages. Successful prevention interventions for alcohol and drug use need to be appreciated and evaluated for their relevance to HIV/AIDS prevention efforts.

All SAMHSA programs will be culturally and ethnically appropriate and relevant to the intended beneficiaries.

Many SAMHSA programs are targeted to groups of individuals with significant cultural and ethnic minority representation. A demonstrated sensitivity to these populations in designing and implementing programs is critical to their success.

- o By 1995 specific educational and communications programs will be available to more effectively reach people with serious mental illness, the homeless, runaway youth and other adolescents, the criminal justice populations, women, and other high risk groups throughout the country.

- o By 2000 the full range of prevention and treatment services to meet the special needs of adolescents, and women will be available in communities. The extension of current models of prevention and intervention will need to reach more communities and those who are isolated from the mainstream.

Program Activities:

All new CSAT Program Announcements and Requests for Applications require applicants to provide screening and treatment arrangements for persons with AIDS. The Criminal Justice Grant Program supports projects which provide substance abuse treatment to individuals incarcerated in prisons, jails or community correctional settings and to those who are pre-trial releasees, post-trial releasees, probationers, parolees or those on supervised release.

CSAP's High Risk Youth Program and Pregnant and Postpartum Women and Their Infants Program seek to integrate HIV/AIDS prevention services under their mandates. CSAP is currently developing a number of initiatives to insure the integration of HIV/AIDS prevention services with alcohol and other drug prevention services. These initiatives include (a) requiring all Community Partnership grantees to include active planning and coordination of HIV/AIDS prevention

in their communities; (b) requiring all proposals to include HIV/AIDS outreach and risk reduction demonstration activities; and (c) incorporating an AIDS prevention component into prevention enhancement protocols, state technical assistance plans, and state prevention plans.

The CMHS is a resource on mental health related issues for CSAP, CSAT and other Federal agencies, especially with regards to providing risk reduction counseling and HIV/AIDS related treatment for their target populations.

4. Coordinate primary health care and substance abuse services to facilitate treatment and prevention of HIV/AIDS.

Programs funded by SAMHSA will be encouraged to collaborate in the development or enhancement of a health and/or health-related infrastructure in local communities where they operate.

A key problem in many communities with high rates of drug abuse, HIV and mental illness is that there is a lack of a health or health-related infrastructure. Clinics may not be located in the communities. Programs may be run by organizations that depend on funds from outside of the community, so that when those funds expire, the program and the organization itself may cease to exist.

When a structure does exist, it is not always viewed as a part of the community and may not be readily accessed. Community members may feel disenfranchised from its services. Historical distrust of public health officials among racial and ethnic minority populations and experiences of discrimination are likely to play a role. People who need services may feel that they will be judged or reported for an illegal activity, such as drug use, if they seek services. They may feel that additional stigmas will result.

Programs funded by SAMHSA will demonstrate how they can contribute to (or help to create) the health or health-related infrastructure within the community they serve. Such programs will demonstrate strategies for community involvement and collaboration with other Federal and non-Federal resources. They will encourage demonstrations of how to continue services when the federal funding ceases.

Initiatives intended to integrate services will be developed, promoted, and funded.

Linkage programs in SAMHSA are important initiatives in the ongoing efforts to ensure the integration of mental health and

substance abuse services in general, including HIV/AIDS services, in communities. SAMHSA will seek to extend the linkages concept to other programs in order to further promote client-friendly services. SAMHSA will pursue new strategies for integrating prevention and treatment programs with mental health services. Given the fragile status of mental health and substance abuse services and prevention activities, a continued emphasis and visibility for this special class of health-related activities is essential.

o By 1995 SAMHSA supported substance abuse focussed, community-based programs will be fully coordinated with the Ryan-White community coalitions and the health promotion and prevention coalitions sponsored by CDC.

Program Activities:

CSAT funds two linkages programs. One is funded in conjunction with HRSA. This program awards grants to substance abuse programs to develop comprehensive care demonstrations that link AIDS programs to the mental health and the primary health care systems. The goal is to ensure availability, accessibility and affordability of comprehensive high-quality treatment for individuals infected with HIV who are in need of primary health care and ADM services. The array of services includes screening and treatment for infectious disease, HIV/AIDS counseling, primary health care, outpatient addiction counseling, mental health services, family/collateral counseling, case management and program evaluation.

The other CSAT linkage program supports projects that link and integrate the delivery of primary health care, mental health and substance abuse services for individuals with alcohol and drug problems. Projects offer a comprehensive continuum of care including HIV/AIDS counseling and mental health services. CSAT will offer models for substance abuse treatment as the focal point of "one stop shopping" for substance abusing populations.

CSAP has a long and extensive history of supporting AOD prevention grants and cooperative agreements. These programs exist in every State, the District of Columbia and many territories. CSAP uniquely fosters its programs in a family focused community based manner. The more than 250 Community Partnership Grants exemplify this philosophy and support community-wide efforts to raise the visibility of HIV/AIDS prevention efforts.

5. Provide supportive services to those living with or affected by HIV/AIDS.

Serving persons infected and affected by HIV/AIDS will be a priority in the provision of mental health services.

SAMHSA will strive to develop and promote strategies, programs and initiatives that will result in meeting the mental health needs of all persons living with HIV and AIDS and all persons otherwise affected and infected with HIV and AIDS.

People at risk for and people living with HIV or AIDS experience a broad range of psychosocial needs and require assistance in coping with the psychological impact. The possibility of early death, stigmatization, and a variety of losses are some of the difficult issues that they confront. People with HIV wonder how long and to what degree will they be able to continue their daily set of activities. They worry about money -- particularly being able to support themselves should they lose their jobs or become unable to work. A recent survey of people with AIDS (National Association of People with AIDS 1992) noted that 32.5% of the respondents noted a need for financial assistance to obtain services such as mental health services, transportation, employment and housing. Nearly half of the respondents noted that they have problems carrying out everyday activities such as going to work, working in the yard or taking a bus. Many indicated that they had trouble obtaining the help they need.

In addition, research and clinical experience have yielded increasing evidence that HIV may infect the brain, resulting in central nervous system impairment and neuropsychiatric complications, including AIDS Dementia Complex. Adjustment disorders, depression, mood disorders, including organic mood disorder, are other possible complications.

Volunteer and professional health care providers, other caretakers and loved ones for the HIV infected population also experience anxiety, grief, losses and, ultimately, burn-out. The cost, both in human and financial resources, is staggering and often preventable. It is important to provide preventive mental health services not only for families, children and adolescents at risk for HIV/AIDS and substance abuse, but for the legion of providers and caretakers. It is clear that there are considerable mental health needs of people infected and affected by HIV and AIDS. Gay people and racial and ethnic minorities are disproportionately affected by HIV and AIDS and may experience ongoing loss and cathartic grief. Specialized programs to address the needs of these populations require ongoing development.

o By 1995, supportive mental health counselling should be available to all those in need.

Program Activities:

Virtually all CMHS-funded projects come in contact with individuals affected by HIV/AIDS in some manner. The Center AIDS program promotes an awareness of HIV/AIDS among all CMHS grantees and serves as a technical resource to grantees when needs arise. The CMHS program goals for HIV/AIDS include: the development of models of primary prevention to reduce the transmission of HIV, risk reduction programming in people with serious mental illness and children with serious emotional disturbance, the development of increasingly sophisticated and relevant pre and post test and risk reduction counselling strategies, the development of comprehensive systems of mental health services for people at risk for contracting the HIV, people living with HIV/AIDS and the many special populations served by CMHS programs, and the training of a diverse provider network. The implementation of this goal depends on the details of health care reform implementation.

V. CONCLUSIONS

Based on an assessment of the current and future state of the HIV epidemic and an analysis of the overall role that SAMHSA should play in responding to the epidemic, SAMHSA offers the following conclusions.

1. There is no indication that the spread of HIV will slow or end in the foreseeable future.

It is unlikely that a cure will be found in the immediate future. We expect there will be a great need to further expand treatment and prevention services well into the next century. People currently at risk are likely to continue to be at risk.

2. From the perspective of the delivery of health care services, as HIV/AIDS makes a transition from becoming a time-limited plague, like cholera, to becoming a chronic condition, like cancer, new challenges will rise.

While SAMHSA will continue to focus on treatment and prevention, we will increase our efforts directed toward those living with this virus, with this disease. Continued efforts to integrate HIV/AIDS services into existing service delivery systems, such as substance abuse treatment and mental health services will be required. The mental health care needs of those affected and infected with HIV/AIDS is expected to dramatically increase as more people with HIV/AIDS live longer.

3. No matter how much service development there is in primary care, SAMHSA will continue to have crucial access to those outside the primary health care system.

Many of the people SAMHSA serves are not linked into the generic health care system. Even with overhaul of the health care system, it is unlikely that all individuals, especially those with needs related to drug use and mental illness, will be adequately reached by the system. Because of its track record in working with these hard-to-reach populations, SAMHSA will continue to have unique access to certain at risk populations.

4. Addressing the needs of at risk young women, children and adolescents must be done in the context of their vulnerability to substance use and abuse as well as the men who exercise control over their lives.

Programs designed for women with HIV or at risk for HIV must be developed in relation to the environment in which they live.

Understanding the context of women, children, and adolescents in relation to the communities in which they live and the significant men in their lives is critical to the development of effective intervention.

5. No matter how effective and comprehensive our health care system becomes, inadequate attention to the behaviors that lead to HIV transmission will enable continued progression of the epidemic.

HIV is transmitted by behaviors that can be modified. The fact that the epidemic can virtually be halted if people change their behaviors continues to demonstrate the best known way to end the epidemic. Aggressive intervention to reduce the risks of transmission is warranted. No degree of effective health care can substitute for behavior changes that reduce the risks of transmission. SAMHSA's mental health and substance abuse programs embrace this goal. SAMHSA will provide to the vast provider network and the mentally ill and substance abusing populations the critical information necessary to support behavior change, and provide insight and direction to other PHS agencies regarding behavior change.

6. In the face of concern over the delayed development of effective treatments for AIDS and vaccines, we must redouble our efforts to provide effective prevention interventions which will decrease the transmission of HIV.

Prevention continues to be the most effective way to respond to the HIV epidemic. With effective drug therapies and vaccines likely only in the distant future, we must give increased attention to effective prevention initiatives. CSAP and CMHS's prevention efforts are unique in their target audiences and strategies.

7. SAMHSA has a critical role to play in the ongoing development and implementation of services and prevention strategies to curtail the HIV/AIDS epidemic.

Access to populations uniquely affected by the AIDS epidemic, the ability to capitalize on expertise in mental health and substance abuse treatment, and the knowledge of working intimately at the community level on prevention strategies are important ingredients that will enhance SAMHSA's effectiveness. In certain areas, the work of SAMHSA is sufficiently circumscribed and meaningful in and of itself to represent programming deserving of ongoing and increased support. In other areas, it is evident that close collaboration is the only means to accomplish the goal of effective programming. The newly forming SAMHSA AIDS Work

Group, in conjunction with the SAMHSA Office on AIDS, will continue to work to assess the needs of those targeted to receive SAMHSA funded services and develop a plan for addressing those needs.

8. The SAMHSA strategic plan for AIDS is dependent on the initiative of the SAMHSA Centers within the mandate for SAMHSA to take the lead in the provision of services strategies to treat and prevent substance abuse and mental illness.

As evidenced in this report, the Centers are continuing to develop specialized and collaborative initiatives. This is being done with very limited financial resources. The areas of greatest significance are in training, outreach, access to the most isolated and disenfranchised populations outside traditional primary health care systems, and development of specific preventive interventions for high risk groups.

9. Effective working relationships with constituency groups are essential to the implementation of SAMHSA's strategic plan for HIV/AIDS.

A dialogue with constituency groups representing the needs of people with HIV and AIDS began during the development of this strategic plan. With the development of this initial plan, and with the organizational development that has taken place, the groundwork for an enhanced and sustained dialogue with constituency groups has been established. The planning and dialogue will be ongoing processes.

10. SAMHSA has the commitment, expertise and human resources to continue the battle to overcome the effects of the HIV epidemic, to improve the lives of those affected by HIV and AIDS, and to lead in the development of new strategies for treatment and prevention.

As a partner with other federal agencies in leading the nation's response to the HIV epidemic, SAMHSA assumes a critical role as part of its mandate to address addiction and mental illness in our nation. SAMHSA's unique role complements and strengthens the nation's ongoing effort to end the HIV epidemic.

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HEALTH RESOURCES AND SERVICES ADMINISTRATION

HRSA PROFILE

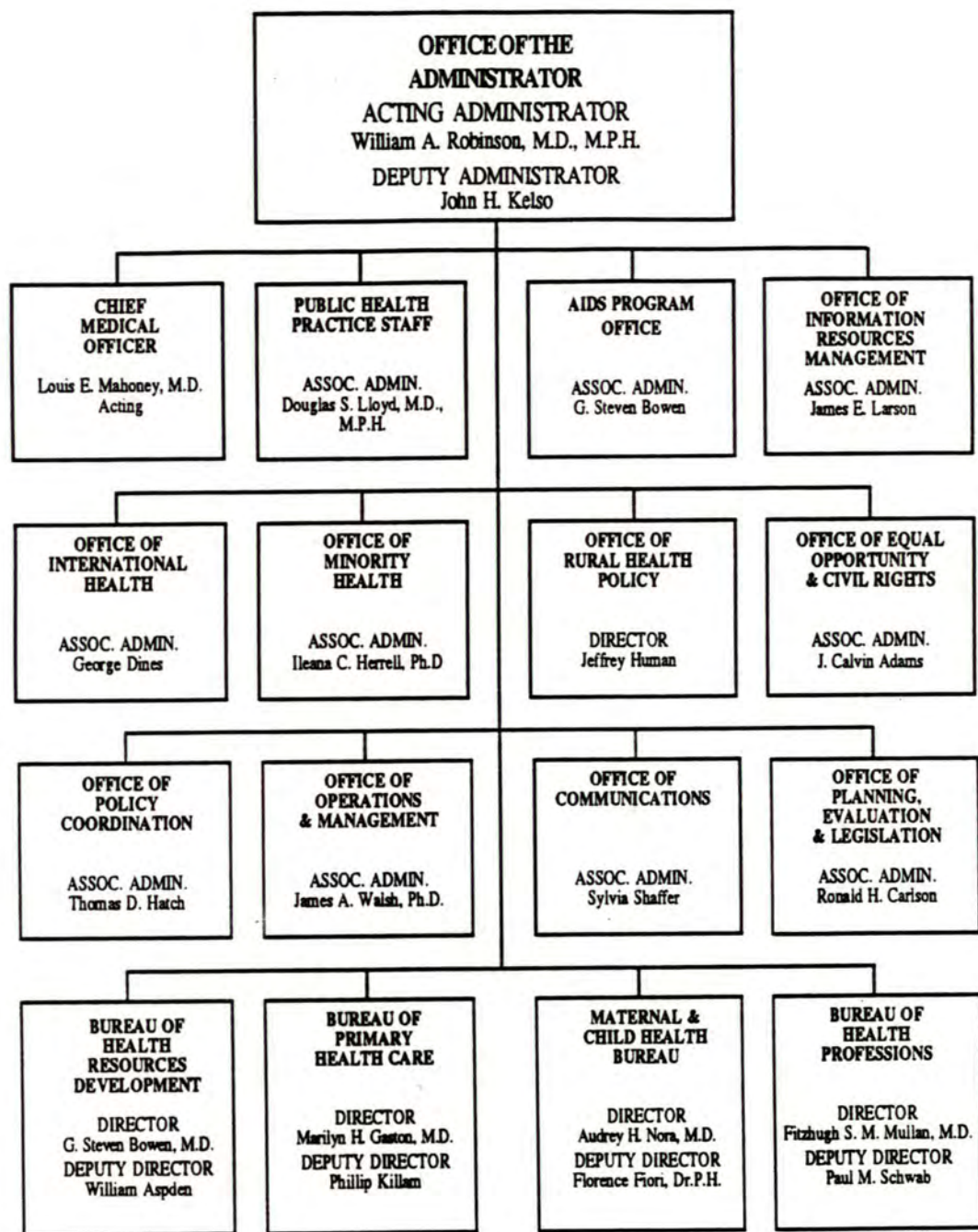


August 1993

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES
Public Health Service

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ADMINISTRATOR'S MESSAGE

As a PHS and HRSA manager, the *HRSA Profile* has been invaluable to me as a ready reference for describing Agency programs for visitors, staff, and new employees. Each edition proved to be even more useful as an informal compendium of Agency activities, issues and accomplishments. I am delighted to share with each HRSA employee the new 1993 *HRSA Profile*, and to thank Ms. Alice Wallis, Office of Policy Coordination, for coordinating this updated portrait of the work and the workers of the Health Resources and Services Administration.

HRSA's mission is to help all Americans gain and maintain access to quality health care services. Long-time Agency programs such as the community and migrant health centers, the National Health Service Corps, health professions education, and maternal and child health activities join with newer rural health, HIV/AIDS services, and public health practice activities to deliver primary health care to diverse populations. There are more recent efforts to identify and meet emerging needs of a growing, ever-changing number of ethnic, minority, and other underserved groups.

The *Profile* chronicles the impact of HRSA programs, varied and yet integrally related in their focus

meeting special health needs of vulnerable Americans, including pregnant women, at-risk mothers and children; the homeless; Hansen's Disease patients; persons living with HIV/AIDS; and those awaiting organ transplants.

As fiscal year (FY) 1994 nears and we move to meet new challenges to the way we do business and the business we do, the *Profile* reflects logistical changes, some programmatic shifts, and newly-created and newly-renamed components within the Bureaus and Office of the Administrator. Our Agency has grown in many important ways. Even as expansion of HRSA's services to the underserved continue under FY 1993 budget authorities, we are moving through the reauthorization cycle for critical program authorities and anticipating the potential change from future legislation and health care reform.

The first months of the Clinton Administration have brought a major involvement of HRSA employees in health care reform efforts. I am proud to have been asked to serve during this interim period as HRSA's Acting Administrator. With the help of all HRSA staff, we will continue to pursue our mission of "Helping to Build a Healthier Nation."

William A. Robinson M.D.

