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MINORITY  
HEALTH FAXES

Office of AIDS  
Research, NIH

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# FAX

DATE: July 18, 1997

TO: Sarah Bianchi / Sarah Hurwitz

FAX NUMBER: 202 456-5557

PHONE NUMBER: 202 456-5594

TOTAL NUMBER OF PAGES EXCLUDING THIS COVER SHEET: 6

FROM: Wendy Wetheimer

PHONE NUMBER: (301)496-0357

Action	Approval	<input checked="" type="checkbox"/> As Requested
Please Comment	Please Reply	For Review
Note and Return	Per Our Conversation	For Your Information

COMMENTS:


*Wetheimer*

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COMMENTS:


whose

**STATEMENT BY****WILLIAM E. PAUL, M.D.****DIRECTOR, NIH OFFICE OF AIDS RESEARCH**

Good afternoon. I am pleased to be here today to highlight AIDS research activities of the National Institutes of Health (NIH). To combat the devastating impact of HIV infection and AIDS, the nation has made a firm commitment to research on all aspects of this dread disease and has expressed support through resources the Congress has made available to the National Institutes of Health. This commitment is now reaping rewards in the form of new and more effective therapies. But these therapies are not a panacea. HIV infection still poses a major threat to our nation and to people everywhere in the world. Within the United States, our minority communities, particularly African-Americans and Hispanics, have borne a disproportionate share of this impact.

In my remarks today, I wish to highlight the progress we have made, speak to the challenges we face and particularly to address the issue of how our research effort recognizes and responds to the needs of those in our minority communities affected with this disease or at risk of infection.

As the members of the Congressional Black Caucus are well aware, a new class of anti-HIV drugs have been introduced. Used in combination with previously available drugs, the resulting highly active anti-retroviral treatment has been shown to remarkably reduce the amount of virus in an infected individual, to have a major impact on diminishing AIDS-defining events, and on helping

to restore immune function. These drugs, coupled with the availability of new techniques to measure the level of virus in the plasma and to characterize the virus, allow physicians to tailor better treatments for their patients and allow them to monitor the benefits of these therapies.

This accomplishment has been based on a combination of fundamental research supported by NIH and drugs and assay technology developed by our pharmaceutical and biotechnology industries in one of the best examples of public/private partnership that can be cited.

The Department of Health and Human Services has recently released for public comment two important documents - the Report of the NIH Panel to Define Principles of Therapy for HIV Infection and the Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents. These two documents provide doctors and their patients with the most up-to-date advice on how to use the new combinations of drugs, including when to begin therapy; when and how to switch therapies; how to monitor the course of the disease; which drugs to use in combination.

Previous NIH-supported research has shown that zidovudine can dramatically reduce the risk of transmission of HIV infection from a pregnant woman to her child. Because of our progress in the treatment of HIV, a panel was recently convened to update the guidelines for the use of AZT in pregnant women. These new guidelines have recently been released for public comment. This subject is of particular importance for our minority community since the great majority of women with AIDS and of HIV-infected infants are members of this community. The progress that has

been made, as exemplified in these guidelines, should continue to have a major benefit for our minority population and for all women at risk of transmitting HIV to their infants.

In view of the disproportionate impact of HIV on African-Americans and Hispanics, it is essential that the clinical trials that NIH supports have adequate representation of these individuals in programs. I am pleased to report that in both of the major clinical trials networks, the adult AIDS Clinical Trials Group (ACTG) and the Community Program for Clinical Research on AIDS (CPCRA), African Americans and Hispanics make up more than 40% of the participants in their trials, a proportion that quite well mirrors the fraction of total cases that occur in these two groups. Indeed, both to be certain that there has been adequate outreach to minority communities and to aid in the development of capacity for minority institutions to make a major contribution to progress against this disease, the adult ACTG has units in three minority institutions. In addition, the CPCRA is based on the philosophy of establishing units in community settings where the patients who are infected seek their primary care.

Other programs that have been organized in such a way as to obtain information of particular importance for the impact of HIV infection on members of our minority groups are the Women's Interagency HIV Study and the Women and Infant Transmission Study. Minorities represent over 82% of the participants in these two important studies.

The NIH recognizes the value of the contributions made by African American health

professionals to the conduct of research and research training. A number of NIH programs and policies are specifically designed to recruit individuals from underrepresented racial and ethnic groups into research careers. These programs provide training and research opportunities across the continuum from high school students to independent investigators, with the goal of increasing the diversity of the labor pool in all segments of health related research.

For example, for individuals at the high school, college, graduate, postdoctoral, and investigator levels, the NIH offers Research Supplements for Underrepresented Minorities. Using this program, the principal investigator on a currently funded research project can request an administrative supplement to support the salary of an individual from an underrepresented group who wishes to participate in the ongoing research.

The NIH has implemented a number of programs to enhance participation of minority clinical investigators, for example, the AIDS Loan Repayment Program, the loan repayment program for individuals from disadvantaged backgrounds, the Howard Hughes Medical Institute (HHMI) training program for early recruitment into clinical research careers, and the Minority Clinical Associate Physician (MCAP) Program at the NIH National Center for Research Resources.

I wish to close my comments on an issue that is of special concern to all who are at risk of contracting this infection. Today, in the United States, as I have already stated, that is disproportionately a population of minority group members. However, HIV infection takes an even greater toll throughout the world. Its impact in subSaharan Africa has been truly

devastating, with mean life expectancies in many of these nations being reduced by twenty years or more. The most important advance that could be made would be to find safe and effective means of preventing transmission. NIH has emphasized many aspects of prevention research. In its behavioral research program, it has laid particular stress on the need for culturally sensitive approaches.

But perhaps the most effective and most durable contribution that could be made would be the development of a truly effective preventive vaccine. President Clinton has challenged us to develop such a vaccine within the next decade. To meet this challenge and to meet the recommendations of outside experts who have recently reviewed the NIH AIDS research program, we have taken three major steps. We have increased the proportion of our resources that are devoted to vaccine research. In the period between 1996 and the budget the President submitted for 1998, AIDS vaccine funding will have increased by more than 33%.

Dr. David Baltimore, a Nobel laureate and President-designate of Cal Tech, has been recruited to provide leadership for the restructuring and reinvigoration of the AIDS vaccine research program through his role as chair of the AIDS Vaccine Research Committee.

The President also announced the creation of the Vaccine Research Center on the NIH campus to mobilize the very considerable scientific resources of this premier medical research institution to the development of an AIDS vaccine, particularly through the development of entirely new and novel approaches to this end.

Much has been accomplished but much more remains to be done. We are grateful for the support

of the Congress and particularly for the thoughtful and enlightened backing that members of the Black Caucus have given to this research program. It is our intention that these resource be used as well as possible to confront this disease and particularly to grapple with its impact in our minority community.

I will be happy to answer any questions you may have.

William E. Paul  
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# COVER LETTER

DATE 07/28 16:05

TO: 2024565557  
FROM:  
TEL NO.

TOTAL PAGES 008 ( INCLUDE THIS PAGE )

**National Heart, Lung and Blood Institute**  
**OFFICE OF SCIENCE AND TECHNOLOGY**

**FAX TRANSMISSION**



DATE: Monday, 7/28/97

PAGES: 17 plus cover sheet

TO: SARAH HURWITZ

FAX #: 202-456-<sup>7431</sup>~~3000~~

FROM: \_\_\_\_\_

CALL (301) 496-

OR FAX (301) 402-1056

COMMENTS: Asthma data, as requested

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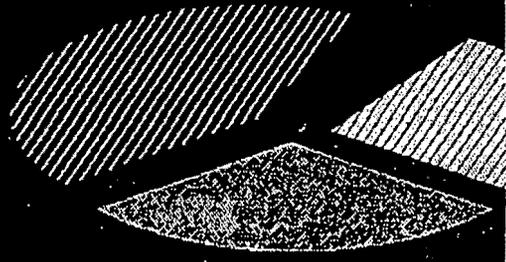
Table 2  
Prevalence of Asthma from the National Health Interview Survey  
United States, 1991-1993

Age	Numbers in thousands					Prevalence per 1,000 Population				
	Total	Male	Female	White	Black	Total	Male	Female	White	Black
Total	12,394	5,729	6,665	10,194	1,831	49.3	46.9	51.6	48.6	58.2
<18	4,360	2,031	1,749	3,337	875	65.9	77.3	53.9	62.9	82.8
18-44	4,612	1,892	2,720	3,875	595	43.6	36.4	50.6	44.4	44.7
45-64	2,115	746	1,369	1,831	253	43.6	32.0	54.3	43.9	50.6
65-74	830	317	513	737	66	45.0	38.3	50.3	44.9	40.2
75-84	367	129	238	325	42	37.6	33.6	40.1	36.8	54.1
85+	90	13	77	90	0	35.2	16.7	43.4	38.8	0.0
65+	1,286	459	827	1,152	108	41.8	35.6	46.2	41.8	41.2
LIA	2,791	1,291	1,500	2,095	588	11.1	10.6	11.6	10.0	18.7
% LIA	22.5	22.5	22.5	20.6	32.1	—	—	—	—	—

Note: Estimates below 64,000 are statistically unreliable as are rates based on those numbers.

LIA: Limited in activity.

Source: Unpublished person count estimates furnished on 6/28/95 from Gary Collins  
National Health Interview Survey, National Center for Health Statistics.



FACT BOOK  
FISCAL YEAR  
1996

*fact book*



- Except for an increase in the percent of the population who are overweight, the prevalence of high cholesterol, hypertension, and smoking declined appreciably (p. 41).
- Hypertension is a highly prevalent condition that is more common in blacks than in whites (p. 41).
- The percent of hospitalized CVD patients who were discharged dead declined markedly between 1974 and 1994 (p. 42).
- The estimated economic cost of CVD is expected to be \$259 billion in 1997:
  - \$158 billion in direct health expenditures.
  - \$25 billion in indirect cost of morbidity.
  - \$76 billion in indirect cost of mortality (p. 44).
- Asthma is the fourth leading chronic condition causing bed disability days (p. 40).
- Asthma and chronic bronchitis are present in at least 5 percent of the population in each age group from childhood to adulthood (p. 42).
- Among 28 industrialized countries, the United States ranked 12th for COPD mortality in men ages 35 to 74 years and 7th in women in that age group in 1993 (p. 43).
- Between 1984 and 1994, the prevalence of asthma increased for all age groups (p. 43). Presently, 14.6 million Americans have the disease.
- The estimated economic cost of these lung diseases is expected to be \$114.7 billion in 1997:
  - \$78 billion in direct health expenditures.
  - \$20 billion in indirect cost of morbidity.
  - \$16 billion in indirect cost of mortality (p. 44).