William A. Robinson, M.D., M.P.H.
Acting Administrator

HRSA NAMES AND NUMBERS

Richard C. Lee, Shortage Designation	594-0207
Marsha Alvarez, Drug Pricing	594-4354
Evan R. Arrindell, DSW, State Activities	594-4485

Bureau of Health Professions

Fitzhugh S. M. Mullan, M.D., Director	443-5794
Paul M. Schwab, Deputy Director	443-5796
Thomas C. Croft, Quality Assurance	443-2300
Anthony Hollins, Program Support	443-5798
Marc L. Rivo, M.D., Medicine	443-6190
Neil H. Sampson, Dental and Public Health Professions	443-6853
Marla E. Salmon, Sc.D., R.N., Nursing	443-5688
Clay E. Simpson, Jr., Ph.D., Disadvantaged Assistance	443-2100
Michael Henningburg, Student Assistance	443-1173
B. Jerald McClendon, Hlth Prof Analysis & Research	443-6936
Shirley L. Johnson, Program Development	443-1590
Thomas E. Balbier, Vaccine Injury Compensation	443-6593

Bureau of Health Resources Development

G. Stephen Bowen, M.D., M.P.H., Director	443-1993
William Aspden, Deputy Director	443-1993
Katherine Marconi, Ph.D., Science & Epidemiology	443-6560
Eric P. Goosby, M.D, HIV Services	443-6745
Antony DeJesus, Program Support (Actg)	443-2630
Emily Haley, Program Development	443-5400
Judy Braslow, Organ Transplantation	443-7577
Martin J. Frankel, Communications and IRM	443-6846
Charlotte G. Pascoe, Facilities Compliance	443-5656
Leonard Krystynak, Facilities Loans	443-5317
Jack Moss, Facilities Assistance & Recovery	443-0271

Maternal and Child Health Bureau

Audrey H. Nora, M.D., M.P.H., Director	443-2170
Florence Fiori, Dr.P.H., Deputy Director	443-2170
Eamon Magee, Program Support	443-9657
Carol Galaty, Program Development	443-2778
Merle McPherson, M.D., Children w/Sp Hlth Care Needs	443-2350
David Heppel, M.D., Maternal & Inf., Child & Adol Hlth	443-2250
Samuel Kessel, M.D., Systems, Education & Science	443-2340
Thurma McCann, M.D., Healthy Start	443-0509

* Area code = 301

** Area code = 504

BUREAUS

HRSA's five major operating components are: The Bureau of Primary Health Care (BPHC), the Bureau of Health Professions (BHP), the Bureau of Health Resources Development (BHRD), the Maternal and Child Health Bureau (MCHB) and the Office of the Administrator.

Bureau of Primary Health Care (BPHC)

The Bureau of Primary Health Care helps assure that health care services are provided to medically underserved populations and to persons with special health care needs.

- The Bureau serves as a national focus for the development of primary health care delivery capacity, and for placement of health care professionals in Health Professional Shortage Areas (HPSAs) to promote a sustained source of health services.
- The Bureau also identifies and designates HPSAs, Medically Underserved Areas (MUAs) and Medically Underserved Populations (MUPs).
- The Federal Employee Occupational Health program has the major role in promoting effective and efficient Federal occupational health programs. This is accomplished through the setting of standards, assessment, consultation and service delivery activities.
- Specific programs also assist individuals with Black Lung and Hansen's Disease.

Community and Migrant Health Centers (CMHCs), Health Care for the Homeless, and the Public Housing Primary Care Program build primary care infrastructure by establishing systems of health care coordinated with social and support services. They provide comprehensive family-oriented primary health services to medically underserved, disadvantaged populations experiencing financial, geographic or cultural barriers to care.

Primary health care services are designed for populations at highest risk. Pregnant women and children, substance abusers, and people with HIV or AIDS receive health care specifically tailored to their special needs through BPHC-funded programs.

The National Health Service Corps (NHSC) recruits community-responsive, culturally competent health care providers to serve in rural and urban areas which have been federally designated as HPSAs. The NHSC field strength was over 1,200 at the end of 1992. For 20 years the NHSC has been a model of community service in exchange for educational assistance scholarships for health professional students and loan repayments for primary care providers. There is an obligation of a year of service for each year of assistance with a minimum 2 year obligation.

BPHC PROGRAMS

- CHCs provide comprehensive ambulatory health services which are family oriented, community-based and community-controlled. Services are provided to approximately 6 million people through about 550 grantees at over 1,400 delivery sites. Approximately 64 percent of CHC users are members of minority groups (31 percent Black, 28 percent Hispanic, and 5 percent other). About 60 percent have incomes under the poverty level and another 25 percent are between 100 and 200 percent of poverty.
- MHCs deliver care-coordinated services to an estimated 535,000 migrant and seasonal farm workers and their families annually through more than 100 MHCs with 364 service delivery sites. Approximately 50 percent of those served are Hispanic, 35 percent Black, and 15 percent White, Asian and other. Services for Special Populations are targeted at particularly high-risk groups within the overall medically underserved populations.
- The Comprehensive Perinatal Care Program (CPCP) provides case-managed, coordinated services to pregnant women and after delivery to their infants

- NHSC Scholarship Program provides tuition, fees, and monthly stipend to students pursuing primary care careers. Special effort is made to recruit minority and disadvantaged students;
- State Loan Repayment Program provides support to states to sponsor repayment agreements with primary care practitioners in federally designated shortage areas; and
- Community Scholarships whereby through a Federal/State/local partnership, communities can sponsor scholarships for students committed to returning home to a shortage area. Fiscal year 1992 funds sponsored 90 students from 11 Community Scholarship programs.

To be eligible for NHSC assistance, an area, population, or facility must be designated as a HPSA. Primary care HPSAs are designated by the rate of poverty and access to primary health care, low birthweight births, infant mortality, and the physician/population ratio. More than 2,000 HPSAs for primary medical care have been identified covering all or part of over 1,800 counties in the United States. There are also over 950 dental HPSAs and over 700 mental health HPSAs.

During FY 1992, \$29 million in NHSC scholarships was awarded to 244 medical, 9 dental, and 110 nurse practitioners, physician assistants, and certified nurse midwife students. Nurse practitioner, physician assistant, and certified nurse midwife students will be available for service in one to four years. Dental and medical students will be available in one to seven years.

During FY 1992, 20 states sponsored 224 health care professionals through the State Loan Repayment Program.

Bureau of Health Professions (BHP)

The Bureau of Health Professions monitors and guides the development of health resources by providing leadership to improve the education, training, distribution, utilization, supply and quality of the Nation's health personnel.

Many programs underwent major changes as a result of reauthorization under the Health Professions Education Extension Amendments of 1992, P.L. 102-408. New and expanded areas of emphasis include minority representation, allied health, rural areas, and HIV/AIDS along with continued strong focus on primary care medicine, nursing, and network programs. Programs were restructured to be responsive to the following national health professions goals: an increased proportion of underrepresented minorities graduating, increased proportion of graduates selecting generalist careers, and increased proportion of graduates practicing in underserved areas. Important themes apparent in the reauthorization include promoting generalism and primary care in training and education; linkages between service and education; community-based training and education; multidisciplinary training and education; targeting of funds to program performance outcomes; linkages with health services financing; and workforce diversity.

The new legislation also included a new research authority to study factors affecting selection of careers in primary care including educational indebtedness; effectiveness of programs for minority and disadvantaged individuals; and effectiveness of State licensing authorities in protecting the public through investigation of and disciplinary actions against health care providers. The reauthorization also gave BHP the authority to establish two new commissions, the National Commission on Allied Health and the National Advisory Council on Medical Licensure.

The Bureau has established Seven Strategic Directions to achieve the Department's Year 2000 National Health Promotion and Disease Prevention

Bureau of Health Resources Development (BHRD)

The Bureau of Health Resources Development has four major programs: Health Facilities; Organ Transplantation; HIV Services; and Trauma Care.

The Health Facilities program monitors compliance by health care facilities with assurances and/or obligations resulting from Hill-Burton grants and loans, and health professions and nurse training construction grants. This program also administers the Housing and Urban Development (HUD) section 242 mortgage insurance program which insures loans to hospitals for construction projects. During 1988-1991, funds were provided under the section 1610(b) authority to support the renovation or construction of non-acute intermediate and long-term care facilities for AIDS patients.

The Organ Transplantation program awards and manages a program of grants to organ procurement organizations (OPOs) and other nonprofit entities to increase the number of organ donors in the United States. The Program also supports the National Organ Procurement and Transplantation Network (OPTN), designed to ensure equitable distribution of available organs to patients and transplant centers, and a Scientific Registry of demographic and clinical information on transplant recipients. In FY 1993, \$803,000 is available for the OPTN and \$1.6 million for the Scientific Registry.

The Division of Organ Transplantation also conducts a program to foster relationships with public and private organizations to promote the concepts of organ donation and transplantation. The program provides information to professional associations, health providers, consumers and insurers, medical societies, State health departments, and the general public. In FY 1993, \$403,000 is available for information programs.

The Division of HIV Services (DHS) plans, develops, implements, and monitors programs which provide health care and support services for people living with HIV disease. DHS is responsible for awarding and monitoring the grant programs estab-

lished by Title I and Title II of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990. The purpose of these programs is to provide resources to eligible metropolitan areas (EMAs) with 2,000 or more reported AIDS cases and to States and territories to improve the quality and availability of care for individuals and families with HIV disease.

Under Title I of the CARE Act EMAs receive formula and supplemental grants to develop comprehensive HIV service delivery systems for individuals and families with HIV. Fifty percent of the available funds are awarded according to a formula based on the number of AIDS cases in the EMA, and fifty percent of the funds are awarded competitively. In FY 1993, \$182.3 million was awarded.

Title II of the CARE Act provides for grants to States and territories to improve the quality, availability, and organization of health care and support services for individuals and families with HIV disease. Funds can be used for consortia, home and community-based care, health insurance coverage, and the provision of treatments for individuals with HIV disease. In FY 1993, \$102.4 million was awarded.

The Trauma Care Systems Planning and Development Act of 1990, authorized under Title XII to the Public Health Service Act, provides for grants to States for the development and implementation of trauma care systems, and grants to improve rural trauma services. Title XII was subsequently amended to include a grant program for trauma care centers for uncompensated trauma services associated with drug related violence and a residency program for emergency medicine.

The Act required the development of a Model Trauma Care Systems Plan for States. The draft model has been completed, and States are using the model, and other national standards, as a guide in developing their own State plans. The Model Plan identifies fourteen mandatory components of a system. It supports a system designed to meet the needs of all injured patients who require care in an acute care facility. In FY 1993, \$3.5 million is available for State grants and \$433,000 is available for rural activities.

culturally competent systems of care for these children and their families. The Division administers a program of block and discretionary grants which support development of systems of care and services for those with special health needs, including those at-risk-for or suffering from chronic illness and disabilities, genetic diseases and hemophilia and HIV infections. It develops policies, guidelines and standards for the delivery of professional services and effective organization and administration of services of health programs for the target population.

The Division activities emphasize the development and implementation of community based services and systems of care designed to improve the health of this special population by conducting national programs of: consultation and technical assistance to State and local agencies and organizations; hemophilia diagnosis, treatment and information services; service improvement, development and implementation; and, government and professional liaison. The Division also provides a maternal and child health focus for the Bureau's involvement in international health issues relating to children and families with special health care needs.

The Division of Systems, Education and Science has primary responsibility for the development, implementation, review, management, administration and monitoring of State activities funded through the Federal-State partnership provided for by Title V of the Social Security Act as amended. It is responsible for all information activities of the Bureau and for the Regional/Central Office activities, work plans and guidance. The Division administers a program of research, professional education and training, and data and analytic efforts to develop new knowledge and skills designed to improve health and prevent disease among mothers, infants, children and adolescents, and children with special health needs.

This Division's activities include the development, coordination, and implementation of technical assistance and consultation to State and local agencies and organizations on research, professional training, and data and information systems as well as the development and dissemination of health education materials. Other Division activities include the Healthy Tomorrow Partnership for Children Program, an initiative to improve access to health care for mothers and children at the community level. This initiative is a joint venture with the American Academy of Pediatrics.

The Division of Healthy Start's specific goal is to implement the Healthy Start Initiative, a major national effort to reduce infant mortality by 50 percent in 15 selected U.S. communities with extremely high infant mortality. Division activities focus on the development of collaborative community efforts to assure that the appropriate comprehensive package of medical, social, educational, and other non-medical services is accessible to pregnant women and infants.

OFFICE OF THE ADMINISTRATOR

Office of Minority Health

The Office of Minority Health (OMH) coordinates efforts to address the special health needs of racial/ethnic minority groups by linking HRSA programs affecting minority health to potential external sponsors. Special health needs include clinical areas where a disparity exists between the health of minority groups and the health of Americans as a whole. OMH also addresses issues involving physical, temporal, structural, financial and linguistic barriers to health care by minority groups; and the use of "culturally competent" approaches to enhance the effectiveness of health service delivery.

Office of Operations and Management

The Office of Operations and Management (OOM) leads, directs and coordinates all phases of management. These include: administrative, financial, personnel, debt, staffing, grants and contracts, procurement, and real and personal property accountability and management. This office coordinates the implementation of the Freedom of Information Act, oversees the development of annual operating objectives and coordinates HRSA work plans and appraisals.

Office of Planning, Evaluation and Legislation

The Office of Planning, Evaluation and Legislation (OPEL) manages the Agency's strategic and program planning, evaluation, health policy formulation and legislative affairs. OPEL also staffs the Interagency Committee on Infant Mortality and the Secretary's Advisory Committee on Infant Mortality. OPEL focuses its efforts on health care reform, primary care, prevention activities/Healthy People 2000, coordinated care; and OPEL staff work with HCFA on reimbursement of services and health professions training.

Office of Policy Coordination

The Office of Policy Coordination (OPC) assists and supports the Administrator in his exercise of leadership and direction and supplies independent expertise, advice and technical assistance throughout the Agency. The office coordinates and monitors the implementation of HRSA policy and administrative priorities, and coordinates Agency activities with the Office of the Assistant Secretary for Health, other PHS agencies, HHS, and other government agencies. OPC manages the Agency's correspondence system and oversees Agency regulations development and process; manages the agency advisory committees; and serves as the Agency's spokesperson and coordinator for women's health issues.

Office of Public Health Practice

The Office of Public Health Practice leads the Agency's efforts to strengthen the practice of public health in the Nation by working with State and local governments, private associations, foundations, schools of public health and preventive medicine, and other organizations to focus attention on and promote solutions to problems that may impair the delivery of public health services, especially as they affect comprehensive primary care to disadvantaged populations. This office also collaborates with other Federal agencies on public health practice issues, and develops and supports specialized programs that enhance the practice of public health.

SELECTED ISSUES AND INITIATIVES

AIDS Activities

HIV SERVICES ACTIVITIES

Titles I and II of the Ryan White Act provides emergency assistance to localities that are disproportionately affected by the HIV epidemic as well as financial assistance to States or other public or private non-profit entities for the delivery of essential services to individuals and families with HIV disease.

Title I of the CARE Act creates a program of formula and supplemental competitive grants to assist metropolitan areas with 2,000 or more reported AIDS cases meet emergency care needs of low-income HIV patients. Title II of the Ryan White Act provides formula grants to States and territories for the operation of HIV service consortia in the localities most affected by the epidemic, for the provision of home and community based care, continuation of insurance coverage for persons with HIV infection, and treatments that prolong life and prevent serious deterioration of health. Up to ten percent of the funds for this program can be used to support Special Projects of National Significance.

In fiscal year 1994, it is anticipated that the uniform data set and reporting system for Title I and II programs will become fully operational. This system will be used to gather information on clients served, service needs, and cost of services. The data set is being developed with the assistance of persons with AIDS, CARE Act grantees, representatives of community-based groups, government, and national organizations.

In FY 1993, grants totalling \$182.3 million were awarded under Title I and \$102.4 million in grant funds was awarded under Title II of the CARE Act.

PEDIATRIC AIDS

MCHB's Pediatric/Family AIDS Demonstration Program, now in its fifth year of operation, is the Department's principal effort to develop national models of family-centered, community-based coordinated care for children, youth, women, and families affected by HIV and AIDS. In FY 1992, 45 projects were funded in 18 States, the District of Columbia, and

Puerto Rico for a total cost of \$19.7 million. Based on data from 28 of 32 direct service projects, approximately 17,000 children, youth, women, men and other family members were served in 1991. Currently 81 percent of the clients are Hispanic and African American.

The purpose of the Pediatric AIDS Program is to improve and expand the infrastructure of comprehensive care services in order to increase the access of HIV/AIDS affected women, infants, children, and youth to a comprehensive system of care that is community-based and family-centered. Funds support comprehensive services through integration into ongoing systems of care and support from appropriate financing mechanisms. The service delivery systems assure the delivery of high quality care at the appropriate level of care, with an emphasis on ambulatory care services that may reduce unnecessary hospital stays.

Three categories of projects have been funded: Pediatric AIDS Projects which provide or coordinate comprehensive, family-centered HIV health and social services; Comprehensive Care Consortia with the unique requirement that private sector funding must match public funding; and National Issues projects which provide information, training, and technical assistance to expand national resource capacity and impact national program development.

CDC/HRSA AIDS DEMONSTRATION PROGRAM

In FY 1989, the Center for Disease Control and Prevention and the HRSA mutually selected three demonstration sites to receive supplemental awards of \$500,000 for participation in a demonstration program. The services provided in this pilot program are prevention, treatment, on-going primary care, surveillance of risk and serologic status, education, intensive support for risk reduction, and case management.

SAMHSA/HRSA DEMONSTRATION

In FY 1989 HRSA's BPHC, in conjunction with the Substance Abuse and Mental Health Services Administration's (SAMHSA) National Institute on

SELECTED ISSUES AND INITIATIVES

them to the increasing problems related to the HIV epidemic. The revised format will be presented over the Adult Learning Satellite Service of the Public Broadcasting System.

Geriatric Initiatives in Health Professions Training

It has been predicted that, as their share of the population increases, the elderly will be utilizing well over half the Nation's medical care services.

HRSA supports Geriatric Education Centers to facilitate the training of health professions faculty, students, and practitioners within specific geographical areas. These centers provide a nationwide network offering education and training opportunities for health professionals, including physicians, nurses, dentists, social workers, pharmacists, occupational therapists, physical therapists, optometrists, podiatrists, dieticians, health administrators, clinical psychologists, and other allied and public health personnel. The centers also develop new curricula, training materials and clinical training sites. There are currently 20 centers, involving 17 States, Puerto Rico and the Trust Territories.

The BHP's Division of Nursing supported 16 Special Project Grants totaling \$2,198,561 in 1992, which provided geriatric education activities for practicing nurses. Projects located in areas where established Geriatric Education Centers are operational collaborated with these centers. Several projects developed learning modules and curriculum materials for schools of nursing and for continuing education in geriatrics for nurses.

In FY 1992, the Advanced Nurse Education program supported 11 masters level programs to prepare Clinical Nurse Specialists in geriatric/gerontological nursing (\$1,693,717), and 11 nurse practitioner programs to prepare Geriatric Nurse Practitioners (\$1,415,436).

Health Education Assistance Loan (HEAL) Program

The HEAL program provides market rate interest loans to health professions students. The loans, made by

non-Federal lending institutions, are fully insured by the Federal government. The potential Federal liability as of September 30, 1992 was \$3.2 billion. The Department continues to be concerned about HEAL borrowers who fail to repay their loans. In FY 1992, \$50 million was paid from the HEAL insurance fund to cover defaults, deaths, bankruptcies and disabilities. In FY 1991, \$58 million was paid in HEAL claims. An additional \$150 million in potential HEAL claims is in litigation.

Congress appropriated a \$340 million insurance authority for loans to students in FY 1993. HEAL was reauthorized for 3 years beginning October 1992. The new law made profound changes in the program by legislating a school performance standard and authorizing the creation of a new office, the Office of HEAL Default Reduction, to achieve a reduction in the number and amount of defaults.

The Administration has been concerned with the long-term solvency of the HEAL insurance fund for several years and has proposed legislative amendments to address the issue, most recently in October 1989. The legislation necessary to maintain a viable program is yet to be enacted. The Administration therefore proposed in the FY 1991 and FY 1992 budgets that the HEAL program begin phasedown.

Healthy People 2000

The Healthy People 2000 national health objectives represent a national strategy for reducing preventable illness, injury, disability, and premature death. The process of reaching agreement on a broad set of national disease prevention and health promotion objectives, and the on-going collaborative process to refine and update implementation planning, provides a useful forum for identifying emerging and changing problem areas and special population issues most likely to be helped by a targeted national effort.

In addition to having had the lead for developing two of the major priority areas of the 22 chapters, HRSA continues to have or share lead responsibilities with Centers for Disease Control and Prevention (CDCP) for PHS-wide implementation planning to

SELECTED ISSUES AND INITIATIVES

a greater representation of Americans in the planning process, and provide assurance of having a more effective impact on improving the health of the Nation.

HRSA Goals and Objectives for the Year 2000

This plan provides a focus and strategy for Agency leadership in working toward HRSA's most important goals and objectives between 1992 and the year 2000. During FY 1992 two documents related to this topic were issued, HRSA's *Goals and Objectives for the Year 2000* in September 1992 and the *1992 Annual Report: Progress on Year 2000 Goals and Objectives* in February 1993. This plan is the result of renewed coordination and collaboration within the Agency and interaction with colleagues throughout the Public Health Service and the broader health care community.

The goals and objectives of the Agency were developed in the context of a number of major influences including health care reform, *The Future of Public Health* (published by the Institute of Medicine, 1988), *Healthy People 2000* (published September 1990), the PHS' *A Plan to Strengthen Public Health in the United States* (published January 1991), the PHS *Action Plan for Women's Health* (published September 1991) and *Meeting the Challenge: USPHS Strategic Plan for Life Sciences Education and Public Science Literacy, Part I* (published April 1992).

The plan has 13 sections including segments on Information Resources Management, Total Quality Management and Equal Employment Opportunity as well as those usually expected in a document of this type (e.g., Access to Primary Care and Preventive Health Services, Primary Care Health Professions). It is expected that the plan will be reviewed on an annual basis and updated as needed, especially since some of the projections used will be affected by subsequent budgetary and appropriation actions. In similar fashion, as the Agency strives to achieve its priority goals for the decade, we expect the objectives to be modified

over time to reflect changing health care needs, improved HRSA program and system integration, the contributions of the Agency's public and private partners, and findings from evaluation studies designed to assess progress in meeting specific objectives.

Immunization Activities

Successful efforts to increase immunization levels in underserved infants and children require three key building blocks: (1) National and State based strategies that assure collaboration and coordination; (2) an adequate supply of vaccine; and (3) an infrastructure to assure that immunizations are given. These building blocks are the foundation for BPHC's immunization strategy to work with the Centers for Disease Control and Prevention (CDCP) to increase immunization levels in underserved infants and children through its grant supported programs.

The intent of both the BPHC and CDCP regarding the Immunization Initiative is to increase the immunization rate in infants and children to 90 percent or more via outreach, tracking and case management; to integrate BPHC programs into the CDCP-initiated Immunization Action Plans; to develop outcome measures in order to gauge progress; and to integrate immunization efforts with delivery of primary care services to underserved children to provide them with a "medical home."

Other immunization-related projects include:

- Using a continuous quality improvement approach - new clinical reporting requirements for immunizations were developed in C/MHCs for both pediatric and adult vaccines
- The MCHB and BPHC participated with the Centers for Disease Control and Prevention in formulating Standards for Pediatric Immunization Practice. The Standards provide guidance to health care providers on overcoming barriers to immunization and taking advantage of opportunities to immunize all children.
- The Primary Care Effectiveness Review - a site visit survey instrument for BPHC-funded health centers includes a review of medical records for immuniza-

SELECTED ISSUES AND INITIATIVES

Foster Grandparent Program and the Retired Senior Volunteer Program, to design a program where members will volunteer time in BPHC-funded programs, participating in immunization activities.

- The MCHB ensures that the maternal and child health programs of the 59 States and other jurisdictions are working towards meeting the goals of having 90 percent of the Nation's two-year olds fully immunized. This is being done by monitoring State programs through the Block Grant application review and, working in collaboration with the Interagency Committee on Immunizations as well as using information from the City MatCH and AMCHP studies, providing technical assistance that addresses immunizations as part of its State and community systems development initiative.
- The BPHC and the BHP are working together to support the President's Summer of Service (SOS) initiative. This effort involves 1500 students ages 16-25 years who are serving the educational, health, public safety, and environmental needs of children at-risk in 16 cities across the country. The Bureau's support has centered on augmenting the efforts of the Immunize Children At-Risk Early project in Philadelphia through the community health centers. The goals of this effort include increasing immunization rates of medically underserved children and providing health professions training experiences to nursing and medical students in underserved settings.

Infant Mortality

HEALTHY START

The specific goal of the Healthy Start Initiative is to reduce infant mortality by 50 percent over a five year period in selected U.S. communities with extremely high infant mortality. Collaborative community efforts focus on the needs of pregnant women and infants to assure that the appropriate comprehensive package of medical, social, educational, and other non-medical services is accessible. These may include: improving

participation in Medicaid among eligible pregnant and low-income women; increasing the number of pregnant women and infants who obtain adequate nutrition and health care referrals through the Women, Infants, and Children (WIC) supplemental nutrition program; integrating smoking and drug abuse cessation programs into prenatal and nutrition programs; and use of outreach workers to educate and recruit high-risk clients.

Following a nationwide request for proposals in September 1991, 15 communities were selected to begin this program. Participating communities represent two rural areas (rural South Carolina and the Aberdeen Area Indian reservation communities) as well as 13 inner cities areas. First year efforts in communities which received Healthy Start awards were spent on building, or expanding, community networks and developing appropriate staff to carry out the comprehensive community plans in their proposal. The 15 communities are now focusing on their implementation efforts.

COMMUNITY INTEGRATED SERVICE SYSTEMS DEVELOPMENT

In response to the need for better coordinated MCH efforts, the MCHB made the development of community-based service systems a top priority. These systems are intended to promote physical, psychological and social well-being for all pregnant women and children, adolescents, and their families; to provide individualized attention for their special health care and related needs, and, to link health care and services with other needed services and programs, including, but not limited to, early intervention, educational, vocational and mental health services. The legislation targets areas of high infant mortality.

Funded for the first time since it was mandated under the Omnibus Budget and Reconciliation Act of 1989, the Community Integrated Service Systems (CISS) program makes possible the implementation of systems building at the local level through the use of strategies that can facilitate realization of comprehensive community-based

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address the medical and drug treatment needs of pregnant women through prevention, education, and treatment approaches. Collaboration between multiple agencies on the community level is encouraged. One hundred forty-one projects have been funded.

The National Perinatal Addiction Prevention Program Resource Center is jointly funded by CSAP, and the MCHB. This National Resource Center acts as the country's focal point for policy, research, information/referral, training, service design, technical assistance, and evaluation findings of programs targeting substance abusing pregnant and postpartum women and their children.

The MCHB/BPHC Interbureau Workgroup was created to share information about program activities, organizational framework and lessons learned with the purpose of enhancing the success of programs through collaboration between the two Bureaus. This group has reviewed activities and service programs in both Bureaus. Particular attention has been given to planning requirements that place overlapping demands on States in order to foster more effective collaboration at the service level.

SECRETARY'S ADVISORY COMMITTEE ON INFANT MORTALITY

The Secretary's Advisory Committee on Infant Mortality was chartered in May 1991. Its purpose is to provide guidance to the Secretary on Department programs which are directed at infant mortality and improving the health status of pregnant women and infants. The Committee recently completed its FY 1993 Annual Report which was submitted to the Secretary in May.

Organ Transplantation

Grants to qualified organ procurement organizations (OPOs) have been awarded since FY 1986 to help improve the effectiveness of organ procurement programs. Several of the grants have been awarded to consolidate programs where multiple OPOs exist, thereby reducing inappropriate competition for donors in large metropolitan areas. Other grant activities have

focused on such issues as increasing minority populations' knowledge of organ donation and transplantation and their responsiveness to the request process, and refining methods of estimating the potential donor pool.

In FY 1992, 10 grants were awarded totaling \$401,000. Activities included: increasing the level of information about organ donation and transplantation with the medical student community, identifying physician and family factors which influence the consent process, and increasing the awareness of these issues among African-Americans through workshops for clergymen.

For FY 1993, the grant program has been changed to specify research efforts only. Special emphasis is being placed on studies that can lead to evaluation of organ procurement organizations' performance levels.

In 1992, the first report on transplant recipient survival rates for all transplant hospitals in the U.S. was published. The primary purpose of the report is to assist potential transplant recipients in choosing a transplant hospital.

Each February the Division of Organ Transplantation convenes a national meeting for transplant surgeons and physicians, organ recovery personnel, recipients, and other interested parties to discuss current policies and practices in the field.

Primary Care

Over 43 million Americans are without access to primary care because they lack health insurance, live in communities without sufficient health resources, have special needs not met by traditional medical care, or face other barriers such as race, language or culture. Within HRSA, BPHC has the major responsibility for the delivery of primary care services to targeted medically underserved populations such as low-income minorities, pregnant women, children, the uninsured, the homeless, substance abusers, HIV-infected persons, the elderly, and migrant and seasonal farmworkers. BPHC integrates its services with those of State and local health departments and organizations within the community served. BPHC programs are designed to

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local health department and a C/MHC, a Model Strategy Workbook is being gathered and will be ready for dissemination in early FY 1994. Also, joint educational workshops for local health officials and C/MHC directors are being developed. These sessions will include topics such as funding sources, governance, contracts, and collaborative relationships. Another ongoing BPHC/NACHO initiative includes the dissemination of useful information to local health officials on topics related to improving access to care (e.g., NHSC application, FQHC designation). Finally, in conjunction with BPHC and with funding support from the Office of Minority Health, OASH, NACHO is completing a bilingual/bicultural health project whose goal is to define, through demonstrations, best practices in health care for multicultural populations.

Through the cooperative agreement with BPHC, USCLHO surveyed local health departments to collect descriptive data on minority focused primary care/prevention programs or activities. The survey helped to identify effective models of increasing minority access to health programs and services. In addition, USCLHO has worked to identify practices in local health systems that effectively address the health care needs of multilingual/multicultural populations.

The NGA Cooperative Agreement is designed to enhance the relationship between the BPHC, the Health Care Financing Administration (HCFA) and the various State and local agencies/organizations involved in the delivery of primary care. NGA has conducted forums on the implementation of Medicaid enhancements that greatly affect the provision of primary care—the Federally Qualified Health Center (FQHC) provisions, the Early Periodic Screening, Diagnosis and Treatment (EPSDT) program, Medicaid Managed Care programs, and the outstationing of Medicaid eligibility workers.

In addition, NGA has worked on a series of policy briefs that discuss the acquisition of cost-based reimbursement by primary care providers and the relationship between case management, C/MHCs and Medicaid. NGA also will examine the collaborative opportunities available for C/MHCs and State-

supported health professions programs to provide community-based primary care training.

BPHC supports 52 primary care cooperative agreements with States and 35 State and regional primary care associations (S/RPCAs) covering 47 States. The CAs are units of State government that convene, advocate for, and coordinate primary care activities, and are required to have a memorandum of agreement with the State PCA, if any, to accomplish joint activities.

The S/RPCAs are nonprofit organizations representing C/MHCs and similar providers of primary care to the underserved. They facilitate communication among centers and between centers and States, and provide education, technical assistance and expertise related to primary care at the State and local levels. CAs facilitate communication between State activities, maternal and child health, State and local health department programs, HIV services and C/MHCs and similar primary care providers.

Each S/RPCA and CA has activities in five program areas: primary care access; retention, recruitment and clinical effectiveness; maternal and child health; and other special populations; and health care financing. Specific activities are determined through an assessment of needs and resources in the State.

PCA key activities this year include: activities to implement FQHC with particular attention to managed care initiatives; collaboration with the CA in the development of a report on interdisciplinary models and the use of physician assistants, nurse practitioners and certified nurse midwives in community-based primary care centers; collaboration with the CA in assuring community development and other technical assistance for high priority interventions identified in the primary care plan; and participation in the primary care plan update.

CA key activities this year include: written documentation of the roles of the CA, S/RPCA, Regional Office and other entities in clinical need

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The NHSC was established by the Emergency Health Personnel Act of 1970. The mission of the NHSC is to improve access to health care through the placement of health personnel to those communities and populations, both urban and rural, which are designated health professional shortage areas.

Health care personnel serve in the NHSC as volunteers, participants in the loan repayment program, or as obligated scholars (individuals who have received an NHSC scholarship to complete their health professions education in return for an obligation to provide approved health services in a designated health professional shortage area). Given the large numbers of underserved areas and the limited number of health personnel available to the NHSC, the program is statutorily mandated to prioritize placement opportunities to ensure the most effective utilization of resources and delivery of health services to areas of greatest need.

The NHSC Revitalization Amendments of 1990 reauthorized both the field program and the scholarship/loan repayment program from 1991 to the year 2000. The FY 1992 appropriation provided \$58.7 million for NHSC Scholarship and Federal and State Loan Repayment Programs.

NHSC Scholarship awards for FY 1992 were made to 363 health professions students obligated to provide primary health services to populations in priority HPSAs. Ten percent of the appropriation was set aside for scholarships for first-year nurse practitioner, nurse midwifery, or physician assistant students. NHSC Loan Repayment contracts for FY 1992 were signed with 326 health professionals for primary health services to priority HPSA populations. Twenty awards were made through the State Loan Repayment Program.

The NHSC, working in conjunction with its regional offices, State cooperative agreements, State health departments, and national and local professional societies utilizes a team approach in implementing its program. Through cooperative efforts and placement of

providers, the NHSC becomes a vital partner in meeting the health care needs of underserved populations.

In HRSA's Long-Range Plan to Improve Access for Underserved Populations, the Corps plays an essential part in meeting long-term expectations to provide health professionals to underserved areas. The plan projects significant increases in both the number of loan repayment agreements to support capacity expansion, and NHSC scholarships which will eventually result in significantly higher numbers of providers available for placement in underserved areas.

BHPr's part in the long-range plan would provide immediate relief to the most severely underserved areas through strengthening training of primary care physicians and non-physician providers at service sites. This would expand the pool and improve the quality of primary care providers willing and able to serve the underserved.

HRSA co-sponsored the third PHS Primary Care Policy Fellowship in June 1993. Its purpose is to provide an opportunity for primary care practitioners, academicians, researchers, and administrators to become more effective advocates for improving primary health care. To date 77 fellows have participated in this program.

Recruitment and Retention of the Disadvantaged and Minorities for the Health Professions

Special strategies are being undertaken to increase the number of minorities in the health professions.

- Two BHPr grant programs — the Health Careers Opportunity Program (HCOP) and the Centers of Excellence (COE) program — serve as the Federal focus for increasing the number of minorities and other individuals from disadvantaged backgrounds in the health and allied health professions. These programs also advance excellence in selected health professions educational institutions that train significant numbers of African, Hispanic and Native Americans. The program supports recruitment and education designed to expand the academic ability

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medicine included in the Council's first report to the Secretary and Congress was expanded in the Council's second report. COGME's second report included recommendations concerning the financing of graduate medical education programs.

COGME's third report sets out a scene of targeted strategies to train more generalist and minority physicians, reduce the number of specialists, and improve their geographic distribution to support health care reform and cost control strategies. The Council is currently developing an implementation plan for the report's recommendations.

The Council is also reviewing the future adequacy of supply of the physician specialties in primary care (family medicine, general internal medicine, and general pediatrics), general surgery, obstetrics-gynecology, and adult and child psychiatry; reform issues in medical education and the movement of medical education into ambulatory settings; and data on trends in indebtedness and other factors affecting the representation of minorities in medicine.

- BPHC promotes NHSC programs by sending literature and making site visits to minority medical schools and other medical schools with large minority populations. Additionally, the National Medical Association, under a contract with HRSA, promotes education for minority health professionals by visiting and providing minority students with information about NHSC scholarship and loan repayment programs. BPHC's Scholarship Program has a special focus for the Secretary's initiative to visit Historically Black Colleges and Universities to explain the scholarship and loan repayment programs and funding preference for scholarships.
- To aid needy health professions and nursing students in meeting educational costs, in FY 1992, the BHPPr continued to operate a number of ongoing scholarship and loan programs, including Exceptional Financial Need Scholarships, Financial Assistance to Disadvantaged Health Professions Students, and low-cost health professions and nursing student loans.

- Programs which target assistance to individuals from disadvantaged backgrounds in schools that meet specific requirements for the conduct of activities were implemented by BHPPr in FY 1991. These programs include: Loans for Disadvantaged Students, Scholarships for Disadvantaged Students, and a Faculty Loan Repayment Program.
- BPHC's Native Hawaiian Health Professions Scholarship program awarded 11 scholarships to Native Hawaiian medical students, obligating them to provide professional service to HPSA populations in Hawaii with the greatest need.

Rural Health

The Office of Rural Health Policy works within the Department and with other Federal agencies, States, national associations, foundations, and private sector organizations to seek solutions to health care problems in rural communities.

The Office assists the Secretary in developing rural health finance policy. In particular, the Office advises the Secretary on how the Medicare and Medicaid programs affect access to health care for rural populations. In recent months, the Office recommended higher Medicare payment updates for primary care physicians and rural hospitals, and a more liberal definition of Essential Access Community Hospitals. The Office also serves as a focal point for examining the rural implications of Federal and State health care reforms.

The National Advisory Committee on Rural Health advises the Secretary on the priorities and strategies that should be considered when providing and financing health care services in rural areas. The Committee meets three times a year and has made more than 100 recommendations to the Secretary designed to improve access of rural residents to primary care and hospital care. In its *Fifth Annual Report on Rural Health to the Secretary of Health and Human Services*, issued in December 1992, the Committee made 25 recommendations, including six on health care reform.