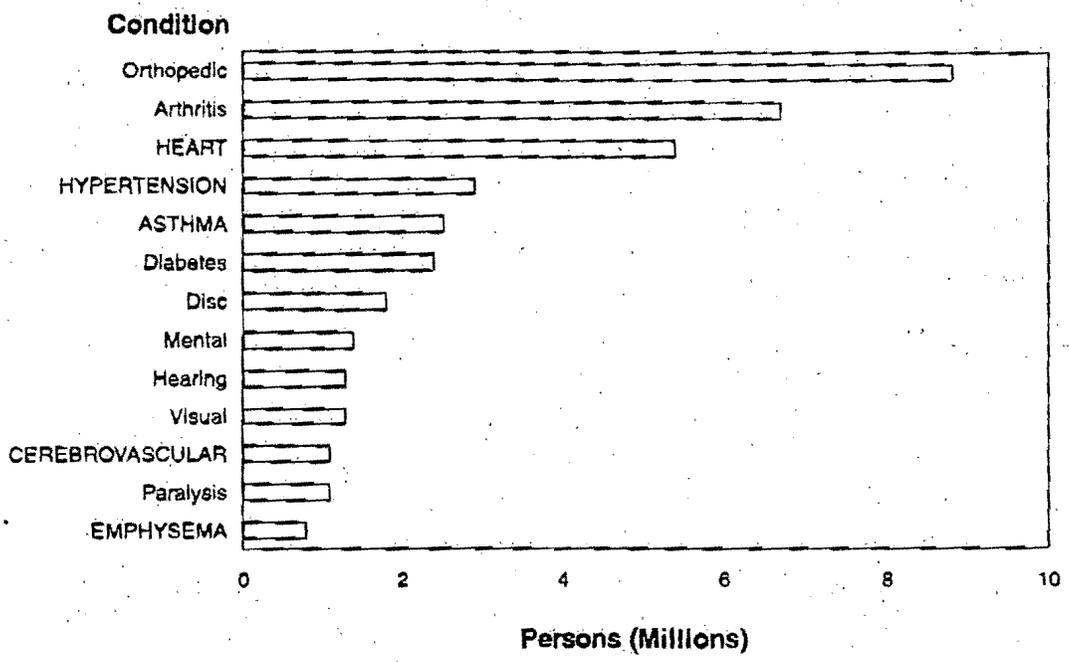
#### Lung Diseases

- Lung diseases, excluding lung cancer, caused an estimated 228,000 deaths in 1995 (p. 31).
- Chronic obstructive pulmonary disease caused 99,000 deaths in 1995 and is the fourth leading cause of death (pp. 32, 33).
- The four leading causes of infant mortality are lung diseases or have a lung disease component; rates declined between 1985 and 1995 for three of them:
  - Congenital anomalies (-26%).
  - Sudden infant death syndrome (-40%).
  - Respiratory distress syndrome (-62%).
  - Disorders relating to short gestation (+13%) (p. 34).
- Lung diseases account for 46 percent of all deaths under 1 year of age in 1994 (p. 34).
- Between 1985 and 1995, the total death rate for COPD increased by 13 percent in contrast with declines for other major causes except lung cancer (p. 35); however, the age-specific trend in COPD is downwards for men under age 75 years and for women under age 45 years (not shown).
- Between 1984 and 1994, the percent increase in death rate for COPD and asthma was greater in women than in men (p. 35).
- Asthma and emphysema are among the leading chronic conditions causing limitation of activity (p. 40).

#### Blood Diseases and Resources

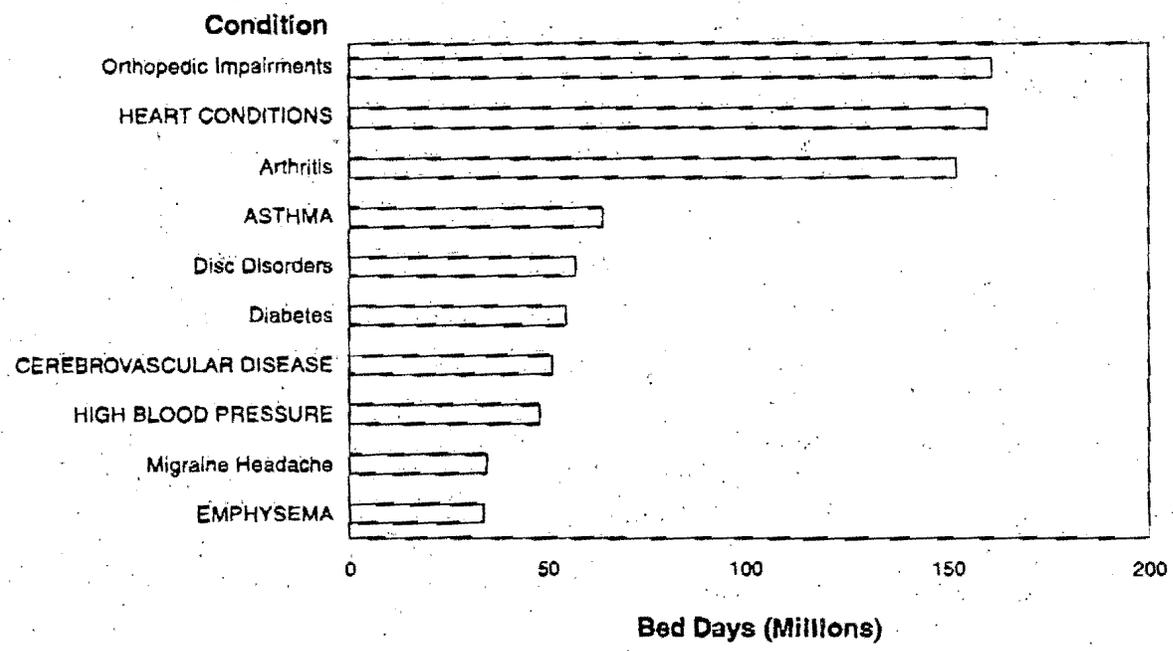
- An estimated 268,000 deaths, 12 percent of all deaths, were attributed to diseases of the blood in 1995. This includes:
  - 259,000 due to blood-clotting disorders.
  - 7,000 due to diseases of the red blood cell.
  - 2,000 due to bleeding disorders (pp. 31, 32).
- A large proportion of the deaths from acute myocardial infarction and cerebrovascular disease involve blood-clotting problems (p. 32).
- In 1997, blood-clotting disorders will cost the Nation's economy \$64 billion, and other blood diseases will cost \$10 billion (p. 44).
- In 1989, 13 million units of blood were collected from almost 9 million donors (not shown).
- In 1989, approximately 20 million units of blood products were transfused to 4 million patients (not shown).

### Prevalence of Leading Chronic Conditions Causing Limitation of Activity, U.S., 1990-92



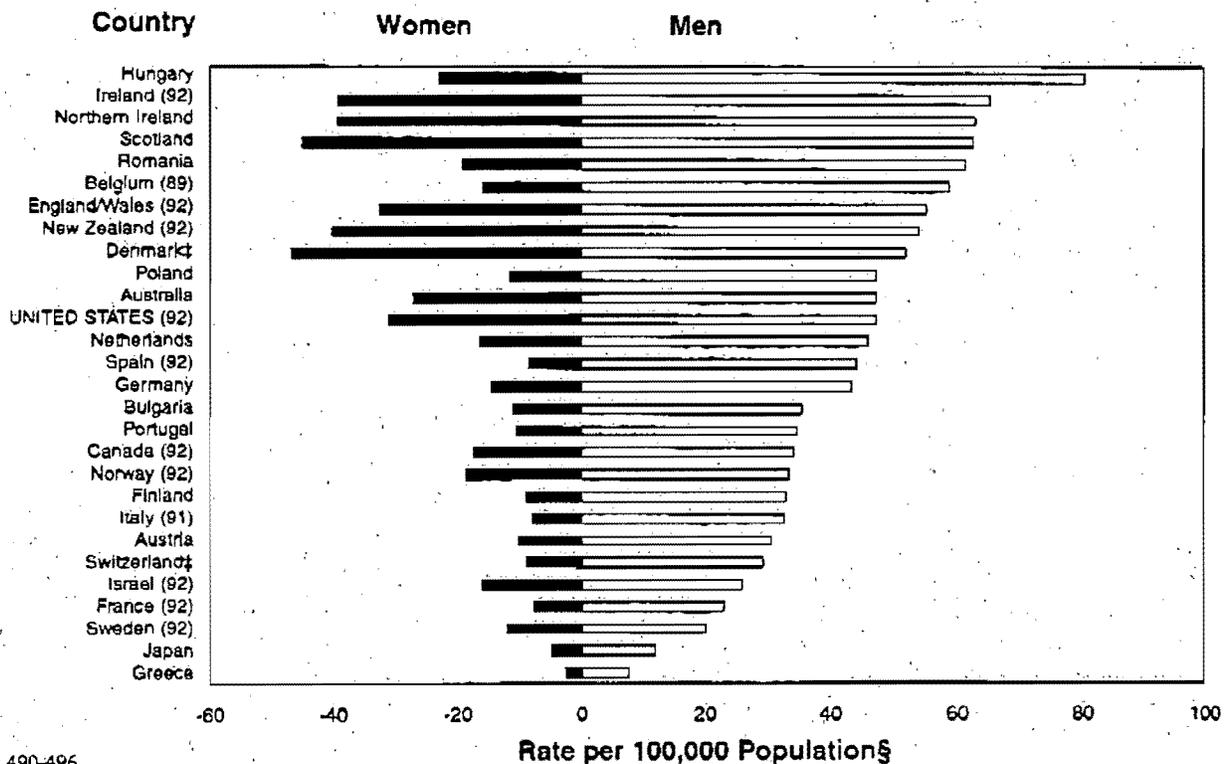
Note: Capitalization indicates diseases addressed in Institute programs.  
 Source: National Health Interview Survey (NHIS), NCHS.