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nated. A special December 1990 issue of the *Journal of Medical Education* featured the allopathic portion of this bibliographic listing.

In FY 1992 BHPf funded 22 projects under its program, Grants for Interdisciplinary Training for Health Care for Rural Areas. Eight new projects are being funded in FY 1993. Thirteen grants for Health Education and Training Centers for the U.S.-Mexico Border Areas and other urban and rural areas of need were funded in FY 1992.

The BHPf, in collaboration with the Health Care Financing Administration, administers the Rural Health Medical Education Demonstration Project. The project provides resident physicians with clinical experience in rural hospitals. Currently there are 7 ongoing projects.

Through an interagency agreement with the Agency for Health Care Policy and Research, the Bureau administers a project at the Arkansas Area Health Education Center to test strategies for disseminating new medical treatment protocols to practicing physicians.

Strengthening Public Health

The Office of Public Health Practice (OPHP) was established by the HRSA Administrator to serve as the Agency's focal point on efforts to strengthen the practice of public health in the Nation—as it pertains to the HRSA mission.

OPHP is involved in a wide range of activities which highlight the role of State and local health departments in assuring the health status of their communities, including: 1) addressing issues raised in *The Future of Public Health* (IOM); 2) providing HRSA management with input on programs which impact on public health practice; 3) working with State and local governments to promote solutions to problems which may impair the delivery of public health services, especially those relating to the establishment of primary care systems; 4) developing and coordinating grants, contracts, and agreements for public health practice activities. OPHP is also the lead HRSA office for activities involving the Joint Council

of Official Public Health Organizations. The Joint Council provides the major public health provider organizations with a mechanism to respond to pressing issues.

Other units within HRSA are also directly involved in public health practice activities. The BHPf administers two programs targeted to improving public health education and training: the Public Health Traineeship program, and the Public Health Special Projects program. The Public Health Traineeship grant program provides funds to assist schools in providing traineeships to individuals pursuing studies in a health profession field in which there is a severe shortage of health professionals. The Public Health Special Projects program supports projects to plan, develop, demonstrate, operate and evaluate projects that further the Healthy People 2000 goals in the areas of preventive medicine; health promotion and disease prevention; and improving access and quality of health services in medically underserved communities.

A 5-year initiative to enhance the analytic skills of maternal and child health professionals is underway in maternal and child health training programs in schools of public health. MCHB and the CDCP are placing maternal and child health epidemiologists in States to assist the MCH problem solving.

The National Nursing Shortage

Since 1986 a shortage of registered nurses has been experienced throughout the United States. The reasons for the shortage are multiple and complex. A report issued in December 1988 by the Secretary's Commission on Nursing contained 16 recommendations through which the public and private sectors can work together to address the problems of recruitment and retention of registered nurses and assure an adequate supply of registered nurses in the future.

The Public Health Service developed an implementation plan in response to those recommendations that were directed to the Federal Government. Among the activities proposed in the plan were assessment of

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the initial designation and continued evaluation of designated trauma centers and regional trauma care systems; standards and requirements for medically directed triage, transport, and transfer of trauma patients, including children; establishment and collection of data to a central data reporting and analysis system; public education on injury prevention and access to trauma care; and coordination between States.

In FY 1992, 33 States submitted applications and 23 States received grant awards totaling \$3.9 million.

Title XII provides that ten percent of the appropriation be used for grants to public and private non-profit entities for research and demonstration projects to improve the availability and quality of EMS and trauma care in rural areas. In FY 1992, five grants totaling \$489,400 were awarded for improving trauma care in rural areas. Two of the grants evaluate the impact of triage and transport protocols; one grant is a preventable mortality study in Montana; and two grants are demonstrations of pre-hospital training programs, including one for pediatrics.

A Model Trauma Care System Plan for States has been developed, as mandated, and States are using this model, and other national standards, as a guide in developing their own State plans.

Vaccine Compensation

The National Vaccine Injury Compensation Program (VICP) was created by the National Childhood Vaccine Injury Act of 1986, as amended, as an alternative mechanism to the tort system for resolving vaccine injury compensation claims. The program was authorized by Congress as a strategy for protecting the Nation's vaccine supply. The Secretary of HHS is the designated respondent for all petitions under the Act.

The Act distinguishes between those deaths or injuries alleged to be associated with vaccines administered prior to the effective date of the VICP, October 1, 1988, and those deaths or injuries alleged to be associated with vaccines administered on or after the effective date. If an injury occurred prior to the effective date, a petition had to have been filed by

January 31, 1991. However, for injuries which occurred on or after the effective date, a petition must be filed within certain periods of time set out in the law.

Each petition is filed and adjudicated by the U.S. Claims Court. The BHP's Division of Vaccine Injury Compensation has the delegated responsibility for review of all medical records and recommendations on compensability for each petition. The Secretary is represented by Department of Justice attorneys in all proceedings before the court.

The program also provides administrative support to the Advisory Commission on Childhood Vaccines (ACCV), which is composed of nine appointed members - three health professionals, three members of the general public, three attorneys, and four ex-officio members. The Commission, which must meet at least quarterly, advises the Secretary on implementation of the compensation program and recommends changes in the vaccine injury table.

The Health Information, Health Promotion and Vaccine Injury Compensation Amendments of 1991 (P.L. 102-168), provided for a number of amendments to the law authorizing the VICP, to ease administration of the program. Among the provisions: The chief special master was authorized to suspend proceedings on any pre-enactment cases for up to 540 days (instead of 180 days), to allow additional time for processing of claims. The provision automatically withdrawing Claims Court jurisdiction after specified time limits was eliminated, allowing petitioners to elect to continue or withdraw the petition. The existing requirement that payments for compensation for pre-enactment cases be made in four equal annual installments, which was administratively cumbersome and expensive for both the program and petitioners, was repealed.

Based on findings of the Institute of Medicine (IOM) Report, *Adverse Effects of Pertussis and Rubella Vaccines* the BHP, in consultation with the ACCV, has been working with other Department staff to develop recommendations for the future of the

House and Senate Authorizing Committees and Chairs

House Committee on Energy and Commerce

John D. Dingell (MI)

Subcommittee on Health and the Environment

Henry A. Waxman (CA)

Senate Committee on Labor and Human Resources

Edward M. Kennedy (MA)

Senate Committee on Finance

Daniel P. Moynihan (NY)

Subcommittee on Health for Families and the Uninsured

Donald Riegle (MI)

House and Senate Appropriations Committees and Chairs

House Appropriations Committee;

Subcommittee on Labor/HHS/Education

William H. Natcher (KY)

Senate Appropriations Committee;

Subcommittee on Labor/HHS/Education

Tom Harkin (IA)

HRSA LEGISLATIVE AUTHORITIES

Bureau of Health Professions (cont.)

PROGRAM	LEGISLATIVE AUTHORITY	THROUGH...
Geriatric Training: Centers;		
Faculty Training	Sec. 777(a)&(b), PHS Act	9/30/95
Geriatric Optometry	Sec. 777(c), PHS Act	9/30/95
Rural Hlth. Training	Sec. 778, PHS Act	9/30/95
Research Projects	Sec. 781, PHS Act	9/30/95
Chiropractic Demonstrations	Sec. 782, PHS Act	9/30/95
Special Initiatives: Two-Year		
Med. Schools; Curriculum Development	Sec. 788, PHS Act	(repealed)
Health Prof. Studies	Sec. 792, PHS Act	Indefinite
Nursing Special Projects	Sec. 820, PHS Act	9/30/94
Advanced Nurse Education	Sec. 821, PHS Act	9/30/94
Nurse Pract/Midwives	Sec. 822, PHS Act	9/30/94
Nursing Educ. Opportunity	Sec. 827, PHS Act	9/30/94
Nurse Traineeships	Sec. 830, PHS Act	9/30/94
Nurse Anesthetists	Sec. 831, PHS Act	9/30/94
Nursing Scholarships	Sec. 843 (expired)	—
Pacific Basin M.O. Training	Sec. 10, PL 101-527	9/30/93
Vaccine Injury Compensation	Sec. 2110-23 & 2131-34, PHS Act	Indefinite
Nat'l. Practitioner Data Bank	Title IV, PL 99-660; Sec. 5, PL 100-93	Indefinite
AIDS Educ. & Training Cntrs.	Sec. 776(a), PHS Act)	9/30/9

Bureau of Health Resources Development

PROGRAM	LEGISLATIVE AUTHORITY	THROUGH...
Facil. Guarantees & Loans	Titles VI/XVI, PHS Act	Indefinite
Organ Transplantation	Secs. 371-378, PHS Act	9/30/93
Health Teaching Facilities	Former Sec. 726, PHS Act	—
Trauma Care	Sec. 1201-33, PHS Act	9/30/93
Trauma Center Violence	Sec. 1241-45, PHS Act	9/30/94
Emerg. Med. Residencies	Sec. 1251, PHS Act	9/30/95
HIV Emerg. Assist., Part A	Sec. 2601-08, PHS Act	9/30/95
HIV Compre. Care, Part B	Sec. 2611-20, PHS Act	9/30/95

APPROPRIATIONS

FY 1993 - FY 1994 Appropriations (in Thousands of Dollars)

PROGRAM BY ACTIVITIES		FY93 Rev. Approp. Comparable	FY94 Rev. Approp.
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BPHC:

Community Health Centers.....	558,808	599,550
Migrant Health.....	57,306	58,600
Health Care for the Homeless.....	57,014	62,561
Health Services for Residents of Public Housing.....	8,923	8,873
Black Lung	3,968	4,142
Pacific Basin	873	968
Nat Health Service Corps	42,020 *	44,720
NHSC Recruitment Programs	73,439	79,250 **
Grants to Communities-Health Prof. Scholarships.....	478	478
Nurse Loan Repayment.....	2,044	2,044
Hansens Disease Center	20,023 *	20,747
Payment to Hawaii	2,976	2,976
Native Hawaiian Health Care.....	3,589	4,336
State Alzheimer's Disease.....	4,959	4,959

Total BPHC	836,420	894,204
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BHPr:

Minority/Disadvantaged:		
Loans for Disadv. Students	7,925	7,925
Centers of Excellence	23,481	23,481
HCOP Grants	24,961	24,961
FADHPS (20% of HCOP)	6,241	6,241
 Subtotal, HCOP	 31,202	 31,202
Except Fin Need Scholar (EFNs)	10,433	10,433
Scholar for Disadv. Students.....	17,102	17,102
Loan Repaymt/Fellowships - Faculty	1,053	1,053
Nurse Opport for Individuals from Disadvantaged Backgrounds.....	3,693	3,693
 Subtotal, Min/Disadvantaged Reps	 94,889	 94,889

Primary Care/Service Linked:

Primary Care Training:		
Family Medicine - Trng/Depts.....	38,194	47,194

General Internal Medicine/Pediatrics	16,847	16,847
Primary Care Loan Program	0	0
Nurse Practitioner/Midwives	15,443	16,943
General Dentistry Training	3,730	3,730
Physician Assistants	4,916	6,554
Podiatric Medicine	615	615
Subtotal, Primary Care Trng	79,745	91,883
Service-Linked Education Networks:		
Area Health Education Ctrs (AHECs)	19,812	22,203
Health Education Trng Ctrs	2,836	2,836
Geriatrics - GECs/Training	10,013	9,175
Rural Health Interdisc	4,017	4,017
Subtotal, Service-Link Ed	36,678	38,231
Subtotal, Primary Care/Svc Linked	116,423	130,114
Meeting Year 2000 Hlth Objectives:		
Advanced Nurse Education	12,004 †	12,253
Public Health and Prev Medicine	7,265	7,816
Allied Hlth Profess - Special Projs	3,467	3,467
Hlth Admin Traineeships/Spec Projs	1,494	995
Subtotal, Year 2000 Objectives	24,230	24,531
Other Nursing Priorities:		
Nursing Special Projects	10,401	10,401
Prof. Nurse Traineeships	14,222 †	15,473
Nurse Anesthetist Traineeships	2,724	2,724
School Nurse Initiative	0	0
Subtotal, Nurse Education	27,347	28,598
Health Professions Data System	643	643
Research of Certain HP Issues	1,123	1,123
Pacific Basin	1,683	1,500
Chiropractic Demo Grants	0	750
Nat Prac Data Bank (User Fees)	(6,000)	(7,500)
Total, BHP	266,338	282,148
MCHB:		
MCH Block Grant	664,534	687,034

EMS for Children	4,810	7,500
Healthy Start	79,325	97,500
Total, MCHB	748,669	792,034
BHRD:		
Hlth Teaching Facilities.....	415	415
Organ Transplantation.....	2,767	2,652
Trauma Care.....	4,368	4,837
Total, BHRD.....	7,550	7,904
Program Management.	120,787 *	121,976
RURAL HEALTH:		
Rural Health	4,176	9,426
Rural Health Outreach Grants	24,779	26,279
State Offices of Rural Health	2,500	2,750
Subtotal, Rural Health	31,455	38,455
Buildings & Facilities.....	982	942
Family Planning	173,418	180,918
Subtotal, HRS (Non-AIDS)	2185619	2318581
AIDS:		
Ryan White:		
Emergency Relief - Part A.....	184,757	325,500
Comprehensive Care - Part B	115,288	183,897
Early Intervention-Part C	47,968	47,968
Pediatric Demo Grants - Part D	0	22,000 ††
Subtotal, Ryan White	348,013	579,365
Pediatric AIDS Service Demos	20,897	0
Education and Training Centers.....	16,435	16,435
AIDS Dental Services	0	7,000
Subtotal, AIDS.....	385,345	602,800
Subtotal, HRS BA	2,570,964	2,921,381
Med.Facil. Guar. & Loan Fund	10,900	9,000

Health Education Assistance Loans:

HEAL Guarantee Authority	(340,000)	(375,000)
Liquidating Account (non-add)	(47,631)	(64,878)
Program Account	22,202	23,512
HEAL Credit Reform - Dir Ops	2,946	2,946
HEAL - Default Reduction (nonadd).....	(700)	(1,000)
Subtotal, HEAL	25,148	26,458
Vaccine - Pre-1988.....	110,000	110,000
Vac Improv Trust Fund (HRSA Claims).....	54,740	84,180
VICTF Direct Ops - HRSA	2,500	3,000
Total, HRSA.....	2,774,252	3,154,019
Health Center Tort Claims.....	1,000	5,000
Total, Revised.....	2,775,252	3,159,019

- * Reflects a reprogramming of \$700k from NHSC Field and \$700k from Prog Mgmt to Hansen's Disease Center.
- ** Reflects \$2.750m moved to State Offices of Rural Health line.
- † Reflects realignment of \$249k from Advanced Nurse Ed to Prof Nurse Traineeships.
- †† Includes Pediatric AIDS Service Demos.
- § Nonadd

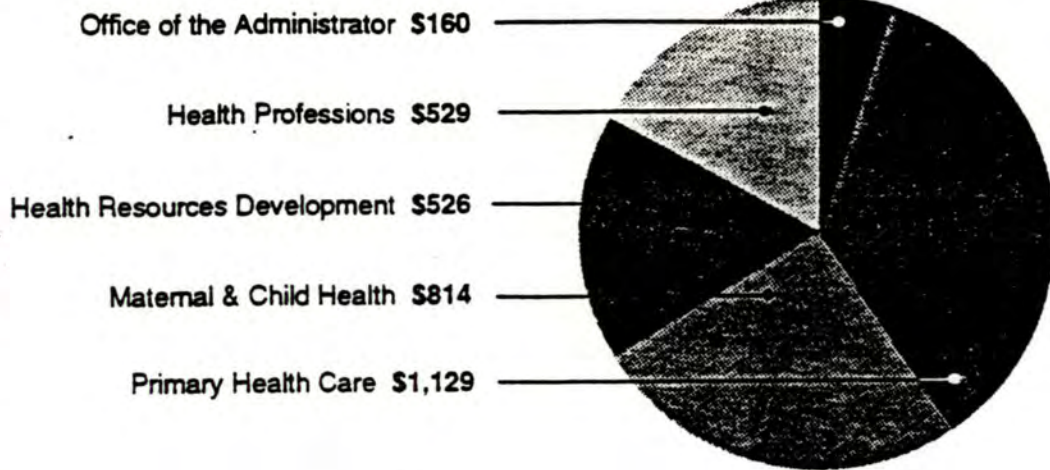
FTEs

Direct:		
NHSC Headquarters.....	47	47
Hansen's Disease Center.....	300	300
Program Management.	1,457	1,422
Family Planning	52	50
HEAL (Exc. Off. of Default Reduct)	18	18
Subtotal, Direct.....	1,874	1,837
Fiscal Services (S&SF).....	131	128
Reimbursements:		
FOH.....	194	189
Relocation Site	9	9
Head Start	9	9
Refugee Assistants.....	18	17
HUD	24	23
OES-ES (ROFEC)	11	10
CDC Hemophilia/HIV	4	4

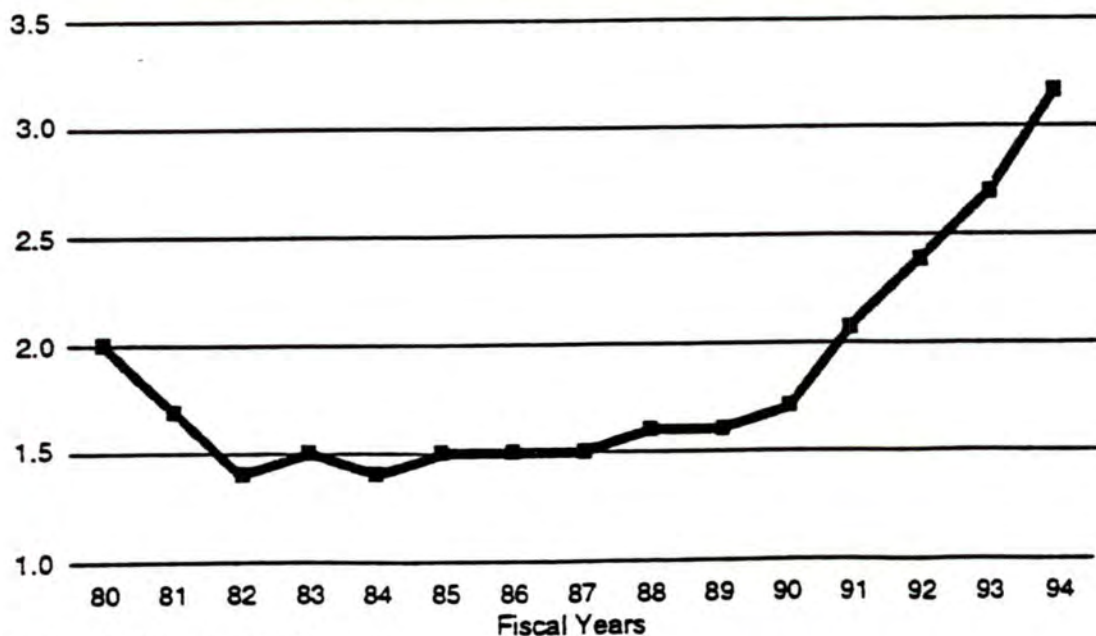
Other Reimbursements BPHC	15	15
Allocations - Appalachia.....	4	4
Vaccine.....	28	27
Data Bank	13	12
		
Subtotal, Reimbursements.....	329	319
		
Subtotal, FTEs.....	2,334	2,284
		
HEAL-Office of Default Reduction.....	7	7
		
Subtotal, FTEs.....	2,341	2,291
		
NHSC Ceiling Exempt	300	300
		
Total, FTEs	2,641	2,591

Total FY 1994 Dollars by Bureau In Millions

TOTAL APPROPRIATION \$3,159,019



Total Budget Authority in Billions



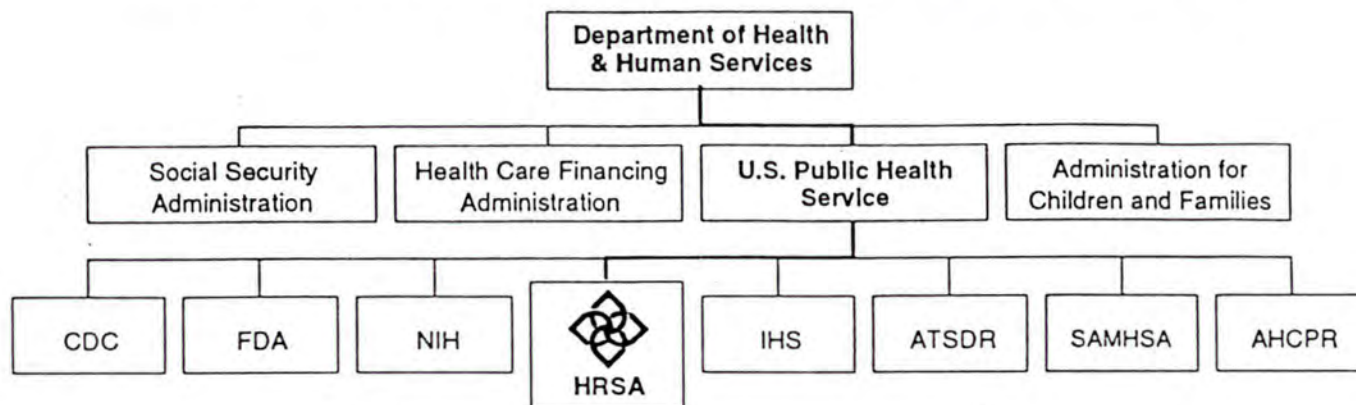
FY 80 and FY 81 includes PHS Hospitals



FACT SHEET

OFFICE OF COMMUNICATIONS • AGENCY FACT SHEET • February 1994

Health Resources and Services Administration



HRSA is one of eight agencies of the Department of Health and Human Services' Public Health Service. It has leadership responsibility for primary care health services and resource issues relating to access, equity, and quality of care. HRSA provides leadership to assure the support and delivery of primary health care services, particularly to the disadvantaged and underserved, and the development of qualified primary care health professionals and facilities to meet the health needs of the Nation. HRSA focuses on support of States, localities, and communities in their efforts to plan, organize, and deliver primary health care, as well as to strengthen the overall public health system.

HRSA pursues its objectives by:

- Supporting states and communities in their efforts to plan, organize and deliver systems of primary health care, especially to underserved urban and rural area residents, migrant workers, the homeless, mothers and children, and other groups with special needs through the **Community and Migrant Health Centers**;
- Providing primary care physicians, psychiatrists, dentists, and other health professionals (obligated to serve in return for scholarship aid or loan repayment) to health professional shortage areas through the **National Health Service Corps**;
- Participating in the **campaign against HIV and AIDS** by funding pediatric AIDS health care demonstration projects, education and training centers to prepare health professionals in the care of AIDS patients, and three titles of the **Ryan White Comprehensive AIDS Resources Emergency Act of 1990** that provide individual and support services to people with HIV/AIDS and their families.
- Providing leadership in addressing the issues and unique problems related to **health care services in rural areas**;
- Providing leadership in improving the education, distribution and utilization of the **health professionals** needed to staff the nation's primary health care system;
- Increasing the number of **minorities in the health professions**;
- Tracking the supply of and requirements for health professionals and addressing professional competence through development of a **comprehensive quality assurance program**;
- Administering the **National Organ Transplant Act** by serving as an information resource on donation, procurement, and transplantation.



HRSA's four major operating components are: The Bureau of Primary Health Care (BPHC), the Bureau of Health Professions (BHP), the Bureau of Health Resources Development (BHRD), and the Maternal and Child Health Bureau (MCHB).

Bureau of Primary Health Care

BPHC helps assure that health care services are provided to medically underserved populations and to persons with special health care needs.

- The Bureau serves as a national focus for the development of primary health care delivery capacity, and for the placement of health care professionals in Health Professional Shortage Areas (HPSAs) to promote a sustained source of health services.

- The Bureau identifies and designates Health Professional Shortage Areas (HPSAs), Medically Underserved Areas (MUAs) and Medically Underserved Populations (MUPs).

- Support for primary health care is provided primarily through Community Health Centers (CHCs), Migrant Health Centers (MHCs), Services for Special Populations, Services for Residents of Public Housing, and the National Health Service Corps (NHSC). These programs, which together serve approximately 6 million medically underserved persons, play a lead role in providing primary health care to those who would otherwise lack access to care, particularly the poor and minorities.

- The Federal Employee Occupational Health program has the major role in promoting effective and efficient Federal occupational health programs. Specific programs assist individuals with Black Lung and Hansen's Disease.

Bureau of Health Professions

BHP monitors and guides the development of health resources by providing leadership to improve the education, training, distribution, utilization, supply, and quality of the Nation's health personnel.

The Bureau has established Six Strategic Directions to achieve the Department's Year 2000 National Health Promotion and Disease Prevention objectives and to guide the implementation of the Bureau's programs. These include:

- Promoting generalism and primary care;
- Increasing minority/disadvantaged health care providers;
- Enhancing links between health professions' education programs and health service settings;
- Achieving quality assurance for health care professionals; and
- BHP administers multidisciplinary programs such as the Area Health Education Centers, the Geriatric Education Centers, and Model Education Projects. It also administers the AIDS Regional Education and Training Centers Program which provides multidisciplinary training for primary health care providers in the care of HIV-infected individuals and people with AIDS. It also operates the National Practitioner Databank, Vaccine Injury Compensation Program, and the Health Professions Loan Repayment Program.

Bureau of Health Resources Development

BHRD has three major programs: Health Facilities; Organ Transplantation; and HIV Services.

- The Health Facilities program monitors compliance by health care facilities with assurances and/or obligations resulting from Hill-Burton grants and loans, and health professions and nurse training construction grants.

- The Organ Transplantation program awards and manages a program of grants to organ procurement organizations (OPOs) and other nonprofit entities to increase the number of organ donors in the United States. The program also supports the National Organ Procurement and Transplantation Network, designed to ensure equitable distribution of available organs to patients and transplant centers, and a Scientific Registry of demographic and clinical information on transplant recipients.

- BHRD's Division of HIV Services (DHS) plans, develops, implements, and monitors programs which provide health care and support services for people living with HIV disease. DHS is responsible for awarding and monitoring the grant programs established by Title I and Title II of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990. These programs provide resources to eligible metropolitan areas (EMAs) with the highest levels of reported AIDS cases and to States and territories to improve the quality and

U.S. Medicine Interviews **Ciro V. Sumaya**

In March Dr. Ciro V. Sumaya became director of the Health Resources and Services Administration (HRSA), the agency in the Department of Health and Human Services which oversees the nation's physician supply and specialty mix, essential ingredients in the debate over health care reform. In fact, before joining HRSA Dr. Sumaya led the workforce group of Hillary Rodham Clinton's task force on national health care reform.

Dr. Sumaya previously held the post of associate dean for affiliated programs and continuing medical education at the University of Texas Health Science Center in San Antonio, where he helped found and direct the HRSA-funded Area Health Education Center of South Texas and helped establish the South Texas Health Research Center.

Dr. Sumaya also has conducted basic research and has held grants from the National Institutes of Health for work on infectious diseases in children.

In the following interview, he describes how his varied background will come into play as he guides HRSA's programs.



Ciro V. Sumaya

What do you hope to accomplish at HRSA?

Well I've just started, so I'm learning a lot. It's a very intense learning curve. But I think some of the areas I'd like to focus on, and try to bring some type of improvement to, relate to seeing that we meet community health needs to an optimum degree.

HRSA is involved with a number of the service needs of communities. What we see before us are a number of impending changes—legislative, through health care reforms, and we see demographic changes occurring around the country. There are constant technologic improvements that are occurring.

So there are a number of factors involved in the whole health arena, and I think what we can do through HRSA, in a strong way, is to try to converge a number of these and to try to improve what eventually is reaching the community. More specifically, we're involved with community migrant health, rural health clinics—a number of health resources that reach underserved populations in particular.

We see a number of changes occurring, and the system we have, which is really an excellent system, needs to be

mainstreamed into what is occurring, particularly with health care reform. That requires a significant amount of consultation, technical assistance, improvement in staffing, improvement in facilities, improvement in the actual data systems that these facilities have, and their interactions with the private sector.

Are such specialized things as the migrant centers going to be needed under health care reform, if we have universal access? Won't they be mainstreamed under health care reform?

They will be mainstreamed, but they will probably remain and not be dismantled. The reason is that these particular facilities and resources have such strong ties to the populations they serve. They have a certain sensitivity; they understand the cultural aspects of the populations they serve.

Moreover, they're geographically situated at sites of the population they serve. So, they should be a very important framework for what health care reform will bring with it—certainly not just moved aside or be dismantled, but instead actually be refurbished and enhanced and extended. But they will need

some support for that, because they will be competing with other groups.

They need to have a more level field for competition, and they need to get more involved in a managed care system. Some have, but that certainly is not the usual type of health care system that has been occurring within community migrant health centers.

Another important area that I'm interested in focusing on is the health care workforce. HRSA is intimately involved with primary health care needs of the nation, with the special emphasis that we have on populations that are underserved. There are many aspects of the health care workforce—primary care, and non-primary care for that matter—that certainly need to be addressed.

Health care reform is looking at that issue, and I think through HRSA we can extend some of the points that will be legislated. I think there is a strong movement toward—and I certainly would push for that—training our health professionals in areas that are the real practice world. The real practice world is not predominantly university hospitals, but it actually is predominantly community settings—clinics, outpatient, ambulatory, and community hospitals, private offices.

How large is that program?

Right now, the usual funding is about \$20 million; it went up a blip this past year to \$22 million. But I would say that's woefully below what it should be funded for the impact that it can have.

Will HRSA be involved in the preventive focus that's been articulated as part of health care reform?

HRSA's role in prevention I think can certainly be strengthened. There are other agencies in the Public Health Service that focus more on prevention, but I think HRSA as well has that focus and within its mission can certainly expand that focus.

We are involved in school-based clinic delivery of services. And within that obviously belongs reaching children, reaching teenagers. We can discuss in this health care setting nutrition, we can discuss problems with teenage pregnancy, with drug addiction. So, we have a venue where we can work with school-age children in a number of areas.

Will you hand out condoms?

I don't know the specifics of what we will be doing, but we certainly are very open to all aspects of prevention.

We are also going to be involved in looking at domestic and family violence, and the prevention of that, again working through our services that we provide to public housing groups and others. I think this is an area that HRSA can be very strong in addressing.

Where does HRSA fit into the federal AIDS picture?

HRSA has a very strong program on AIDS; AIDS is one of our highest-funded programs. We oversee the Ryan White CARE Act programs, very important programs that affect the needs of high-incidence cities. We're working with states and territories on providing significant support for pharmaceuticals and medications, insurance needs.

We're working in early prevention programs through facilities that provide

comprehensive primary care, so that we try to reach at-risk populations early. Again, looking at the preventive mode here, trying to have counseling and testing—try to identify early and then manage their health-care early.

And pediatric AIDS clinics, addressing mothers and children. And we have the training of health care providers around the country in how they can manage patients or in the prevention areas.

Does recent evidence that AIDS is increasing very rapidly in the heterosexual population, and particularly among women, mean that your strategy needs to change in any respect?

We're constantly on the look-out for areas that are changing, either the types of individuals who are getting infected or new drugs that can be used. For example, studies show that use of AZT in pregnant women is decreasing the incidence of infection in the newborn child.

Such being the case, we will be looking at that Public Health Service-wide, to see how we can implement new knowledge like this, presuming that it's accurate, into the communities.

What is your personal outlook on AIDS—do you see any lights on the horizon or are we just treading water and slowly going under?

With AIDS, with many viral infections, it's difficult to try to find effective treatments, it's difficult to try to find effective vaccines. HIV may have some additional obstacles. But there is considerable work in that area, and we do have some medications that have been developed that are of some effectiveness, though obviously we need a bigger and much better armamentarium of medications.

We are working as well on a number of treatments for other illnesses that occur in individuals who are infected with HIV. In fact, that's a growing area.

I think that prevention still is the answer to try to reduce this devastating disease to much lesser numbers and to

have a lesser impact. But prevention is many times difficult. We have some preventive measures that were easier to work with—the blood supply—I think we handled that pretty well. We have structural barriers, condoms being one, which are not 100 per cent but still reduce the possibilities of transmission.

But when you talk about prevention in terms of lifestyle changes—that is much harder to accomplish. Nonetheless, I think it's an area that needs greater attention, and we need to start in younger age groups. We have to make sure that as we interact with people we are as effective as possible—this means many times having peers do much of the interaction.

It means understanding the cultural aspects of the individual. It's working with people who are part of the community. If we provide messages or any type of interaction, it has to be at a level that they feel comfortable in. They have to have input into how we're trying to address this issue.

You just came from Texas, and along the border with Mexico there are serious problems in health and prevention. Were you involved in those issues while you were there?

I was very involved with border health issues. In fact, I was the project director of an AHEC in south Texas which was on the Rio Grande, right on the border. We had a number of programs, working with the communities, in addressing their health care issues.

These dealt with improving the health care capacity of this region to meet needs of the area. So, it meant starting training programs and having students receive some of their training at these sites. And also, developing training programs locally, developing a library system in that area, starting to work more with the schools to stimulate students into the health professions.

In addition, at the University of Texas Health Science Center in San Antonio, we started a South Texas Health Research Center.

ACQUIRED IMMUNODEFICIENCY SYNDROME

Obligations 1/
(Dollars in Thousands)

	<u>FY 1989</u>	<u>FY 1990</u>	<u>FY 1991</u>	<u>FY 1992</u>	<u>FY 1993</u>	<u>FY 1994</u>	<u>FY 1995</u>
Health Resources & Services							
Administration	\$59,932	\$112,467	\$265,902	\$316,612	\$390,341	\$607,796	\$700,796
Centers for Disease Control & Prevention	377,592	442,812	496,951	479,620	498,253	543,253	543,253
National Institutes of Health:							
NCI	122,247	149,299	160,869	165,668	173,029	213,457	222,712
NHLBI	38,088	42,056	46,406	46,208	48,058	54,977	57,910
NIDR	3,920	4,662	6,214	8,154	8,375	11,431	12,097
NIDDK	3,557	5,306	6,290	7,172	6,446	10,438	11,047
NINDS	13,069	16,158	16,651	17,592	18,416	22,105	23,291
NIAID	311,277	394,088	430,940	448,940	459,698	544,791	578,109
NIGMS	10,830	14,614	15,588	16,100	16,850	23,945	25,409
NICHD	22,437	26,749	32,609	34,729	38,807	56,426	64,155
NEI	4,828	5,533	5,680	5,902	6,283	8,381	8,870
NIEHS	4,138	4,258	4,514	4,229	4,272	5,608	5,903
NIA	443	859	985	1,072	1,153	1,664	1,723
NIAMS	673	1,238	1,633	1,694	1,760	2,795	2,958
NIDCD	--	--	495	483	618	1,507	1,560
NIMH	48,373	63,331	72,720	76,140	78,433	87,182	92,704
NIDA	60,824	92,635	122,688	125,269	127,047	143,376	151,733
NIAAA	6,130	7,980	7,996	7,990	6,823	9,457	10,000
NCRR	67,616	46,147	47,429	50,051	50,881	61,383	64,960
NINR	702	987	2,545	2,710	2,966	4,444	4,702
FIC	4,619	4,898	5,351	5,593	5,684	8,852	9,357
NLM	20	493	519	1,057	1,101	3,082	3,191
OD	12,865	10,284	11,737	13,689	14,581	25,744	26,661
B&F	5,772	12,880	4,966	7,000	3,753	--	--
National Institutes of Health	742,428	904,455	1,004,825	1,047,440	1,075,034	1,301,045	1,379,052

ACQUIRED IMMUNODEFICIENCY SYNDROME

	<u>FY 1989</u>	<u>FY 1990</u>	<u>FY 1991</u>	<u>FY 1992</u>	<u>FY 1993</u>	<u>FY 1994</u>	<u>FY 1995</u>
Substance Abuse & Mental Health Services Administration	58,009	49,865	30,118	26,025	25,655	28,111	32,951
Agency for Health Care Policy & Research	6,830	8,470	10,237	10,135	9,624	10,624	12,000
Office of the Assistant Secretary for Health	<u>6,405</u>	<u>7,676</u>	<u>5,334</u>	<u>4,794</u>	<u>5,330</u>	<u>5,323</u>	<u>5,323</u>
Subtotal, L/HHS PHS Agencies	1,251,196	1,525,745	1,813,367	1,884,626	2,004,237	2,496,152	2,673,375
Health Care Financing Administration	545,000	780,000	1,050,000	1,360,000	1,675,000	1,990,000	2,240,000
Social Security Administration	170,000	249,000	360,000	501,000	670,000	835,000	1,015,000
Office of Civil Rights	<u>2,700</u>	<u>2,700</u>	<u>2,700</u>	<u>2,700</u>	<u>2,800</u>	<u>2,600</u>	<u>2,600</u>
Subtotal, L/HHS Agencies	1,968,896	2,557,445	3,226,067	3,748,326	4,352,037	5,323,752	5,930,975
Food & Drug Administration	73,775	57,428	63,395	72,302	72,628	72,399	72,399
Indian Health Service	<u>800</u>	<u>2,670</u>	<u>1,803</u>	<u>3,170</u>	<u>3,303</u>	<u>3,556</u>	<u>3,556</u>
TOTAL, HHS	\$2,043,471	\$2,617,543	\$3,291,265	\$3,823,798	\$4,427,968	\$5,399,707	\$6,006,930
Veterans Affairs Department	136,000	220,000	258,000	279,000	325,000	331,000	349,000
Defense Department	86,000	125,000	127,000	129,000	159,000	129,000	99,000
Agency for International Development	40,000	74,000	78,000	94,000	117,000	117,000	117,000

ACQUIRED IMMUNODEFICIENCY SYNDROME

	<u>FY 1989</u>	<u>FY 1990</u>	<u>FY 1991</u>	<u>FY 1992</u>	<u>FY 1993</u>	<u>FY 1994</u>	<u>FY 1995</u>
Justice/Bureau of Prisons	2,000	4,000	6,000	7,000	9,000	10,000	12,000
State Department	1,000	1,000	1,000	1,000	1,000	1,000	1,000
Labor Department	1,000	1,000	1,000	1,000	1,000	1,000	1,000
Housing & Urban Development	-	-	-	107,000	196,000	253,000	257,000
Office of Personnel Management - FEHB	<u>-</u>	<u>-</u>	<u>-</u>	<u>58,000</u>	<u>98,000</u>	<u>108,000</u>	<u>119,000</u>
TOTAL, HIV/AIDS	\$2,309,471	\$3,042,543	\$3,762,265	\$4,499,798	\$5,333,968	\$6,349,707	\$6,961,830

1/ Reflects obligations. Does not agree with appropriation history tables.