### Leading Chronic Conditions Causing Bed Disability, U.S., 1990-92



Note: Capitalization indicates diseases addressed in Institute programs.  
 Source: NHIS, NCHS.

### Death Rates for Chronic Obstructive Pulmonary Disease and Allied Conditions\* by Gender, Ages 35-74 Years, Selected Countries, 1993†



\* ICD/9 codes 490-496.

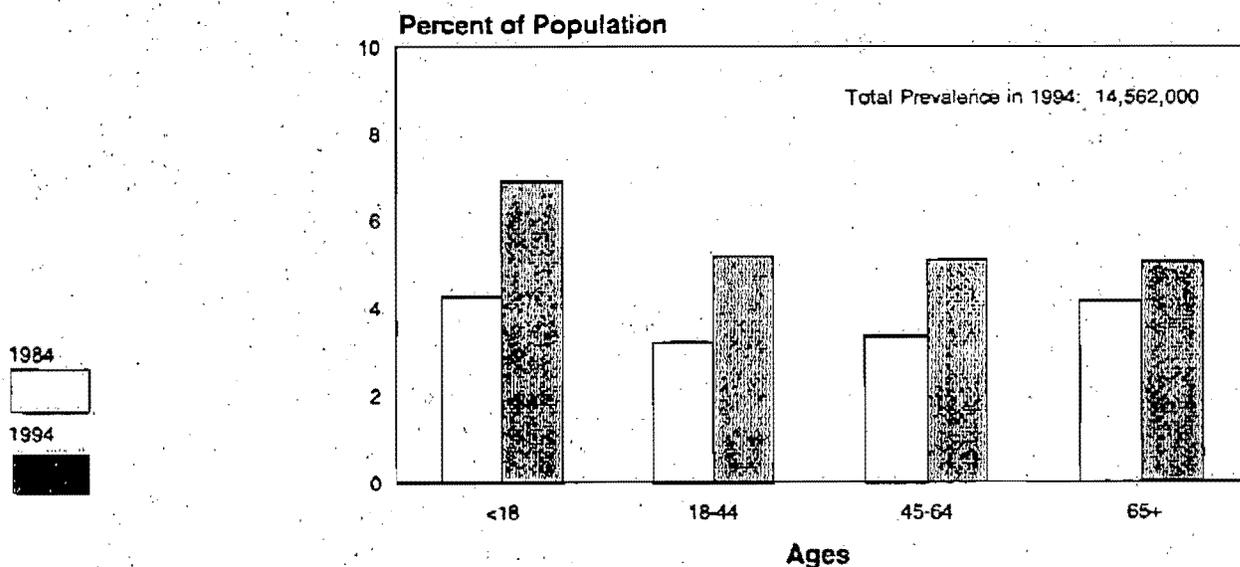
† Years may vary as indicated.

‡ ICD/8 codes 490-493.

§ Rates are age adjusted to the European standard population.

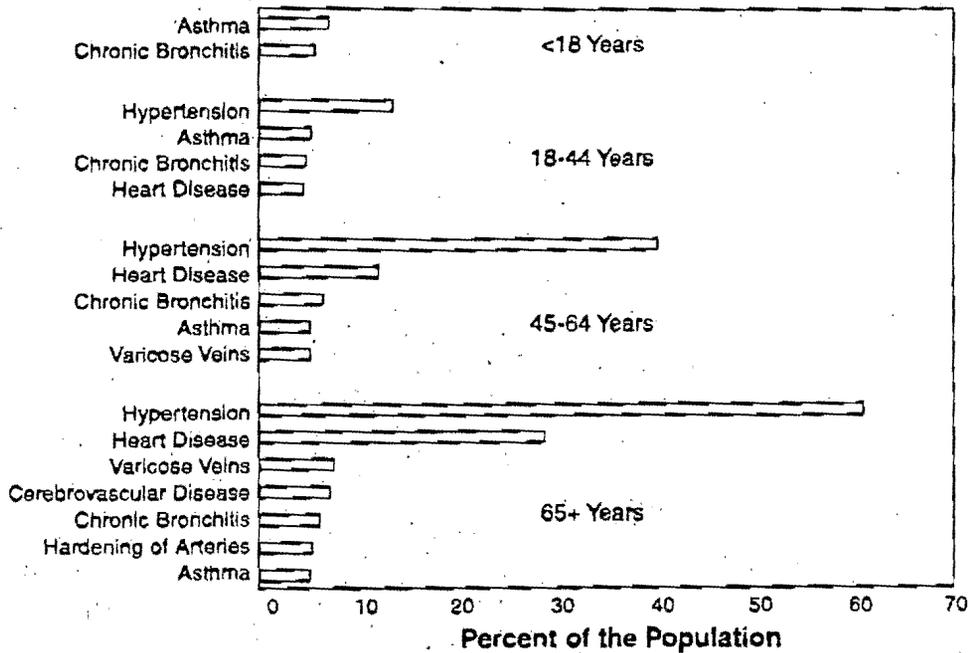
Source: Published and unpublished data from WHO.

### Prevalence of Asthma by Age, U.S., 1984 and 1994



Source: NHIS, NCHS.

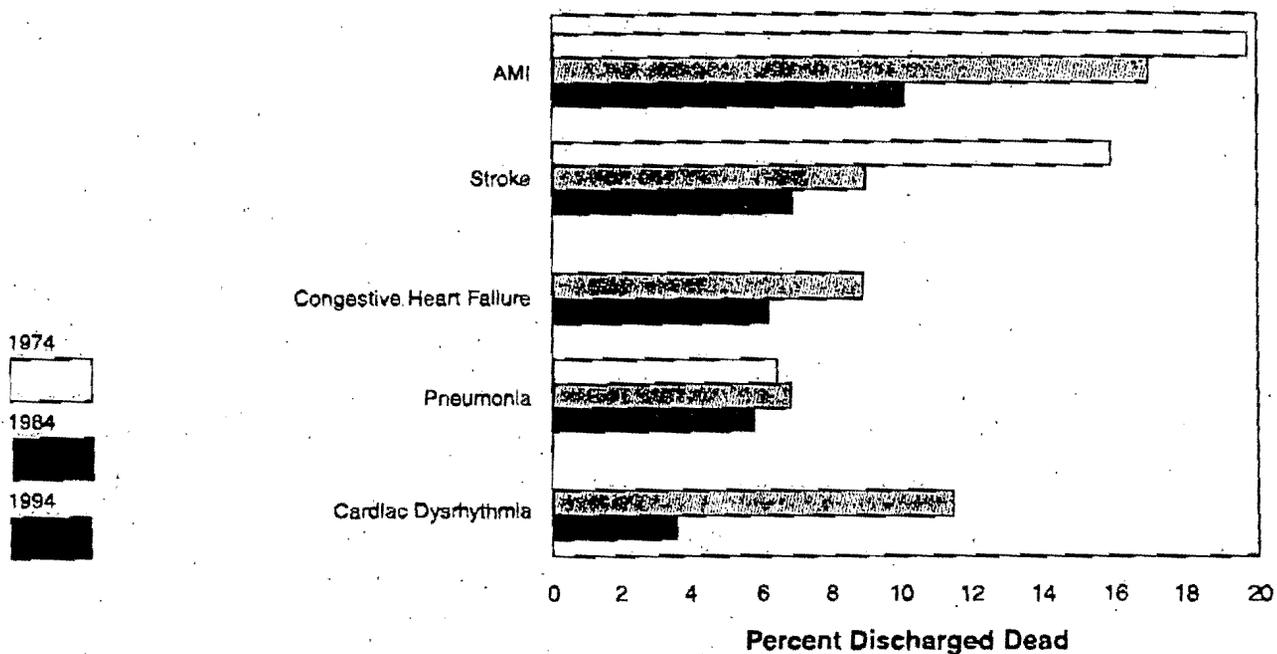
### Prevalence of Common Cardiovascular and Lung Diseases by Age, U.S., 1994



Note: Each estimate for heart disease refers to the number of persons with one or more forms: coronary, arrhythmic, other. Numbers depicted in bars are not additive by disease because some persons have more than one disease.

Source: NHIS and, for hypertension, National Health and Nutrition Examination Survey, NCHS.

### Common Cardiovascular and Lung Diseases With High Percentage Discharged Dead From Hospitals, U.S., 1974, 1984, 1994



Source: National Hospital Discharge Survey, NCHS.

of activities across the continuum of biomedical research, with an emphasis on fundamental mechanisms. Multidisciplinary programs are supported to advance basic knowledge of disease and to generate the most effective methods of clinical management and prevention. Clinical trials, which are an important part of the research program, provide an opportunity to test and apply promising preventive or therapeutic measures.

Arteriosclerosis, CHD, and hypertension were areas of major emphasis within the Division's research program in fiscal year (FY) 1996. Examples of newly supported programs include those that focus on research in gene-nutrient interactions in the pathogenesis of congenital heart defects, etiology of excess CVD in diabetes mellitus, angiogenesis and vascular remodeling in the microvasculature, and innovative ventricular assist systems. Additional examples are Specialized Centers of Research (SCORs) that examine genetic determinants of high blood pressure; ischemic heart disease, sudden cardiac death, and heart failure; and ischemic heart disease in blacks. Solicitations of applications were issued for research on the elucidation of mechanisms responsible for myocardial dysfunction, specifically those involved in the transition from cardiac hypertrophy to overt heart failure; and for research on atherosclerotic lesions using human tissues. The Division provides significant support to minority institutions through such research career and training programs as the Minority National Research Service Award, Minority School Faculty Development Award, Research Development Award for Minority Faculty, and Short-Term Research Training for Minority Students Award.