HEALTH RESOURCES AND SERVICES ADMINISTRATION
AIDS FUNDING HISTORY - FY 1986 - FY 1994
(dollars in thousands)

	FY 86	FY 87	FY 88	FY 89	FY 90	FY 91	FY 92	FY 93	FY 94	FY 95 Pres. Bdgt.
Emergency Assistance (Title I, Part A)						87,831	121,601	184,757	325,500	364,500
Comprehensive Care (Title II, Part B)						87,831	107,649	115,288	183,897	213,897
Early Intervention Services (Title III, Part C)						44,891	49,836	47,968	47,968	66,968
Pediatric/Adolescent Services & Research (Title IV, Part D)									22,000	27,000
SubTotal RYAN WHITE C.A.R.E. PROGRAMS						\$220,553	\$279,086	\$348,013	\$579,365	\$672,365
AIDS Education and Training Centers *		1,900	11,106	14,640	14,549	17,078	16,975	16,435	16,435	16,435
Pediatric/Family HIV Program *			4,787	7,806	14,803	19,518	19,737	20,897		
AIDS Dental Services *									7,000	7,000
AIDS Facilities Renovation *			6,702	3,903	4,342	4,029				
AIDS Service Demonstration Grants **	15,312	10,000	14,361	14,692	17,209					
Low Prevalence Areas **				3,904						
Formula Grants for Home Health **					19,737					
Subacute Care **					1,480					
Drug Reimbursement **		30,000		15,000	29,606					
Community Health Care Service for AIDS **					10,777					
TOTAL HRSA AIDS BUDGET AUTHORITY	\$15,312	\$41,900	\$36,956	\$59,945	\$112,503	\$261,178	\$315,798	\$385,345	\$602,800	\$695,800

* Non Ryan White

** No longer authorized - Incorporated into Ryan White programs.

Updated: 2-09-94

OCIRM/KED

Ryan White CARE Act of 1990

Appropriated Funding Levels by Fiscal Year (\$Millions)

	<u>1991</u>	<u>1992</u>	<u>1993</u>	<u>1994</u>	<u>1995(a)</u>
Title I	\$ 87.8	\$121.6	\$184.8	\$325.5	\$364.5
Title II	\$ 87.8	\$107.7	\$115.3	\$183.9	\$213.9
Title III	\$ 44.9	\$ 49.8	\$ 48.0	\$ 48.0	\$ 67.0
Title IV	\$ 0	\$ 0	\$ 0	\$ 22.0	\$ 27.0
Totals	\$220.5	\$279.1	\$348.1	\$579.4	\$672.4

(a) President's Budget Request

BHRD EVALUATION STUDIES
22Nov93

- 92-121 *Determining the Feasibility of Collecting Demographic and Access Data from Records Maintained by Facilities Under the Hill-Burton Program*
- 92-122 *Assessment of Loan Management Procedures to Identify Strategies to Improve Health Care Facilities' Financial Performance*
- 92-123 *Consortium Approaches to the Delivery of HIV-Related Services Under the Ryan White CARE Act*
- 92-126 *Data Systems for Reporting Activities under the Ryan White CARE Act Title I and II Grant Programs--Part III*
- 92-127 *Adequacy of Information Resources Management (IRM) in BHRD Programs*
- 92-128 *Factors that Influence Inclusion and Removal from Organ Transplant Waiting List*
- 92-129 *Institutional Factors Which Influence the Likelihood of Living-Related Kidney Transplant Operations*
- 92-130 *Motor Vehicle Agencies' Existing Donor Card Programs and their Effectiveness in Increasing Public Awareness*
- 92-131 *Assessment of Community HIV/AIDS in Metropolitan Areas Expected to Receive Initial Ryan White Title I Funding in FY 1992*
- 92-134 *Study of Accounting Definitions and Unit Costs to Providers of Delivering Health and Support Services Supported Under Title I and II of the Ryan White Comprehensive AIDS Resources Emergency Act*
- 93-140 *Use of Existing Data Sets to Analyze Changes in Hospital Utilization in Title I Cities by Patient with HIV/AIDS*
- 93-141 *Changes in the Provision of Services for Drug Using/ Recovering Women with HIV in Ryan White Title I Cities*
- 93-142 *Evaluating How the Needs of Women with HIV Are Being Addressed in the Title I Planning Process*
- 93-143 *Assessment of the Feasibility and Characteristics of of Population-Based Trauma Reporting Systems*
- 93-144 *Reasons African-American and White Waiting List Patients are Unavailable for an Organ Offer*

- 93-145 *The Hill-Burton Uncompensated Care Program: Patient Demographics and Utilization*
- 93-146 *Migration of Individuals Between the Commonwealth of Puerto Rico and the United States: Implications for the Delivery of HIV-Related Services*
- 93-147 *Identification and Description of HIV-Related Service Delivery Systems in Rural Areas*
- 93-148 *Factors Which Facilitate Participation of People with HIV Care Consortia Under the Ryan White CARE Act*
- 93-149 *Development of Database for Assessing HIV Care Consortia Under the Ryan White CARE Act*
- 93-151 *Evaluation of Initial Implementation of the Uniform Reporting System for Titles I and II of the Ryan White CARE Act*
- 93-153 *Evaluation of Impact of CARE Act on Capacity Building in Community-Based Agencies Serving Hispanic Populations*
- 93-154 *Application of Search Conference Model in Designing and Conducting HIV Services Evaluation Workshop*
- 93-155 *Preparation of Report and Journal Article Outline for Meeting on Development of HIV Services Evaluation Questions*
- 93-156 *Methodology to Assess the Impact of URS on Organization of Ryan White CARE Programs*
- 94-100 *Evaluation of the Effectiveness of a Cable Network Campaign on Organ Donation Education*
- 94-101 *Development of a Study Design for Evaluating Variations in OPO Organ Procurement Rates*
- 94-102 *Twelve Month Post-Transplant Reimbursement Coverage for Immunosuppressive Drug Therapy: The Effects on Patients*
- 94-103 *Evaluating Trauma Care Costs, Charges, and Reimbursement*
- 94-104 *Evaluating Trauma Care Systems*
- 94-105 *Identification and Description of HIV-Related Service Delivery Systems in Rural Areas - Phase II*
- 94-106 *Evaluation of the Impact of CARE Act on Strategies Used by Health and Support Service Agencies Serving African Americans*

- 94-107 *Development of a Self-Assessment Tool for HIV Health Services Planning Councils and HIV Care Consortia*
- 94-108 *The Management of People Co-Infected with HIV and TB in Title I EMA's*
- 94-109 *Evaluation of a Computer Assisted Optimization Approach to HIV Service Planning*
- 94-110 *The Use of Multiple Respondents in the National Follow-Back Survey*

Bureau of Health Resources Development

HIV/AIDS Publications

**DHHS PHS HRSA BHRD OCIRM
Communications Branch
5600 Fishers Lane, Room 7A-54
Rockville, Maryland 20857**

**(301) 443-6846
FAX (301) 443-3604**

June 1994

AIDS/HIV PUBLICATIONS

THE FOLLOWING PUBLICATIONS ARE AVAILABLE FROM THE BUREAU OF HEALTH RESOURCES DEVELOPMENT, OFFICE OF COMMUNICATIONS AND IRM, RM 7A-54. IF MORE THAN 20 COPIES ARE NEEDED, PLEASE MAKE REQUEST 5 DAYS IN ADVANCE.

1. Information About the Ryan White Comprehensive AIDS Resources Emergency Act of 1990

This publication describes the Titles of the Ryan White Comprehensive AIDS Resources Emergency Act of 1990 and include listings of grantee contacts, addresses, phone numbers and grant award amounts.

2. Title I FY 1993 Formula Application Guidance

3. Title I FY 1993 Supplemental Grant Application Guidance

For: Atlanta, Baltimore, Boston, Chicago, Dallas, Ft. Lauderdale, Houston, Jersey City, Los Angeles, Miami, Newark, New York, Oakland, Philadelphia, San Diego, San Francisco, San Juan, and Washington, D.C.

4. Title I FY 1993 Supplemental Grant Application Guidance

For: Anaheim, Detroit, Nassau-Suffolk, New Orleans, Ponce, Seattle, and Tampa-St. Pettersburg

5. Title II FY 1993 Applicaton Guidance for States

6. Bureau of Health Resources Development Program Evaluation Studies FY 1994

This publication describes the 1994 evaluation studies to be conducted by the Bureau of Health Resources Development. Each study includes a brief description, the organization conducting the study, the name and phone number of the staff person in charge, and the estimated cost of the study.

7. HIV/AIDS Workgroup on Health Care Access Issues for American Indians and Alaska Natives

This report describes the barriers to receiving services faced by American Indians and Alaska Natives with HIV/AIDS disease.

8. HIV/AIDS Workgroup on Health Care Access Issues for Women

This report describes the barriers to receiving services faced by women with HIV/AIDS disease.

9. HIV/AIDS Workgroup on Health Care Access Issues for Hispanic Americans

This report describes the barriers to receiving services faced by Hispanic Americans with HIV/AIDS disease.

10. HIV/AIDS Workgroup on Health Care Access Issues for African Americans

This report describes the barriers to receiving services faced by African Americans with HIV/AIDS disease.

11. AIDS Resource Listing - Information Contacts

A listing of names and addresses of some State and Federal programs for people with AIDS/HIV disease. Also includes HIV/AIDS newsletters, hotlines and State resources.

12. AIDS Resource Listing - Selected CDC Guidance

A listing of CDC MMWR issuances on HIV/AIDS related topics.

13. Development of Special Projects of National Significance (SPNS)

Describes how the Health Resources and Services Administration (HRSA) interpreted and implemented the authorizing legislation for SPNS, how the projects funded this authority have served to demonstrate innovative approaches to the care of individuals with HIV infection and AIDS, and how HRSA has approached the issue of program evaluation and information dissemination.

14. Special Projects of National Significance - Adolescent Care Demonstration and Evaluation Projects 1994-1997

15. Special Projects of National Significance - Projects Providing Advocacy for Health and Support Services

Initial Report, January 1994, Cross-Cutting Evaluation of Four HIV/AIDS Legal Advocacy Projects

16. Consortium Approaches to HIV Services Delivery Under the Ryan White CARE Act
17. Persons Living with AIDS Community Discussion Group Meeting
Summary Report - July 19-20, 1993
18. Determining the Unit Cost of Services: A Guide for Estimating the Cost of Services Funded by the Ryan White CARE Act of 1990
19. Methods for Identifying Perceptions of Baltimore HIV Services
(Barriers and Beliefs Before CARE Act Funding)

AIDS/HIV JOURNAL PUBLICATIONS

1. First Year of AIDS Service Delivery Under Title I of the Ryan White CARE Act, G. Stephen Bowen, MD, MPH; Marconi, Katherine, PhD., Kohn, Sally, MPH; Bailey, Dorothy, BS; Goosby, Eric, MD; Shorter, Sonya; Niemcryk, PhD. Public Health Reports; September/October, 1992, Vol 107, #5.

Reviews the emergency assistance for ambulatory HIV medical and support services provided in the first year by eligible metropolitan areas funded under Title I of the Ryan White CARE Act of 1990; The varied responses and processes by which these 16 urban areas receiving Title I funds met legislative mandates; the central nature of planning councils under Title I and their formation and functioning; and issues related to current implementation and future expansion of Title I to additional eligible metropolitan areas.

2. State Responses to Title II of the Ryan White Comprehensive AIDS Resources Emergency Act, Mc Kinney, M; Weiland, M; Bowen, G.S.; Goosby, E.P.; Marconi, K.M. Public Health Reports; January/February 1993; Vol 108, #1; pp. 4-11.

This article reviews state expenditures during the first year of the Ryan White CARE Act funding within the context of Title II guidelines and the federally funded grant programs that preceded and helped shape Title II.

3. An Analysis of the Greater Baltimore HIV Services Planning Council, Kachur, S.Patrick, M.D., M.P.H.; Sonnegg, Amanda J., Ph.D.; Cintron, Rebecca, M.D.; Farup, Christina, M.D.; Silbersiepe, M.D.; Celentano, David D., Sc.D.; Kwait, Jennafer, B.A., AIDS and Public Policy Journal, Vol. 7, #4, Winter 1992

This is a description of the process which occurred as the Greater Baltimore HIV Services Planning Council conducted its legally mandated responsibilities as a Title I Ryan White Program. The study reports on how the Planning Council set priorities, developed a plan for the delivery of HIV services and coordinated the private and public sector resources to build an HIV delivery system in the Baltimore metropolitan area.

4. The Role of Primary Care in the Prevention and Treatment of Drug Abuse and AIDS

This is a report of the February 13-14, 1989 workgroup of 15 consultants and policy makers who met to discuss HRSA's role with regard to the role of primary care services in the prevention of substance abuse treatment and AIDS.

5. Methodology for Obtaining Quantitative Data on the Ryan White HIV Delivery Systems in Baltimore and Oakland

This is description of the methodology used to obtain quantitative data about the HIV medical and social services delivered by the Title I Ryan White Programs in Baltimore and Oakland. The Study methodology was developed by the University of Maryland School of Medicine, the Johns Hopkins University School of Hygiene and Public Health, and the University of California-Berkley School of Public Health through a contract with HRSA's Bureau of Health Resources Development.

6. Federal Funding for Health Services Research on AIDS
Rudzinski, Marconi, McKinney; HA Summer, 1994, p. 1-8

7. Delivery of Oral Health Care Through the Ryan White CARE Act to People Infected with HIV
Schneider, Hardwick, Marconi, Niemcryk, Bowen; Journal of Public Health Dentistry, Fall 1993, p. 258-264

8. Consortium Approaches to the Delivery of HIV Services Under the Ryan White CARE Act
McKinney; AIDS and Public Policy Journal, Fall 1993, p. 115-125

9. Medical Adherence Among Prenatal, HIV Seropositive, African American Women: Family Issues
Shelton, Marconi, Pounds, Scopetta, O'Sullivan, Szapocznik; Family Systems Medicine, 1993, p. 1-14

10. American Medical Association Advisory Group on HIV Care: HIV Early Intervention - AMA Physician Guidelines
Macher; AMA, Chicago, 1994

11. HIV information dissemination to primary care providers. In: AIDS as a Family Disease - Proceedings of the Second National Workshop of the AIDS Education and Training Centers. Division of AIDS Education. Center for Continuing Education in the Health Professions. University of Medicine and Dentistry of New Jersey, 1994, p. 92-93

12. The state of the art HIV clinical conference call series. In: AIDS as a Family Disease - Proceedings of the Second National Workshop of the AIDS Education and Training Centers. Division of AIDS Education. Center for Continuing Education in the Health Professions. University of Medicine and Dentistry of New Jersey, 1994, p. 191-192

13. Educating primary care providers about HIV disease: Multidisciplinary interactive mechanisms.
Public Health Reports, May/June 1994, p. 305-310
14. Tuberculosis in Alaskan native women with HIV disease: The first cases.
Proceedings of the Tenth International Conference on AIDS. Tokyo, August 1994

Ryan White CARE Act - Title I and II Technical Assistance Documents

1. T.A. Topics No. 1, Managing the Conflict of Interest

This monograph provides a framework to identify the characteristics and problems of conflict of interest issues, and to suggest strategies for solving or avoiding them in the future.

2. T.A. Topics No. 2, Health Insurance Programs for Persons with AIDS/HIV Disease

An overview of health insurance programs, supported by State and Ryan White CARE Cat funds, for people with AIDS/HIV disease who are or will be without health insurance coverage.

3. T.A. Topics No. 3, Conducting a Step-wise Assessment of Unmet Service Needs Yielding Quantified Results

Provides a framework for estimating and quantifying the unmet need for community-based HIV care in local metropolitan areas.

4. T.A. Topics No. 4, Housing and Residential Services for People with AIDS/HIV

5. T.A. Topics No. 5, Home Care for People with HIV Disease

6. T.A. Topics No. 6, The Provision of Services to Infants, Children, Women and Families Under Title II of the Ryan White CARE Act

7. T.A. Topics No. 7, Major Programmatic and Administrative Accomplishments and Challenges: FY 1992 State Experiences Under Title II

Uniform Reporting System (URS)

1. Annual Administrative Report (AAR) Guidance
2. Volume I: Uniform Reporting System (URS) Client Level Guidance
3. Volume II: Elements Reported by Drug Assistance Programs
4. Volume III: Elements Reported by Health Insurance Programs
5. Protecting the Confidentiality of HIV-Related information Under the Uniform Reporting System: A Guide for State and Local Agencies Receiving Ryan White CARE Act Grants - Suggested procedure for reviewing confidentiality practices
6. Protecting the Confidentiality of HIV-Related Information: A Guide for Providers - Suggested procedures, specifically for service providers, for reviewing confidentiality practices.



FACT SHEET

Bureau of Health Resources Development •

Division of HIV Services •

MAY 1994

Title I of the Ryan White CARE Act

On August 18, 1990, Congress enacted Public Law 101-381, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. The purpose of the CARE Act is to improve the quality and availability of care for people with HIV disease and their families.

The act was named after the Indiana teenager who became an active public educator on HIV/AIDS after he contracted the disease. Ryan White died the same year the legislation was passed.

The CARE Act, which is authorized through Fiscal Year 1995, has four titles:

- Title I: HIV emergency relief grant program for cities
- Title II: HIV care grants to states
- Title III: Early intervention services
- Title IV: Pediatric care and reports and evaluations

The Health Resources and Services Administration, an agency of the U.S. Public Health Service, administers Titles I and II within its Bureau of Health Resources Development, Division of HIV Services. HRSA's Bureau of Primary Health Care administers Title III(b), which is the only section under Title III that received funds in FY 1992, 1993 and 1994. The Pediatric/Family AIDS Demonstration Program, which was administered by HRSA's Maternal and Child Health Bureau, was transferred to Title IV of the CARE Act in FY 1994. MCHB will continue to administer it.