### Division of Lung Diseases

Lung diseases are among the leading causes of death and disability in the United States. More than 25 million persons have chronic bronchitis, emphysema, asthma, or other obstructive or interstitial lung diseases. Pulmonary diseases accounted for 26 percent of all hospitalizations of children under 15 years of age in the United States in 1994.

As an underlying cause, lung diseases, excluding cancer, account for 228,000 deaths annually, and lung diseases are a contributing cause to

perhaps an equal number of additional deaths. The lung disease problems addressed by the Institute will cost the Nation about \$115 billion in 1997, of which \$78 billion will be for health expenditures and \$37 billion will be for lost productivity.

The DLD plans and directs a coordinated research program on the causes of lung diseases and on their prevention, diagnosis, and treatment. Its activities focus on understanding the structure and function of the respiratory system, increasing fundamental knowledge of mechanisms associated with specific pulmonary disorders, and applying new findings to evolving treatment strategies for patients.

The NHLBI established six centers for gene therapy in FY 1993. Presently, the centers are focusing mainly on cystic fibrosis (CF) research but include other areas associated with gene therapy for heart, lung, and blood diseases. Basic, preclinical, and clinical studies are directed toward developing safe, efficient, and efficacious vehicles for delivering genes to appropriate target cells. Basic science and clinical findings are identifying new directions needed to generate improved gene transfer vectors, to manage the inflammatory and immune consequences of vector transfer, and to develop alternative vector systems. A grant program was initiated to stimulate research on the molecular pathogenesis and pathophysiology of CF and to develop new approaches to therapy. Several grants were cofunded with the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

Asthma research is an area of high priority for the Division. The DLD supports a collaborative multicenter study in human pedigrees from various racial/ethnic groups to identify the major genes responsible for asthma. With recruitment near completion, gene mapping studies have been initiated. Identification of the genes important to asthma will facilitate development of new modes of treatment and will lead to an understanding of causal interactions between genes and environmental factors that are relevant in asthma. In 1996, the Division sponsored two workshops on asthma prevention to stimulate research in this critical area. It supports several research programs designed to develop and evaluate effective strategies for improving asthma care among Latino and black children, who

appear to suffer disproportionately from the disease. Some of the findings from this research were recently published in the document *Asthma Management in Minority Children: Practical Insights for Clinicians, Researchers, and Public Health Planners*.

Additional asthma research projects involving children include a 5-year, multicenter clinical trial to examine the long-term effects of three different asthma medications on 1,000 children and a study to develop and evaluate innovative approaches to ensure optimal disease management and prevention in the elementary school setting. The DLD is also participating in a collaborative study with the National Institute of Child Health and Human Development (NICHD) to determine the effects of asthma and its treatment on pregnancy and the effects of pregnancy on asthma.

The Division supports an asthma clinical research network of interactive asthma clinical research groups to rapidly assess novel treatment methods and to ensure that these findings on optimal management of asthmatic patients are rapidly disseminated to practitioners and health care professionals. One trial is investigating the long-term effects of two short-acting beta-agonist treatment regimens and another is studying the use of colchicine in moderate asthma. Additional clinical trials are examining the effectiveness and side effects of a long-acting beta-agonist and corticosteroids.

To promote the application of scientific findings in the clinical setting, the Division prepared a report on the diagnosis and management of asthma in the elderly. Currently, it is preparing an update of the *National Asthma Education and Prevention Program's Expert Panel Report on Asthma Management*. A report entitled *Global Strategy for Asthma Management and Prevention* was published in FY 1995 as part of a collaboration between the NHLBI and the World Health Organization (WHO); a followup series of practical guides was published in FY 1996. With its international partners, the DLD is participating in the organization of "Global Initiative for Asthma," a program to increase awareness of asthma and its public health consequences, promote the study of the association between asthma and the environment, and reduce asthma morbidity and mortality throughout the world.

Smoking-related diseases are a major cause of mortality and morbidity in the United States. Division-supported research in this area includes a randomized trial on the effect of inhaled corticosteroids on the natural history of lung function in continuing smokers.

Acquired immunodeficiency syndrome (AIDS) and tuberculosis (TB) research are also important areas of investigation for the Division. Specific programs include a clinical study of cardiopulmonary complications of HIV infection in infants and children and several programs to address the pathobiology of *pneumocystis carinii*, the basic cell biology of pulmonary manifestations of AIDS, the development of lung-specific drug delivery systems for enhanced TB treatment, and behavioral interventions for control of TB. A new program started in FY 1996 will support research on cellular and molecular events involved in the regulation of HIV activation in the lung. Microbial and other cofactors, cytokines, and chemokines that allow HIV to remain quiescent in lung cells and those that stimulate viral replication are being investigated.

Several newly initiated programs include a prospective randomized clinical trial to assess innovative treatment methods in patients at risk for developing adult respiratory distress syndrome; an epidemiological study to investigate causes and environmental and genetic risk factors for sarcoidosis; a study of causes of noninfectious pneumonia, an often fatal complication of bone marrow transplantation; and a multi-institutional collaboration to create a molecular profile of bronchopulmonary dysplasia that will provide insight into the condition and offer directions for developing new reagents for clinical interventions.

The Division supports several other activities. Examples include research training and career development programs to provide postdoctoral opportunities to beginning investigators, prevention programs to extend important services to communities, and demonstration and education activities to transfer basic research and clinical findings to health care professionals and patients.

Support for all the activities of the Division constitute not less than 15 percent of the funds allocated to the NHLBI, as required by legislation.

### Division of Blood Diseases and Resources

Blood diseases, including both acute and chronic disorders, resulted in 268,000 deaths in 1995; 259,000 of them were due to thrombotic disorders and 9,000 were due to diseases of the red blood cells and bleeding disorders. In 1997, thrombotic disorders and other blood diseases will cost an estimated \$74 billion, of which \$45 billion will be for health expenditures and \$29 billion for lost productivity. Blood resources include nearly two dozen products derived from more than 14 million units of whole blood collected from almost 9 million American donors that are subsequently transfused annually to patients. In 1992, an estimated 23 million units of blood products were transfused to 5 million patients. Adverse effects following blood transfusion include development of hepatitis C—the risk being about 1:103,000 per unit of blood or blood product transfused. The risk of being infected with HIV is estimated to be 1:493,000 per unit. Universal screening of donor blood for antibodies to human immunodeficiency virus (HIV) began in 1985, and universal screening for antibodies to hepatitis C virus began in 1990. The screening tests, which have been improved over the years, have greatly reduced the risk of infection to transfusion recipients.

The DBDR develops, administers, and coordinates programs that will reduce morbidity and mortality caused by blood diseases and lead to their primary prevention. These programs include hemophilia, Cooley's anemia, sickle cell disease, and disorders of hemostasis and thrombosis. The Division also has a major responsibility to ensure the adequacy and safety of the Nation's blood supply. A full range of activities, including studies of transmission of disease through transfusion, development of methods to inactivate viruses in donated blood, improvement of blood donor screening procedures, research to reduce human error in transfusion medicine, and studies of emerging diseases that may be transmitted by blood transfusion, are used to achieve this goal.

Finding an effective therapy for sickle cell disease remains a high priority. Despite progress in the area of treatment for the disease, no universally effective therapeutic agent exists. The drug hydroxyurea, although promising, may have long-term side effects, and its safety and efficacy in children are unknown. Following the

announcement of an RFA in 1996, eight highly meritorious applications were awarded in areas such as computer-generated antisickling compounds, removal of pathological iron from sickle red blood cells, methods for gene transfer, and transgenic models of sickle cell disease.

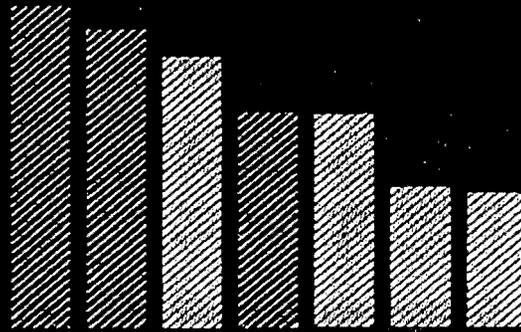
Dissemination of research findings to the medical community through workshops, conferences, and consensus development conferences is an important function of the Division. Topics covered include plasma transfusion, platelet transfusion therapy, diagnosis of deep-vein thrombosis, impact of routine HIV antibody testing of blood and plasma donors on public health, infectious disease testing for blood transfusions, stem cell therapy, and immune function in sickle cell disease.

To meet its overall responsibilities, the Division maintains an integrated and coordinated program of grants, contracts, training and career development awards, and academic awards. SCORs in thrombosis, transfusion medicine, and hematopoietic stem cell biology and Comprehensive Centers in sickle cell disease are currently being supported.

### Division of Epidemiology and Clinical Applications

The DECA has the primary responsibility for epidemiologic studies, clinical trials, prevention studies, and demonstration and education research in heart and vascular, lung, and blood diseases and for basic and applied research in behavioral medicine. The Division identifies research opportunities; stimulates and conducts research on the causes, prevention, diagnosis, and treatment of these diseases; and assesses the need for technologic development in the acquisition and application of research findings in these areas. It evaluates and uses basic and clinical research findings in defined populations (such as occupational groups, school children, health professionals, and minorities) and community settings, with an emphasis on studies of primary and secondary prevention in nonhospitalized patients or populations.

Understanding the significant role that risk factors have in the development of CVD is a major focus of the Division. Epidemiological studies of CVD risk factors in Native Americans and middle-aged blacks, population-based



MORBIDITY &  
 MORTALITY:  
 1996 CHARTBOOK  
 ON CARDIOVASCULAR,  
 LUNG, AND BLOOD  
 DISEASES

*chartbook*

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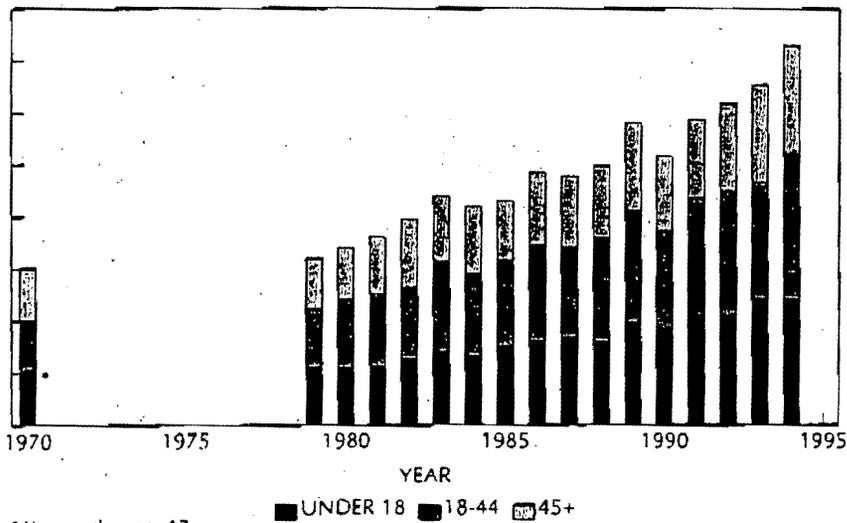
*chartbook*



# Asthma

**CHART 4-15**  
**PREVALENCE OF ASTHMA BY AGE,**  
**NHIS, U.S., 1970-1994**

PREVALENCE (MILLIONS)

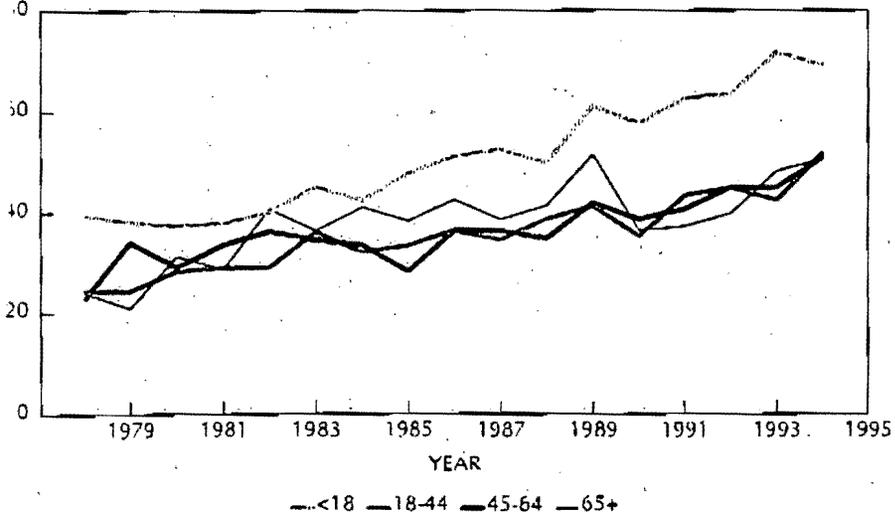


\* Younger than age 17.

Total prevalence of asthma increased appreciably between 1979 and 1994, reaching 14.6 million persons in 1994. The increase occurred in all three age groups shown.<sup>13,35,42</sup>

**CHART 4-16**  
**PREVALENCE RATE OF ASTHMA**  
**BY AGE, NHIS, U.S., 1978-1994**

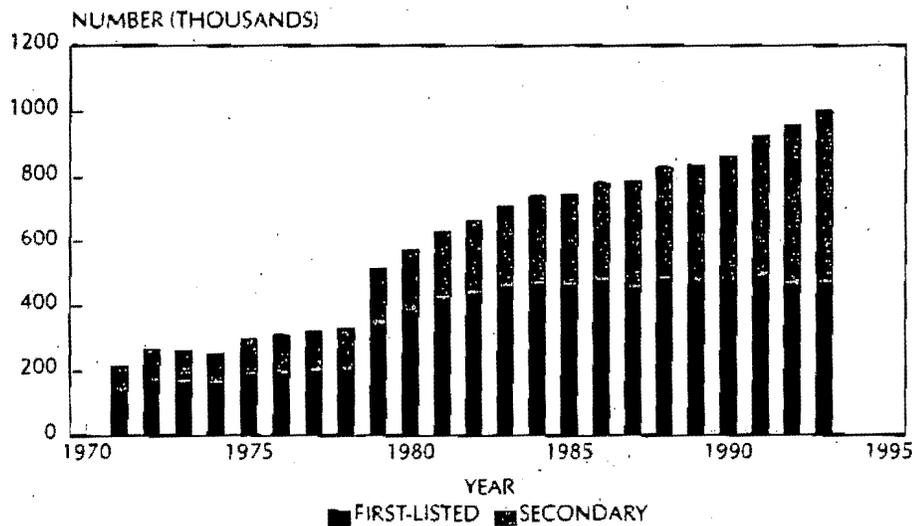
PREVALENCE/1,000 POPULATION



The prevalence rate of asthma is slowly increasing in most age groups, especially younger than age 18.<sup>13,35</sup>

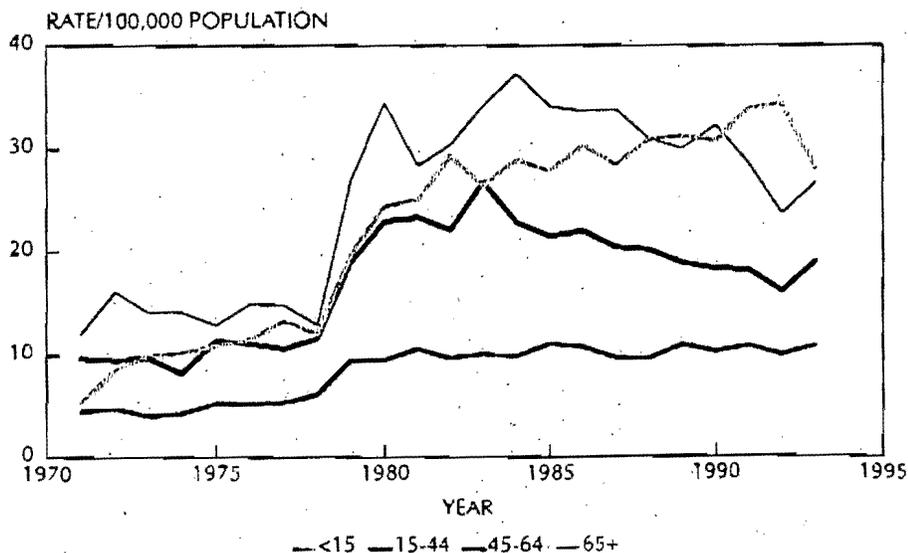
Asthma

CHART 4-17  
NUMBER OF HOSPITALIZATIONS FOR ASTHMA,  
U.S., 1971-1993



The number of hospital discharges for asthma as the first-listed discharge on the hospital face sheet has held relatively steady at just over 400,000 per year from 1981 to 1993. Asthma as a secondary diagnosis increased steadily during that period so that by 1993, asthma was the primary or secondary diagnosis in 1 million hospitalizations.<sup>26,36</sup>

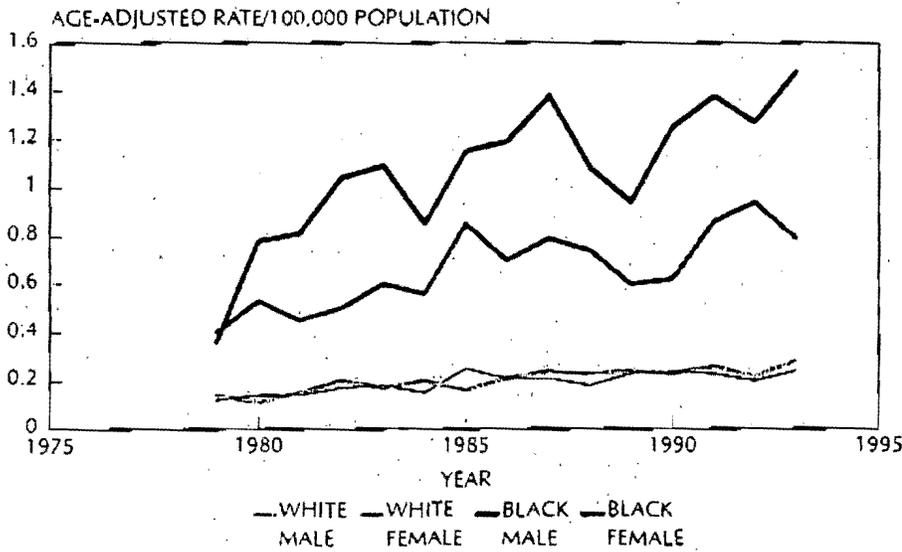
CHART 4-18  
HOSPITALIZATION RATES FOR ASTHMA  
BY AGE, U.S., 1971-1993



Hospitalization rates for asthma by age tended to increase from 1971 to 1993.<sup>26,36</sup>

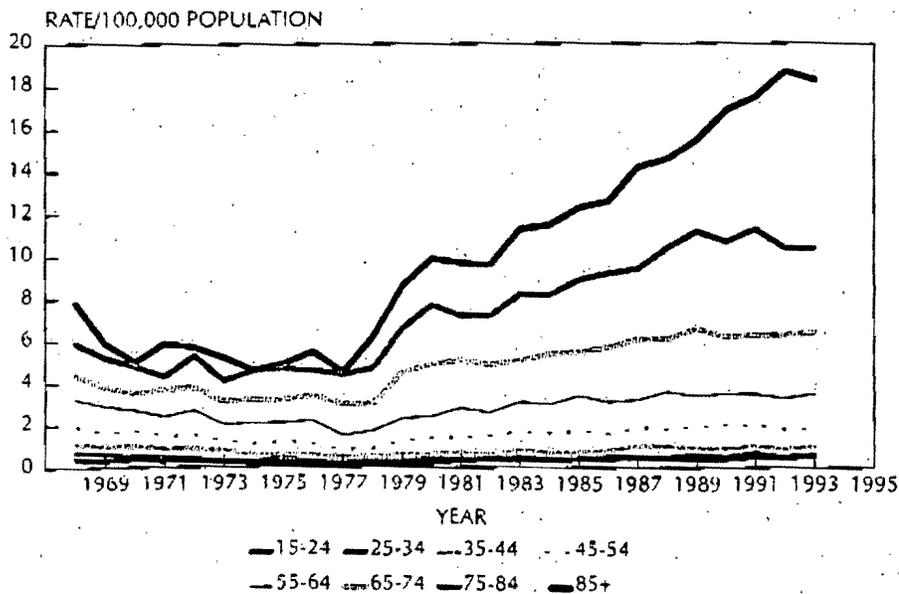
### Asthma

**CHART 4-19**  
**DEATH RATES FOR ASTHMA AGE 1 TO 24**  
**BY SEX AND RACE, U.S., 1979-1993**



Death rates for asthma in persons for age 1 to 24 increased during the 1979-1993 period in the four race-sex groups shown. Because rates are higher in blacks than in whites, the absolute increase was greater in blacks, but the rates of increase were about the same. Essentially no change occurred in the black-white gap in death rates as calculated from the black/white ratios of the death rates.<sup>7</sup>