Title I, the HIV Emergency Relief Grant Program, provides funds to cities and metropolitan areas that are disproportionately affected by the HIV epidemic. There are two types of Title I grants; formula and supplemental.

Formula Grants

Cities are automatically eligible for Title I formula grants if they reported 2000 or more AIDS cases, or a per capita incidence of .0025 or higher, to the U.S. Centers for Disease Control by March 31 of the previous fiscal year.

Grants are used for community-based outpatient

health and support services for low-income persons living with AIDS/HIV and their families, including comprehensive medical care, prescription drugs, counseling, transportation, meals-on-wheels programs, home care and hospice care.

Title I grants may also be used to provide inpatient case management for AIDS/HIV patients to prevent unnecessary hospitalization or to expedite hospital discharge.

In FY 1991, the first grant year, 16 cities/metropolitan areas qualified for Title I formula grants. In FY 1992, that number rose to 18, in FY 1993, to 25 and in FY 1994 to 34.

Title I grants are made to the city's chief elected official, who in the first year of funding must establish an HIV health services planning council to set priorities for HIV care delivery, prepare a plan for the use of the CARE funds and monitor how efficiently funds are being used. Administrative costs may not exceed five percent of the grant.

Supplemental Grants

All cities that receive Title I formula grants are eligible to compete for Title I supplemental grants, which are awarded later in the fiscal year to cities demonstrating additional critical needs. Half of each year's Title I appropriation is reserved for formula grants; the other half is for supplemental grants.

Funding

The total amount of Title I grant money awarded since FY 1991 is \$707.8 million. The following chart shows the eligible cities that have received Title I formula grants and supplemental grants and amounts since FY 1991. Years in which "N/A" appears with relation to a city means that the city did not qualify for a formula grant that year.

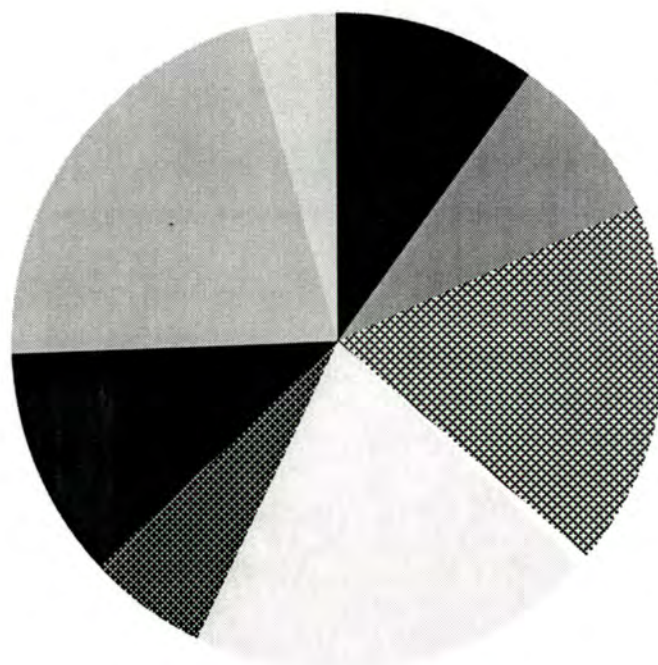
Title I HIV Health Services Planning Council

Ryan White C.A.R.E. Act

Must include representatives
from 11 specific groups:

- Health care providers
- AIDS CBOs
- Local public health agencies
- State government
- HRSA AIDS demo grantee
- Hospital/health planning agencies
- Social service providers
- Title III grantee
- Affected communities
- Non-elected community leader
- Mental Health care providers

Title I Service Categories, FY 93



- Nonservice 9.9
- Substance Abuse 8.4
- Dental Care 2.4
- Support Services 15.7
- Hospice Care 0.5
- Other 20.3
- Mental Health 5.9
- Case Management 10.9
- Rehabilitation 0.4
- Primary Care 21.3
- Home Health 4.4

"Nonservice" includes administration, council support, and needs assessment.

"Other" includes AIDS Drug Assistance Program, outreach, and volunteer services.

[Title XXVI, Part A, PHS Act]

Metropolitan Areas
[ranked by FY 1994 total received.]

[* New EMA in FY 1994]

BHRD/FMB : 6/21/94 at 2:28 pm

$\$ \text{ Avg/Case} = \$2,988$
 Avg/Case assume: that 35% of cumulative cases will be living.
 $\text{Avg. Total Crant} = \$5,380,188$

\$ Avg/Case = \$3,282
Avg/Case assumes that 35% of cumulative cases will be living.
Avg. Total Grant = \$6,634,778

\$ Avg/Case = \$3,633
Avg/Case assumes that 35% of cumulative cases will be living.
Avg. Total Grant = \$7,293,080

\$ Avg/Case = \$3,872
Avg/Case assumes that 40% of cumulative cases will be living.
Avg. Total Grant = \$9,411,441

\$707,824,998
11,863,559
\$719,688,557

TITLE II**RYAN WHITE CARE ACT**

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990, Public Law 101-381, was signed into law August 18, 1990. Its purpose is to provide emergency assistance to localities that are disproportionately affected by the HIV epidemic. The Act also makes financial assistance available to States and other public or private nonprofit entities for the development and operation of essential services for individuals and families with HIV disease. The Act is authorized through fiscal year 1995 and has four titles: Title I – HIV emergency relief grant program for cities; Title II – HIV care grant to States; Title III – early intervention services; and Title IV – reports and evaluations.

The Health Resources and Services Administration (HRSA) manages the majority of the CARE Act. HRSA's Bureau of Health Resources Development administers Titles I and II. Its Bureau of Primary Health Care administers Title III.

Formula Grant

Title II of the Act provides formula grants to States, U.S. Territories, the District of Columbia and Puerto Rico to provide health care and support services for people with AIDS and HIV infection. Grants are awarded based on: (a) average per capita income of State to U.S. population; and (b) the number of diagnosed AIDS cases reported to, and confirmed by, the U.S. Centers for Disease Control and Prevention for the two federal fiscal years preceding the grant awards.

The legislation mandates that:

- States use 15% of their grant to provide health and support services to infants, children, women and families with HIV disease;
- States reporting 1 percent of all U.S. AIDS cases use 50 percent of their CARE grant to create and operate HIV consortia in areas where the greatest number of HIV patients live. Priority funding must go to consortia that received assistance from the previously funded HRSA adult/pediatric HIV care providers, people with HIV/AIDS, and community organizations that offer services to HIV patients. Consortia must use CARE funds to plan, develop, and deliver comprehensive outpatient health care and support services for people living with AIDS and HIV.
- States may use CARE grant funds for home and community based care services, to continue health insurance premiums and coverage for people with HIV/AIDS, and to provide and coordinate care and drug treatments that prolong life or prevent serious deterioration of health for those with the HIV disease.
- States are to balance the needs of urban areas with those of rural areas.

Matching Funds

States that were first funded under Title II in 1991 (those with more than one percent of the total AIDS cases reported nationally in the previous two years), must contribute resources (either cash or in-kind contributions) to match the grant according to a yearly formula.

1991	\$1 State for every \$5 Federal
1992	\$1 State for every \$4 Federal
1993	\$1 State for every \$3 Federal
1994-95	\$1 State for every \$2 Federal

In subsequent years, States that must contribute matching funds start with the 1991 schedule.

Funding

The Title II grants made in April 1994 were based on AIDS cases reported between October 1, 1992 and September 30, 1993. The minimum grant allotment States must receive is \$100,000. HRSA has awarded a total of \$495.7 million for grants under Title II. By fiscal year these awards were: 1991-\$87.8; 1992-\$107.7; 1993-\$115.3; 1994-\$183.9.

Special Projects of National Significance

The CARE Act directs that up to 10 percent of appropriated Title II funds be used to support a competitive grant program, Special Projects of National Significance (SPNS). The SPNS projects are expected to: (a) build programs of care that address special care needs of individuals with HIV; (b) serve special populations; (c) or organize care in new and innovative ways. The results of the SPNS demonstrations are expected to be disseminated so that they can be replicated in other areas.

Accomplishments

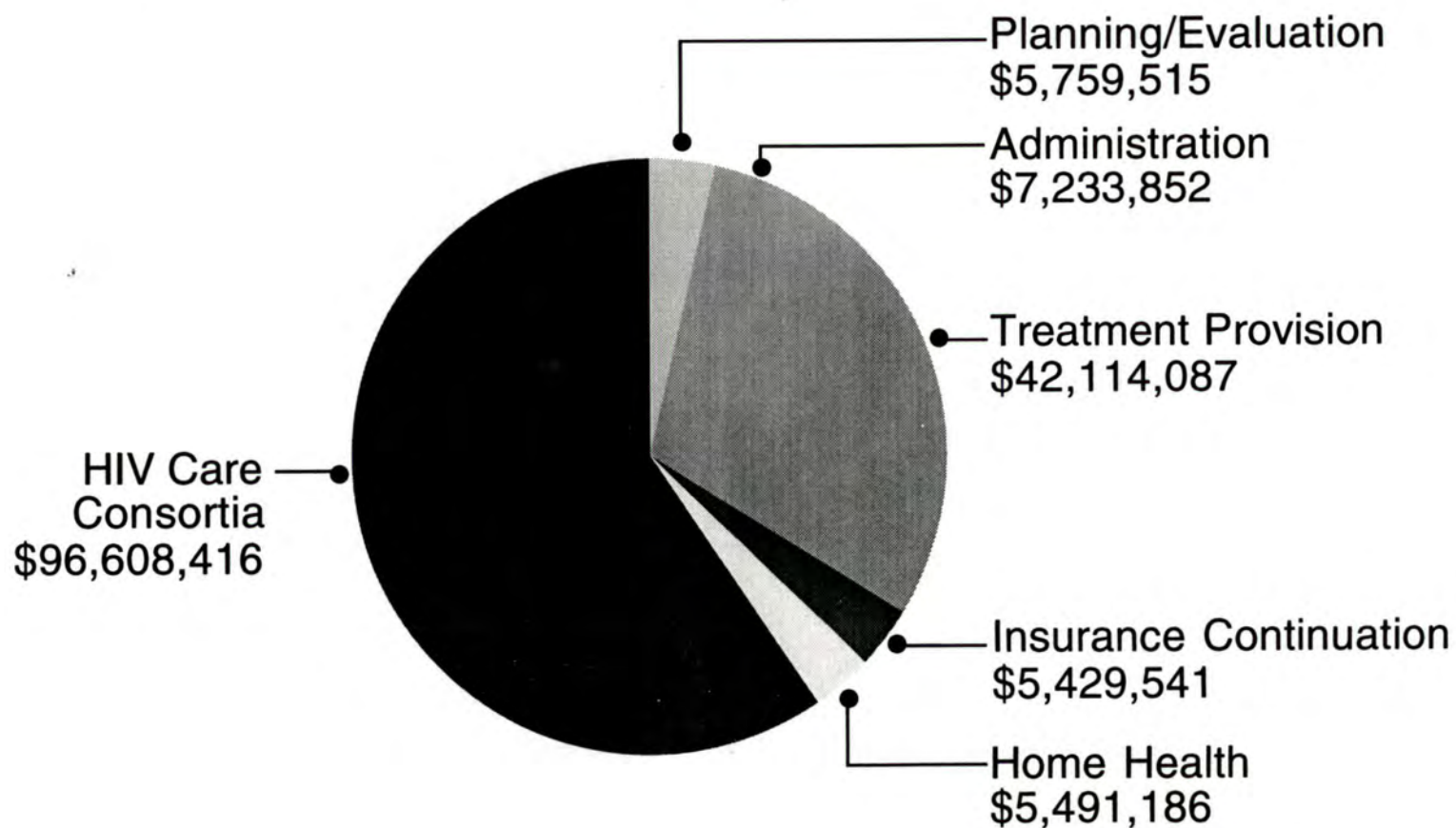
Under Title II in FY 1993:

- 42 States supported HIV care consortia
- 22 States funded home and/or community-based care programs
- 47 States/territories provided HIV/AIDS treatments
- 19 States allocated funds for the continuation of health insurance for people with HIV/AIDS.

For more information, contact:

Eric P. Goosby, M.D., Director
Division of HIV Services
Bureau of Health Resources
Development
5600 Fishers Lane, Room 7A-55
Rockville, Maryland 20857
(301) 443-6745
FAX (301) 443-8143

Title II Service Categories, FY 93



RYAN WHITE C.A.R.E. ACT - TITLE II: HIV CARE GRANTS

MARCH 25, 1994

STATE	FY 1991			FY 1992		
	FORMULA GRANT * AWARD	STATE MATCH REQUIRED (\$1 for \$5)	MINIMUM CONSORTIA AMOUNT	FORMULA GRANT AWARD	STATE MATCH REQUIRED (\$1 for \$4)	MINIMUM CONSORTIA AMOUNT
ALABAMA	\$483,388	\$0	\$0	\$636,291	\$0	\$0
ALASKA	100,000	0	0	100,000	0	0
ARIZONA	653,285	0	0	687,616	0	0
ARKANSAS	276,192	0	0	440,564	0	0
CALIFORNIA	12,953,753	2,590,751	6,476,877	15,559,171	3,889,793	7,779,586
COLORADO	727,458	0	0	832,808	0	0
CONNECTICUT	763,464	152,693	381,732	915,334	228,834	457,667
DELAWARE	151,980	0	0	173,168	0	0
DIST. OF COL.	1,094,364	218,873	547,182	1,385,438	346,360	692,719
FLORIDA	7,397,516	1,479,503	3,698,758	9,856,630	2,464,158	4,928,315
GEORGIA	2,366,100	473,220	1,183,050	2,885,813	721,453	1,442,907
HAWAII	329,429	0	0	366,974	0	0
IDAHO	100,000	0	0	100,000	0	0
ILLINOIS	2,289,116	457,823	1,144,558	2,829,336	707,334	1,414,668
INDIANA	621,522	0	0	728,781	0	0
IOWA	110,588	0	0	164,436	0	0
KANSAS	245,985	0	0	256,907	0	0
KENTUCKY	299,687	0	0	406,244	0	0
LOUISIANA	1,308,109	261,622	654,055	1,672,504	418,126	836,252
MAINE	118,205	0	0	136,527	0	0
MARYLAND	1,554,569	310,914	777,285	2,027,034	506,759	1,013,517
MASSACHUSETTS	1,454,614	290,923	727,307	1,793,707	448,427	896,854
MICHIGAN	1,046,092	209,218	523,046	1,213,083	303,271	606,542
MINNESOTA	357,781	0	0	417,361	0	0
MISSISSIPPI	488,542	0	0	590,409	0	0
MISSOURI	1,043,394	208,679	521,697	1,330,744	332,686	665,372
MONTANA	100,000	0	0	100,000	0	0
NEBRASKA	100,000	0	0	117,188	0	0
NEVADA	330,545	0	0	443,483	0	0
NEW HAMPSHIRE	100,000	0	0	104,655	0	0
NEW JERSEY	4,215,417	843,083	2,107,709	4,711,438	1,177,860	2,355,719
NEW MEXICO	203,312	0	0	254,732	0	0
NEW YORK	13,802,740	2,760,548	6,901,370	16,909,338	4,227,335	8,454,669
NORTH CAROLINA	986,337	197,267	493,169	1,253,338	313,335	626,669
NORTH DAKOTA	100,000	0	0	100,000	0	0
OHIO	1,117,823	223,565	558,912	1,373,305	343,326	686,653
OKLAHOMA	393,500	0	0	490,547	0	0
OREGON	513,063	0	0	658,551	0	0
PENNSYLVANIA	2,241,191	448,238	1,120,596	2,536,697	634,174	1,268,349
RHODE ISLAND	173,200	0	0	194,400	0	0
SOUTH CAROLINA	688,747	0	0	795,067	0	0
SOUTH DAKOTA	100,000	0	0	100,000	0	0
TENNESSEE	605,992	0	0	737,498	0	0
TEXAS	5,731,924	1,146,385	2,865,962	7,329,198	1,832,300	3,664,599
UTAH	199,022	0	0	234,917	0	0
VERMONT	100,000	0	0	100,000	0	0
VIRGINIA	970,120	194,024	485,060	1,351,047	337,762	675,524
WASHINGTON	1,025,356	205,071	512,678	1,322,995	330,749	661,498
WEST VIRGINIA	127,689	0	0	153,234	0	0
WISCONSIN	354,601	0	0	459,433	0	0
WYOMING	100,000	0	0	100,000	0	0
GUAM	2,954	0	0	4,323	0	0
PUERTO RICO	4,716,952	0	2,358,476	5,681,717	0	2,840,859
VIRGIN ISLANDS	38,397	0	0	27,019	0	0
PACIFIC TRUST	0	0	0	0	0	0
TOTAL GRANTS	\$77,474,015	\$12,672,400	\$34,039,479	\$95,151,000	\$19,564,038	\$41,968,934
Other Setasides	10,356,985			12,498,000		
Appropriation	\$87,831,000			\$107,649,000		

HRSA/BHRD/FMB

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* Combined Drug Reimbursement and
HIV CARE grants.