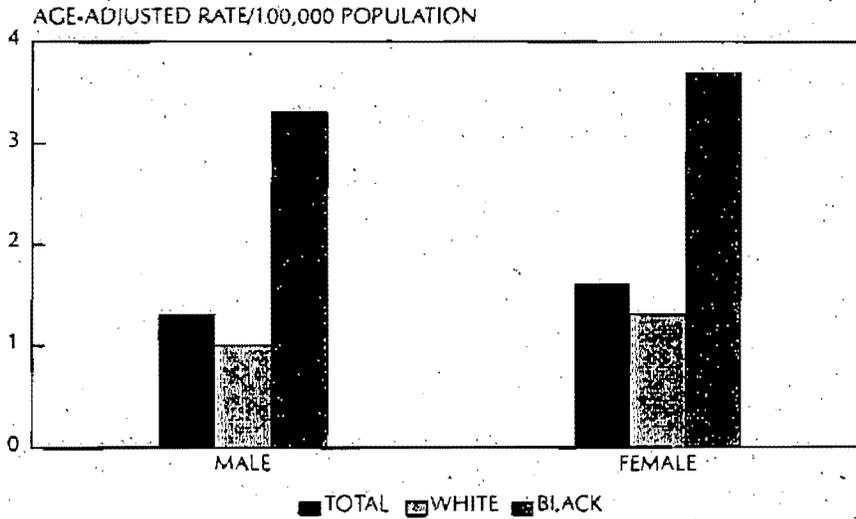
**CHART 4-20**  
**DEATH RATES FOR ASTHMA**  
**BY AGE, U.S., 1968-1993**



The fall and rise in asthma mortality since 1968 has occurred in all age groups.<sup>7,17</sup>

### Asthma

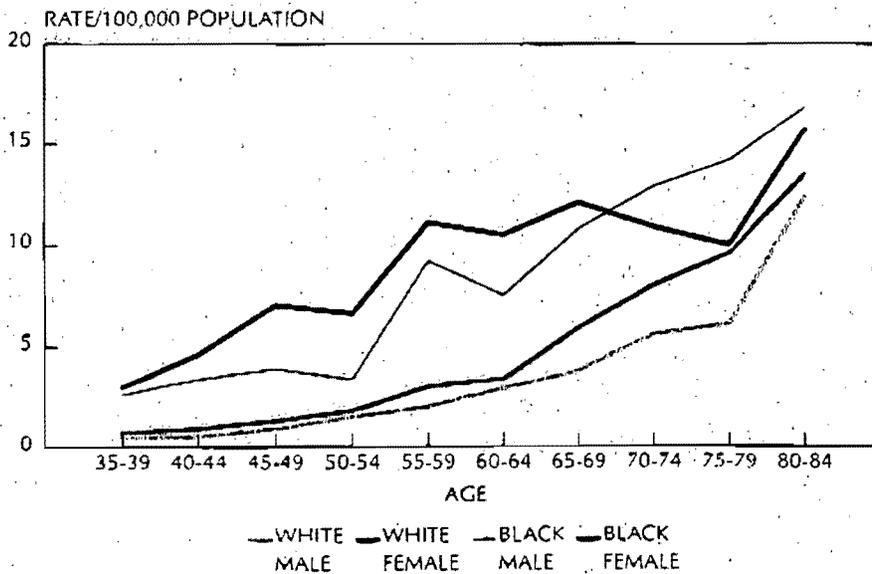
**CHART 4-21  
DEATH RATES FOR ASTHMA  
BY RACE AND SEX, U.S., 1993**



Age-adjusted death rates for asthma are:<sup>17</sup>

- Three times higher in black males than in white males.
- Almost three times higher in black females than in white females.
- Slightly higher overall in females than in males.

**CHART 4-22  
DEATH RATES FOR ASTHMA  
BY AGE, RACE, AND SEX, U.S., 1993**



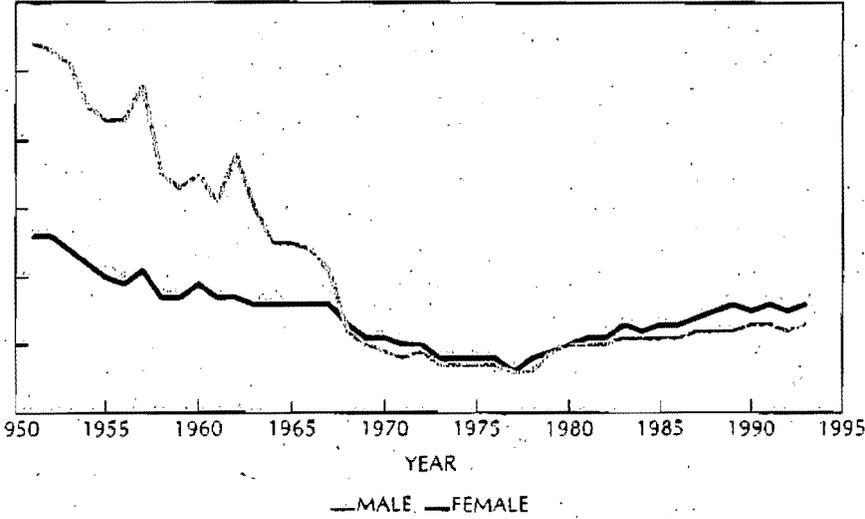
Age-specific death rates for asthma are much higher in blacks than in whites in nearly every age group.<sup>17</sup>

The rates are higher in white females than in white males.

### Asthma

**CHART 4-23  
DEATH RATES FOR ASTHMA  
BY SEX, U.S., 1951-1993**

AGE-ADJUSTED RATE/100,000 POPULATION

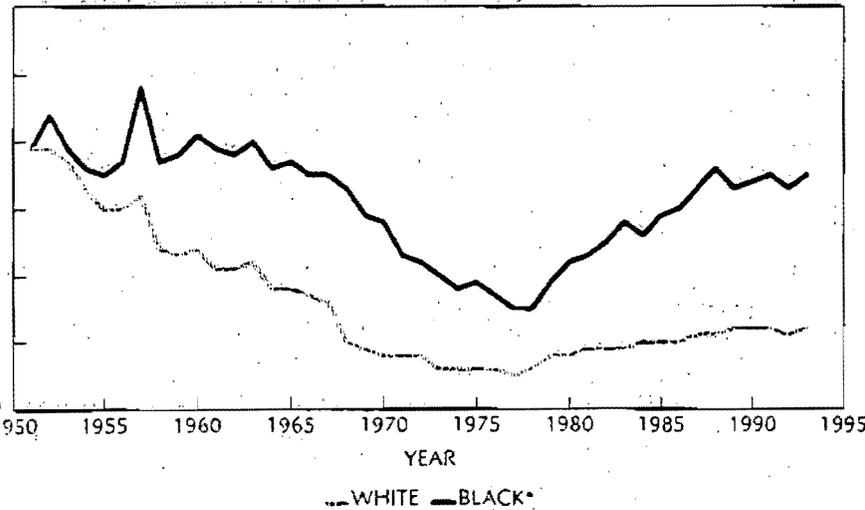


Asthma mortality shows a steep decline up to 1968 and is then followed by an increase.<sup>7</sup>

Rates had been much higher in males than in females before the mid-1960s but are now about the same for both sexes.

**CHART 4-24  
DEATH RATES FOR ASTHMA  
BY RACE, U.S., 1951-1993**

AGE-ADJUSTED RATE/100,000 POPULATION

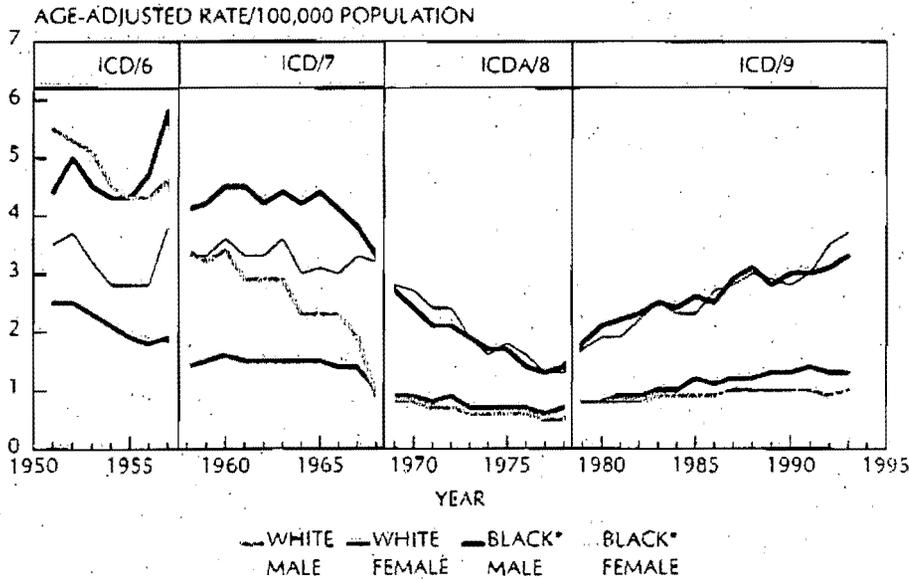


The black-white gap in asthma mortality is widening, with rates much higher in blacks than in whites.<sup>7</sup>

\* Nonwhite from 1951 to 1967.