RYAN WHITE C.A.R.E. ACT - TITLE II: HIV CARE GRANTS

MARCH 25, 1994

STATE	FY 1993			FY 1994			FY91-94 TOTAL FORMULA GRANTS
	FORMULA GRANT AWARD **	STATE MATCH REQUIRED (\$1 for \$3)	MINIMUM CONSORTIA AMOUNT	FORMULA GRANT AWARD	STATE MATCH*** REQUIRED (\$1 for \$2)	MINIMUM CONSORTIA AMOUNT	
ALABAMA	\$938,176	\$0	\$0	\$1,421,553	\$0	\$0	\$3,479,408
ALASKA	100,000	0	0	100,000	0	0	400,000
ARIZONA	751,528	0	0	1,855,383	371,077	927,692	3,947,812
ARKANSAS	528,077	0	0	821,978	0	0	2,066,811
CALIFORNIA	17,183,378	5,727,793	8,591,689	28,172,762	14,086,381	14,086,381	73,869,064
COLORADO	937,655	0	0	1,794,570	358,914	897,285	4,292,491
CONNECTICUT	1,068,399	356,133	534,200	2,246,095	1,123,048	1,123,048	4,993,292
DELAWARE	229,208	0	0	515,066	0	0	1,069,422
DIST. OF COL.	1,441,594	480,531	720,797	2,155,767	1,077,884	1,077,884	6,077,163
FLORIDA	11,228,316	3,742,772	5,614,158	16,361,686	8,180,843	8,180,843	44,844,148
GEORGIA	3,124,415	1,041,472	1,562,208	4,527,285	2,263,643	2,263,643	12,903,613
HAWAII	371,756	0	0	545,494	0	0	1,613,653
IDAHO	100,000	0	0	130,115	0	0	430,115
ILLINOIS	3,598,455	1,199,485	1,799,228	5,363,921	2,681,961	2,681,961	14,080,828
INDIANA	753,940	0	0	1,394,908	0	0	3,499,151
IOWA	215,475	0	0	333,799	0	0	824,298
KANSAS	324,039	0	0	605,134	0	0	1,432,065
KENTUCKY	467,575	0	0	641,709	0	0	1,815,215
LOUISIANA	1,844,076	614,692	922,038	2,494,411	1,247,206	1,247,206	7,319,100
MAINE	121,410	0	0	205,421	0	0	581,563
MARYLAND	2,130,393	710,131	1,065,197	3,625,966	1,812,983	1,812,983	9,337,962
MASSACHUSETTS	1,837,845	612,615	918,923	3,501,905	1,750,953	1,750,953	8,588,071
MICHIGAN	1,486,048	495,349	743,024	2,874,019	1,437,010	1,437,010	6,619,242
MINNESOTA	501,656	0	0	970,420	0	0	2,247,218
MISSISSIPPI	546,105	0	0	900,115	0	0	2,525,171
MISSOURI	1,459,224	486,408	729,612	2,716,091	1,358,046	1,358,046	6,549,453
MONTANA	56,197	0	0	100,000	0	0	356,197
NEBRASKA	146,689	0	0	292,135	0	0	656,012
NEVADA	531,149	0	0	924,894	0	0	2,230,071
NEW HAMPSHIRE	102,372	0	0	160,060	0	0	467,087
NEW JERSEY	4,505,948	1,501,983	2,252,974	6,650,657	3,325,329	3,325,329	20,083,460
NEW MEXICO	259,454	0	0	485,763	0	0	1,203,261
NEW YORK	17,618,806	5,872,935	8,809,403	26,126,095	13,063,048	13,063,048	74,456,979
NORTH CAROLINA	1,366,064	455,355	683,032	1,996,053	998,027	998,027	5,601,792
NORTH DAKOTA	19,872	0	0	100,000	0	0	319,872
OHIO	1,476,544	492,181	738,272	2,519,172	1,259,586	1,259,586	6,486,844
OKLAHOMA	512,925	0	0	1,133,726	0	0	2,530,698
OREGON	675,020	0	0	1,170,946	0	0	3,017,580
PENNSYLVANIA	2,849,791	949,930	1,424,896	4,421,998	2,210,999	2,210,999	12,049,677
RHODE ISLAND	210,219	0	0	452,600	0	0	1,030,419
SOUTH CAROLINA	763,896	0	0	2,091,875	418,375	1,045,938	4,339,586
SOUTH DAKOTA	100,000	0	0	100,000	0	0	400,000
TENNESSEE	905,045	0	0	1,675,354	0	0	3,923,889
TEXAS	7,078,303	2,359,434	3,539,152	11,813,825	5,906,913	5,906,913	31,953,250
UTAH	304,258	0	0	511,096	0	0	1,249,293
VERMONT	100,000	0	0	100,000	0	0	400,000
VIRGINIA	1,430,800	476,933	715,400	2,403,511	1,201,756	1,201,756	6,155,478
WASHINGTON	1,270,740	423,580	635,370	2,262,586	1,131,293	1,131,293	5,881,677
WEST VIRGINIA	135,148	0	0	173,904	0	0	589,975
WISCONSIN	481,719	0	0	1,069,752	0	0	2,365,505
WYOMING	44,037	0	0	100,000	0	0	344,037
GUAM	3,379	0	0	3,379	0	0	14,035
PUERTO RICO	6,121,433	0	3,060,717	7,521,643	0	3,760,822	24,041,745
VIRGIN ISLANDS	36,048	0	0	68,703	0	0	170,167
PACIFIC TRUST	0	0	0	0	0	0	0
TOTAL GRANTS	\$102,394,599	\$27,999,713	\$45,060,286	\$162,705,300	\$67,265,275	\$72,748,646	\$437,724,914
Other Setasides	12,893,801			21,191,700			56,940,486
Appropriation	\$115,288,400			\$183,897,000			\$494,665,400

HRSA/BHRD/FMB
[Printed: 3/25/94 at 12:13 pm]

** With offsets, total budgets for Montana,
North Dakota & Wyoming. at \$100,000.

*** First year match for Arizona, Colorado,
and South Carolina at \$1 for \$5.

SPNS: FACT SHEET

SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE BACKGROUND INFORMATION

PROGRAM DESCRIPTION

The Special Projects of National Significance (SPNS) program supports the demonstration and evaluation of innovative HIV health and support service delivery models. SPNS utilizes the competitive grant proposal process, in accordance with the U.S. Public Health Service regulations, to assure the equitable distribution of discretionary funds. SPNS is administered by the Bureau of Health Resources Development, an operating unit within the Health Resources and Services Administration (HRSA)¹. The authority to operate SPNS is cited in Title II, Section 2618 (a) of the Ryan White Comprehensive AIDS Resources Emergency (C.A.R.E.) Act of 1990 (Public Law 101-381).

PROGRAM GOALS

SPNS projects must endeavor to meet the following three program goals:

- (1) to evaluate project effectiveness;
- (2) to appraise and specify the innovative aspects of the project; and
- (3) to determine the potential for the project's replicability in either similar locations or on a national level.

To meet these goals, the SPNS program requires an appropriate and strong program evaluation component to the proposed project and the public dissemination of the evaluation findings.

FUNDING HISTORY

As specified in the Ryan White C.A.R.E. Act, the Secretary of DHHS may set aside up to 10 percent of Title II funds for SPNS grants. Congress' appropriation for Title II for FY 1991 resulted in \$10.9 million being designated for SPNS. Congress, though, placed two conditions on the use of the funds. First of all, a portion of the funds went to reimburse dental schools for uncompensated care provided to HIV infected patients. Secondly,

¹U. S. Public Health Service; Department of Health and Human Services (DHHS)

SPNS provided transitional funding for a group of HRSA grantees receiving HIV service delivery funds under an expiring authorization until they could be fully funded by the Ryan White C.A.R.E. Act.

Twenty-two (22) applicants received the first SPNS grants in October, 1990. Another four applicants were awarded grants from FY 1991 funds beginning April, 1991. The average annual budget for this initial group of 26 grantees was \$250,000. The SPNS program continued its support of the initial 26 projects in FY 1992 and FY 1993.

For FY 1993, approximately \$1.2 million were available for new grants. These funds were used to provide outreach and early intervention services for adolescents at high risk for HIV infection. Ten applications were approved and funded in October, 1993.

FUNDING PRIORITIES

To meet the demand for innovation in HIV/AIDS service delivery, SPNS strives to remain on the forefront of knowledge and skills in HIV service delivery--particularly as the epidemic shifts demographically. Systematic input from service providers, federal representatives, service recipients and all others involved in HIV programs is utilized in developing and prioritizing "categories" of HIV/AIDS service delivery to which SPNS funds are dedicated. These categories allow applicants creativity in program design, while fostering precise program evaluation.

During the first two years of operation, FY 1991 and FY 1992, the following categories were given funding priority:

1. Demonstration of models to increase access to care through reduction of sociocultural, financial, and transportation barriers among one of the four special population groups listed below:
 - (a) rural residents
 - (b) women, children and adolescents
 - (c) incarcerated and recently released inmates
 - (d) Native Americans/Alaskan Natives
2. Demonstration of advocacy models to reduce discrimination against people infected with HIV, assuring timely and adequate receipt of health and support services
3. Reduction of social isolation by people with HIV to improve their quality of life

4. Integration of mental health services with primary care to assure a comprehensive treatment plan

Another category was added in FY 1993 which focuses on identifying and caring for adolescents infected with or at high risk for HIV.

In establishing special project categories for FY 1994, consideration was given to the priority service areas identified in the concept paper, "Future Directions: Increasing Knowledge about Health and Support Service Delivery to People with HIV Infection."² The four major service delivery system categories that were identified are as follows:

1. Comprehensive primary care service delivery systems for people with HIV within one of several distinct environments or settings
2. Coordinated delivery of HIV health and support services to specific mobile populations in the United States, ensuring the delivery of continuous services throughout the course of HIV infection
3. Reduction of cultural, linguistic, and/or organizational barriers to care in a geographically defined area (e.g. neighborhood, community, region, state)
4. Provider training and education models that develop, test and evaluate strategies for increasing, improving or updating knowledge about HIV infection and its treatment for providers in rural areas, correctional facilities, or mental health service programs and facilities

In addition to funding programs in the new service delivery system categories, funds in FY 1994 will be used to support dissemination and refinement of previously evaluated projects. Funds will also be applied in FY 1994 towards collaborative efforts with other federal agencies in order to evaluate and improve mental health services to HIV infected persons.

²"Future Directions: Increasing Knowledge About Health and Support Service Delivery to People with HIV Disease, Proposed Priorities and Recommendations for the Special Projects of National Significance Program." Health Resources and Services Administration. Public Health Service. U.S. Department of Health and Human Services. April 1994.

SPNS encourages comments and suggestions on the operation of the program and ideas for new categories that address emerging trends in HIV/AIDS health care delivery.

SPNS PROGRAM CONTACTS

William Grace, Ph.D., Chief
George Sonsel, LCSW, Deputy Chief
Russell Brady, Project Officer

Special Projects of National Significance Branch
Office of Science and Epidemiology
Bureau of Health Resources Development
Room 7A-19, 5600 Fishers Lane
Rockville, Maryland 20857

Phone: (301) 443-9976
Fax: (301) 594-2511

***SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE
GRANTEE LISTING***

I. IMPROVE ACCESS TO HEALTH CARE

A. RURAL RESIDENTS

North Carolina Department of Environment, Health and Natural
Resources

P. O. Box 27687

Raleigh, NC 27611-7687

(919) 733-7081 FAX (919) 715-3144

Contact Persons: Hope Lucas, M.P.H.
Claudia Egelhoff

Ware County Board of Health

Southeast Health Unit

1101 Church Street

Waycross, GA 31501

(912) 285-6002 FAX (912) 285-6004

Contact Person: Helen Wildes

Missouri Department of Health

1730 E. Elm Street

Jefferson City, Missouri 65101

(314) 751-6002 FAX (314) 751-6447

Contact Person: Liz Hager-Mace

B. WOMEN, CHILDREN & FAMILIES

New York University College of Dentistry

Special Patient Care/Dental Center

Washington Square

345 East 24th Street

New York, NY 10010

(212) 998-9770/7943 FAX (212) 998-9761

Contact Person: Eugene Hittelman, Ph.D., Ed.D.

University of Miami School of Medicine
Department of Obstetrics and Gynecology
P.O. Box 016960 (D-53)
Miami, Florida 33101
(305) 547-5832 FAX (305) 325-1282
Contact Person: Dr. Mary O'Sullivan

Arecibo Municipal Government
P.O. Box 1066
Arecibo, Puerto Rico 00613
(809) 880-6944 FAX (809) 880-6944
Contact Person: Ms. Lourdes Ayende

C. CORRECTIONS

Rhode Island Department of Health
3 Capitol Hill, Room 105
Providence, RI 02908-5097
(401) 277-2320 FAX (401) 277-1272
Contact Persons: Mary Lou DiCiantis, Ph.D.
Mary Marnielli

Department of Public Safety and Correctional Services
Plaza Office Center, Suite 309
6776 Reisterstown Road
Baltimore, MD 21215--2342
(410) 764-4130 FAX (410) 764-5112
Contact Persons: Newton Kendig, M.D.
Anthony Swetz, Ph.D.

The Fortune Society, Inc.
39 West 19th Street
New York, NY 10011
(212) 206-7070 FAX (212) 366-6323
Contact Person: JoAnne Page

Family Planning Council of Southeastern PA
260 Broad Street, Suite 1900
Philadelphia, Pennsylvania 19102
(215) 985-2657 FAX (215) 732-1610
Contact Person: Alicia Beatty-Tee

D. NATIVE AMERICANS, ALASKAN, HAWAIIANS, AND AMERICAN INDIANS

National Native American AIDS Prevention Center (Headquarters)
3515 Grand Avenue, Suite 100
Oakland, California 94610
(510) 444-2051 FAX (510) 444-1593
Contact Person: Ron Rowell, M.P.H.

National Native American AIDS Prevention Center
Ahalaya HIV Case Management Project
1200 N. Walker, Suite 605
Oklahoma City, OK 73103
(405) 235-3701 FAX (405) 235-1801
Contact Person: Betty Duran

II. LEGAL AND ADVOCACY SERVICES

Indiana AIDS Action Network
3951 North Meridian Street, Suite 200
Indianapolis, IN 46208
(317) 920-3190 FAX (317) 920-3199
Contact Person: Paul Chase, J.D.

Michigan Protection and Advocacy Services
29200 Vassar Boulevard, #501
Livonia, Michigan 48152-2181
(313) 473-2990 FAX (313) 473-4104
Contact Person: Jay Kaplan

Protection and Advocacy System
1720 Louisiana N.E, Suite 204
Albuquerque, NM 87110
(505) 256-3100 FAX (505) 256-3184
Contact Person: Jim Jackson

Massachusetts AIDS Discrimination Initiative (MADI)
95 Berkeley Street, Room 651
Boston, Massachusetts 02116
(617) 482-5665 & 969-6591 FAX (617) 482-5664
Contact Person: Ms. Cynthia Gilles

III. SOCIAL ISOLATION

Henry Street Settlement
265 Henry Street
New York, NY 10002
(212) 233-5032 FAX (212) 791-5710
Contact Person: Lorraine Ahto

OUTREACH, INC.
3030 Campbellton Road, S.W.
Atlanta, Georgia 30311
(404) 346-3922 FAX (404) 346-3036
Contact Person: Ms. Sandra McDonald

IV. MENTAL HEALTH AND PRIMARY CARE

Montefiore Medical Center
Department of Family Medicine
111 East 210th Street
Bronx, New York 10467
(718) 405-4133 FAX (718) 405-4148
Contact Person: Mark Winiarski, Ph.D.

Boston City Hospital/Division of Psychiatry
ACC-4
818 Harrison Avenue
Boston, Massachusetts 02118
(617) 534-4228 FAX (617) 534-4517
Contact Person: Abraham Feingold, Psy.D.

St. Joseph's Hospital and Medical Center
703 Main Street
Patterson, New Jersey 07503
(201) 977-2595 /2073 FAX (201) 977-2479
Contact Person: Helen Isenberg

Chase-Brexton Clinic, Inc.
101 West Read Street, Suite 211
Baltimore, MD 21201
(410) 837-2050 FAX (410) 837-2071
Contact Person: David Shippee, Executive Director

Indiana Integration of Care Projects
Indiana State University
Terra Haute, Indiana 47809
(812) 237-3910 FAX (812) 237-4348
Contact Person: Michael Schuff, Ph.D.

Seattle King County Department of Health
400 Yesler Way Building, 3rd floor
Seattle, Washington 98104-2614
(206) 296-4568 FAX (206) 296-4803
**Contact Persons: Sheila Smith, Project Coordinator
Karina K. Uldall, M.D.**

National Community AIDS Partnership *
Visiting Nurse Association of America
520 South Lafayette Park Place, Suite 500
Los Angeles, CA 90057
(213) 386-7200 FAX (213) 386-4227
Contact Person: Dennee Frey

V. ADOLESCENT

University of Minnesota, Youth and AIDS Project
Adolescent Early Intervention Project
Box 721 UMHC
Minneapolis, MN 55455
(612) 626-2855, 627-6823, 627-6820
FAX (612) 626-2134
PAGER (612) 889-2122
Contact Person: Gary Remafedi, M.D., M.P.H.

* University of Minnesota, Youth and AIDS Project
Adolescent Early Intervention Project
428 Oak Grove Street
Minneapolis, MN 55403
(612) 627-6824 FAX (612) 627-6819
Contact Person: Judith A. Kahn, M.S.W.

Walden House, Inc. (Headquarters)
520 Townsend Street
San Francisco, CA 94103
(415) 554-1100 FAX (415) 554-1499
Contact Person: Brian Greenberg, Ph.D.

Walden House, Inc.
214 Haight Street
San Francisco, CA 94102
(415) 554-1480 FAX (415) 241-5599
Contact Person: Rob Burch, Ph.D.

Bay Area Young Positives, Inc.
518 Waller Street
San Francisco, CA 94117
(415) 487-1616 FAX (415) 487-1617
Contact Persons: Antigone Hodgins
Bobby Weissman

Boston, Children's Hospital
Div. of Adolescent/Young Adult Medicine
Boston Adolescent HIV Network Program/Boston HAPPENS
300 Longwood Avenue
Boston, MA 02115
(617) 735-7181 FAX (617) 739-5458
Contact Person: Elizabeth R. Woods, M.D., M.P.H.

Children's Hospital of Los Angeles
P.O. Box 54700, Mailstop #2
Los Angeles, CA 90054-0700
(213) 669-4506 FAX (213) 644-1928
Contact Person: Michelle Kipke, Ph.D.

YouthCare
333 First Avenue West
Seattle, WA 98119-4103
(206) 282-9907 x211/221 FAX (206) 282-6463
Contact Persons: Karen Frazier
Adam Tenner

Indiana Department of Health
Indiana Youth Access Project
1330 West Michigan Street
Indianapolis, IN 46206-1964
(317) 633-0893 FAX (317) 633-0663
Contact Person: Dennis Stover

University of Alabama at Birmingham School of Medicine
Department of Pediatrics/Teenage Access Project
1600 Seventh Avenue, South, Room ACC, Suite 618
Birmingham, AL 35233
(205) 934-5262 or 5252 FAX (205) 934-1150
Contact Person: Marsha S. Sturdevant, M.D.

Greater Bridgeport Adolescent Pregnancy Program
200 Mill Hill Avenue
Bridgeport, CT 06610
(203) 384-3629 FAX (203) 384-4034
Contact Person: Rudy Feudo, Ph.D.

National Community AIDS Partnership *
Youth Empowerment Services
375 Woodside Avenue, Bldg. W-3
San Francisco, CA 94127
(415) 753-7780 FAX (415) 753-7759
Contact Person: Janet Shalwitz, M.D.

Gay & Lesbian Adolescent Social Services
650 North Robertson Blvd., Suite A
West Hollywood, CA 90069
(310) 358-8727 FAX (310) 358-8721
Contact Person: Jason Wittman, M.S.W.

* National Community AIDS Partnership (Headquarters)
1140 Connecticut Avenue, N.W., Suite 901
Washington, D.C. 20036-4001
Contact Person: Paula Van Ness