Asthma

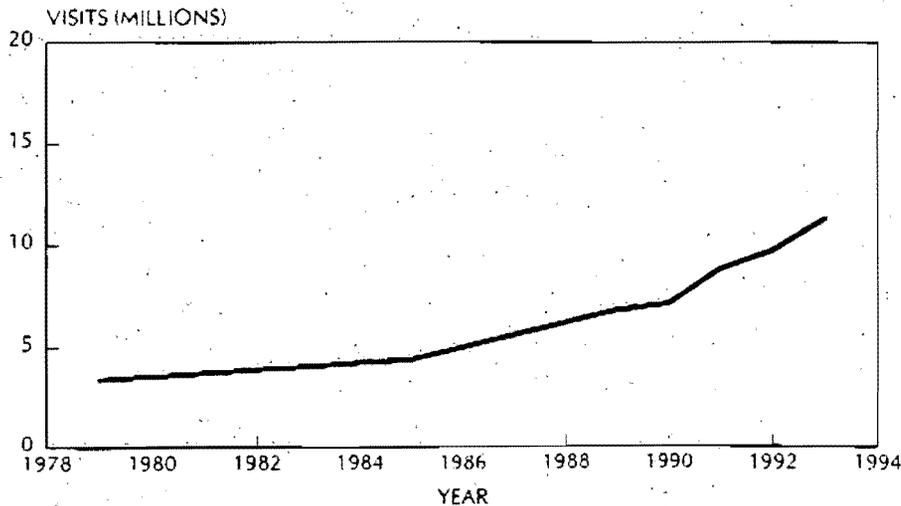
CHART 4-25  
DEATH RATES FOR ASTHMA  
BY RACE AND SEX, U.S., 1951-1993



\* Nonwhite from 1950 to 1967.

Trends in asthma mortality are much more uniform across sex-race groups since 1970 as compared with the 1950-1970 period.<sup>7</sup>

CHART 4-26  
PHYSICIAN OFFICE VISITS FOR ASTHMA,  
U.S., 1979-1993



The number of physician office visits for asthma increased substantially during the 1979-1993 period and rapidly since 1990.<sup>45</sup>

UNIVERSITY OF NORTH CAROLINA AT CHAPEL HILL

Facsimile Cover Sheet

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articles in section 12

Over the last two decades, considerable emphasis has been placed on the importance of adequate prenatal care for minority populations, who have been identified as having a greater risk of poor pregnancy outcome. To the extent that health care educational messages and campaigns have been effective, one might hypothesize that minority women who do receive prenatal care would be more likely than White women to be given information on these topics. These data indicate that this is not the case and suggest the need for continued and expanded medical education programs to increase provider awareness of the importance of these issues as part of prenatal care services to all women, particularly women at higher risk of poor pregnancy outcome.

The findings that there are variations in the content of prenatal care by ethnicity of the mother, site of care, and age, among other factors, also have implications for the interpretation of investigations focusing on the impact of the adequacy of prenatal care, as measured by the month of initiation of prenatal care and by the number of prenatal care visits. Indices of prenatal care utilization have been used to investigate ethnic differences in pregnancy outcome.<sup>30,31</sup> Although ethnic variations in prenatal care utilization have been repeatedly uncovered, the magnitude of these variations was insufficient to explain prevailing ethnic disparities in pregnancy outcome measures. The present findings, indicating that the content of prenatal care is not consistent for all ethnic groups, must now be considered as another potential explanation.

However, it should be stressed that although these data suggest that Black women receive less prenatal care on alcohol and tobacco use, it would be imprudent to overspeculate on whether these ethnic differences in the content of prenatal care advice are likely to appreciably explain the observed ethnic disparities in pregnancy outcome—given the lower likelihood of Black women's smoking and drinking before delivery. However, the content of prenatal care and the linkage of content and maternal needs in our understanding of the causes of racial disparities in birth outcomes must now be considered.

**Conclusion**

The present study suggests that large numbers of women of all races do not receive sufficient health behavior modification information as part of the content of their prenatal care. In particular, Black

**TABLE 4—The Odds of Not Receiving Advice on Prenatal Care Behaviors During Pregnancy**

	Alcohol Cessation OR (95% CI)	Smoking Cessation OR (95% CI)	Breast-feeding OR (95% CI)	Drug Use Cessation OR (95% CI)
Race: Black (vs White)	1.29 (1.10, 1.51)	1.20 (1.01, 1.39)	1.15 (0.99, 1.32)	1.01 (0.85, 1.57)
Marital status				
Single (vs married)	0.92 (0.75, 1.14)	1.02 (0.82, 1.26)	1.40 (1.15, 1.72)	0.76 (0.65, 1.05)
Separated or divorced (vs married)	1.01 (0.78, 1.32)	1.42 (1.07, 1.87)	1.15 (0.90, 1.46)	0.95 (0.73, 1.23)
Household income				
<\$2,000 (vs ≥\$18,000)	1.15 (0.91, 1.45)	1.30 (1.01, 1.65)	1.39 (1.11, 1.74)	1.07 (0.84, 1.36)
\$2,000-\$11,999 (vs ≥\$18,000)	1.23 (0.98, 1.55)	1.33 (1.08, 1.77)	1.17 (0.94, 1.45)	1.13 (0.88, 1.40)
\$12,000-\$17,999 (vs ≥\$18,000)	1.21 (0.97, 1.51)	1.40 (1.11, 1.77)	0.98 (0.78, 1.18)	1.08 (0.85, 1.32)
Maternal education				
<12 y (vs >12 y)	1.32 (1.05, 1.65)	1.21 (0.98, 1.54)	1.42 (1.15, 1.75)	1.18 (0.93, 1.45)
High school grad (vs >12 y)	1.13 (0.87, 1.33)	1.10 (0.84, 1.30)	1.13 (0.96, 1.30)	1.07 (0.82, 1.34)
Maternal age				
≤19 y (vs 20-29 y)	1.13 (0.80, 1.40)	0.83 (0.73, 1.18)	0.96 (0.73, 1.11)	0.81 (0.73, 1.15)
30-34 y (vs 20-29 y)	1.31 (0.85, 1.20)	1.13 (0.96, 1.30)	1.08 (0.92, 1.27)	1.27 (1.08, 1.50)
≥35 y (vs 20-29 y)	1.83 (1.43, 2.35)	1.81 (1.24, 2.08)	1.08 (0.83, 1.38)	1.64 (1.28, 2.09)
Women, infants, and children program participation (no vs yes)	1.29 (1.05, 1.55)	1.94 (1.26, 1.99)	1.57 (1.31, 1.88)	1.29 (1.00, 1.66)
Primary site of prenatal care				
Publicly funded site (vs private office)	0.87 (0.72, 1.06)	1.04 (0.77, 1.21)	0.79 (0.65, 0.97)	0.78 (0.62, 0.97)
Hospital clinic (vs private office)	0.84 (0.68, 1.03)	0.97 (0.69, 1.35)	1.05 (0.88, 1.29)	0.78 (0.63, 0.96)
Health maintenance organization (vs private office)	0.92 (0.69, 1.12)	0.86 (0.62, 1.20)	0.75 (0.57, 1.00)	0.78 (0.58, 1.02)
Other sites* (vs private office)	0.73 (0.50, 1.05)	0.89 (0.47, 1.60)	0.91 (0.68, 1.26)	0.65 (0.46, 0.94)
Type of payment for care				
Paid with own money (vs did not pay)	1.02 (0.87, 1.21)	1.04 (0.88, 1.24)	1.08 (0.91, 1.24)	1.08 (0.92, 1.27)
No insurance (vs private insurance)	1.00 (0.79, 1.25)	1.01 (0.80, 1.29)	0.78 (0.61, 0.99)	1.10 (0.88, 1.40)
Not paid by Medicaid (vs paid by Medicaid)	0.84 (0.63, 1.12)	0.89 (0.68, 1.19)	0.98 (0.88, 1.14)	1.12 (0.78, 1.60)
Not paid by other government program (vs paid by program)	1.05 (0.78, 1.34)	1.04 (0.72, 1.50)	0.95 (0.74, 1.25)	1.34 (0.85, 1.99)
Not paid by other source (vs paid)	1.02 (0.79, 1.48)	1.33 (0.98, 1.84)	0.98 (0.72, 1.28)	1.28 (0.93, 1.74)
Trimester that prenatal care began: second or third trimester (vs first)	1.11 (0.92, 1.27)	1.03 (0.87, 1.21)	1.05 (0.96, 1.17)	0.94 (0.85, 1.04)
Previous pregnancy history: prior adverse outcome (vs no pregnancy or no adverse outcome)	0.97 (0.73, 1.37)	0.98 (0.83, 1.17)	0.89 (0.75, 1.03)	0.83 (0.68, 1.01)
Drank alcohol in year before delivery (yes vs no)	0.53 (0.46, 0.61)			
Smoked in year before delivery (yes vs no)		0.15 (0.12, 0.18)		
Race by single marital status interaction				1.43 (1.00, 2.04)

Note. Odds are estimated from multiple logistic regression models among the sample of 8310 respondents in the 1988 National Maternal and Infant Health Survey. OR = odds ratio; CI = confidence interval.  
\*Other sites of care could be school clinic, work clinic, hospital emergency room, or other unspecified site.

women are more likely not to receive health behavior advice that could reduce their chances of having an adverse pregnancy outcome. Specifically, they are less likely to report receiving smoking and alcohol cessation advice. □

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Facsimile Cover Sheet

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cessation of drug use followed a pattern similar to that of smoking advice, with women of poorer socioeconomic status receiving more advice. Advice on cessation of illegal drug use was significantly more frequent for single, less educated, younger, and poorer women. Public clinics gave more advice than private sources of care.

Advice promoting breast-feeding was the advice reported least often. In general, there was some tendency for women of higher socioeconomic status to get more breast-feeding advice. Breast-feeding advice was more frequent in Whites, married women, and women with more than 12 years of education; it was least frequent in the lowest-income women. Site of prenatal care presents a complex picture, with HMOs and publicly funded clinics the most frequent providers of breast-feeding information. WIC participants reported only a 54.7% rate of receiving breast-feeding advice from their health care providers.

Table 3 shows the unadjusted and adjusted ORs (controlling for all variables in the logistic model) for not reporting receipt of advice on each of the four health behaviors, by race. Before adjustment, Black women were significantly more likely to report not receiving advice on cessation of alcohol consumption, smoking cessation, and breast-feeding promotion. After adjustment, a significant racial disparity in advice for alcohol and smoking cessation still remained. Breast-feeding promotion just missed reaching significance and was similarly skewed towards more advice for White women. The unadjusted OR for race in the analysis of drug use cessation was 0.99. When race was analyzed with the covariates, before interaction terms were assessed, the adjusted OR became significant (1.28), indicating that racial disparities were masked in the bivariate analysis. However, there was a significant interaction between race and marital status: Black single women were 1.4 times more likely than White single women not to receive advice on drug use cessation, whereas there were no racial differences among married women.

Table 4 presents the full logistic analysis for each of the outcome variables. For advice on cessation of alcohol consumption, only six variables were significant: drinkers were more likely to be given advice; and older women (>35 years), women with less than 12 years of education, Black women, WIC nonparticipants, and women who began prenatal care after

TABLE 2—The Association of Prenatal Care Advice with Race and Selected Covariates among the Sample of 6310 Respondents in the 1992 National Maternal and Infant Health Survey

	% Reporting Advice Received about Alcohol	% Reporting Advice Received about Smoking	% Reporting Advice Received about Drugs	% Reporting Advice Received about Breast-feeding
<b>Race</b>				
Black	60.2	64.2	66.1	47.3
White	70.3	70.7	65.8	52.4
				12.80**
<b>Marital status</b>				
Married	69.8	69.3	64.8	53.0
Divorced or separated	66.1	69.0	67.3	50.4
Single	63.9	70.4	79.4	45.4
				26.23**
<b>Maternal education</b>				
<12 y	60.3	73.2	67.7	47.0
High school graduate	67.5	70.7	66.3	51.3
>12 y	72.1	67.2	64.9	63.1
				13.94**
<b>Maternal age, y</b>				
15-19	61.6	71.4	71.1	50.6
20-29	66.8	71.4	67.9	62.0
30-34	71.3	67.2	61.5	60.4
35+	66.1	68.2	55.5	61.4
				1.67
<b>Household income</b>				
<\$8,000	63.7	70.5	69.9	45.9
\$8,000-\$11,999	63.1	70.2	67.8	50.9
\$12,000-\$17,999	64.7	69.5	67.1	55.1
\$18,000-\$29,999	69.0	71.1	64.8	53.8
\$30,000-\$59,999	71.0	68.7	64.8	51.0
\$60,000+	78.4	67.1	64.2	51.4
				21.62**
<b>Prenatal care payment*</b>				
Medicaid	62.0	71.0	70.0	49.9
Private insurance	70.3	68.2	64.0	50.5
Own money	70.0	68.9	64.8	53.6
Other government help	69.1	74.9	73.2	52.8
Other type of payment	69.2	75.9	71.7	63.3
<b>Site of prenatal care</b>				
Private office	66.3	68.8	63.4	50.6
Publicly funded site	68.0	69.9	71.7	56.2
Health maintenance organization	72.3	70.0	67.7	56.7
Hospital clinic	69.4	71.7	70.8	48.0
Other site of care	79.2	76.0	74.1	53.4
				18.05**
<b>Trimester that prenatal care began</b>				
First	70.0	69.6	65.8	62.3
Second	62.5	69.9	66.1	48.1
Third	64.3	64.0	67.6	49.4
				7.80*
<b>Received Women, Infants, and Children program assistance</b>				
Received	66.9	74.3	71.6	54.7
Did not receive	65.4	67.7	63.8	50.2
				13.13**
<b>Drank alcohol in year before delivery</b>				
Drank	76.1			
Did not drink	60.8			
				225.33**
<b>Smoked in year before delivery</b>				
Smoked		80.4		
Did not smoke		59.5		
				822.27**

\*Women could provide more than one source of payment; therefore, no  $\chi^2$  value was calculated.  
 \*P < .05; \*\*P < .01; \*\*\*P < .001.

**TABLE 3—Unadjusted and Adjusted Odds Ratios Comparing Blacks with Whites on Prenatal Care Advice in the 1998 National Maternal and Infant Health Survey**

Outcome	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Did not receive drinking cessation advice	1.57 (1.41, 1.74)	1.29 (1.10, 1.51)
Did not receive smoking cessation advice	1.35 (1.21, 1.50)	1.20 (1.01, 1.39)
Did not receive advice on breast-feeding	1.22 (1.11, 1.35)	1.15 (0.99, 1.32)
Did not receive advice on illegal drug use	0.99 (0.89, 1.09)	1.28 (1.10, 1.48) <sup>a</sup> 1.01 (0.85, 1.17) <sup>b</sup>

Note: OR = odds ratio; CI = confidence interval.  
<sup>a</sup>Model without interaction.  
<sup>b</sup>Model with significant interaction.

the first trimester were all less likely to be given advice.

For advice on smoking cessation, there were seven significant factors. Smokers were substantially more likely than nonsmokers to receive advice. Older and separated women received less smoking cessation advice. Although the bivariate analysis indicated that income was not significant, the multivariate analysis showed that lower-income women with incomes of less than \$6 000, \$6 000–\$11 999, and \$12 000–\$17 999 received less advice than upper-income women. WIC nonparticipants also reported less advice.

For breast-feeding promotion, there were six significant factors, and each was stronger than race. Single women, women with less than 12 years of education, women with the lowest income levels, and WIC nonparticipants received less advice promoting breast-feeding. Women who received most of their prenatal care at publicly funded sites or HMOs or who had no private insurance were more likely to report receiving advice than women who received care at private physicians' offices.

Three factors predicted not receiving drug cessation advice. Race, in the presence of interaction, was not significant. Older women (ages 30–34 and 35+ years) and WIC nonparticipants received less advice; women who used either public prenatal care sites or hospital clinics received more advice than those who received care at private offices. Once again, WIC nonparticipants received less advice.

Interaction terms (with race) were examined for each of the four health behavior outcome measures. They were not significant or informative for smoking, alcohol, or breast-feeding advice. A significant interaction term (race by marital status) was noted for illegal drug use (OR = 1.43).

## Discussion

Advice about prenatal health behavior is not a uniform feature of all prenatal care. Regardless of race, one third or more of the women surveyed reported receiving no prenatal advice on alcohol, tobacco, or drug use, and approximately 50% received no prenatal information on breast-feeding. The observation that women who smoked or drank were more likely to report receiving prenatal advice on tobacco or alcohol use is a positive indication that services were being targeted to at-risk groups. Notwithstanding, given the emphasis placed on the importance of providing all women with prenatal advice on substance use and breast-feeding, these findings indicate that much improvement is still needed in the content of prenatal care being provided to women in the United States.

The content of prenatal care is not uniform across racial groups. Compared with White women, Black women receiving prenatal care advice were significantly less likely to report receiving advice on drinking and smoking cessation, and the disparity in breast-feeding advice approached significance. This is the other critical finding of the study.

The current analyses suggest that although race is an important factor in the content of prenatal care, other programmatic and sociodemographic factors are equally, if not more, important. First, advice about two of the behaviors, smoking and drug use, was skewed towards poorer women, whereas advice about alcohol use and breast-feeding was skewed towards wealthier women. Health care providers may be giving advice based on their stereotypes of who is involved in what type of behaviors and not on a principle of equity. Second, the site of prenatal care was important. Advice on illegal drug use was

more common for patients of publicly funded sites and hospital clinics than for private-office patients. Patients of HMOs and publicly funded sites were also found to have a lower risk of not receiving breast-feeding advice compared with private-office patients. Third, participation in the WIC program, which mandates prenatal care advice on these behaviors as part of its basic package of services,<sup>23,24</sup> had a protective effect in each multivariate analysis, with WIC nonparticipants reporting less prenatal advice. Fourth, older women (>35 years of age) were more likely to report not receiving advice on alcohol, tobacco, and drug use. This finding may reflect a perception on the part of the providers that these women were in less need of this advice because of earlier pregnancies, particularly in the case of illegal drug and alcohol use. Alternatively, providers may have perceived that these messages would be less effective in terms of changing established behaviors (e.g., tobacco use) and consequently may have stressed them to a lesser degree.

Although interactions were explored for each of the outcome measures, a significant interaction between marital status and race was only identified in the analysis of advice on illegal drug use. This finding suggests that White single women were targeted for advice on illegal drug use more often than Black single women or tended to report receiving such advice in greater proportions. These data are insufficient to propose an explanation for these findings. Illegal drug use is a sensitive area of discussion, and further investigation of these findings may need to explore to what extent differences in ethnic and cultural characteristics of providers and patients may inhibit the provision of advice in this area.

This study is limited in that it is based on the self-reports of the women surveyed. It is unclear whether women may be more likely to overestimate or underestimate the actual receipt of prenatal advice or whether error rates vary by type of advice, site of prenatal care, ethnicity of the mother, birth outcome, or other factors. Some studies have found that maternal recall is relatively accurate for birth outcomes,<sup>25,26</sup> whereas maternal recall of exposures during pregnancy has been mixed.<sup>27,28</sup> Moreover, patients and providers may have different recall on the content of a visit.<sup>29</sup> Nonetheless, it is women's perception, not the providers' report of their practice, that is ultimately most likely to be linked to health behavior changes.

*Health-Hemophilia case***FAX****Date** *June 16, 1997***Four pages including cover sheet**

**TO:** *Elena Kagan*  
*Deputy Assistant to the*  
*President for Domestic*  
*Policy*  
*West Wing*  
*The White House*

**Phone** *202/456-5584*  
**Fax Phone** *202-456-2878*

**FROM:** *Dick Meltzer*  
*Washington Counsel, P. C.*  
*Suite 601*  
*1150 Seventeenth Street, NW*  
*Washington, D. C. 20036*

**Phone** *202/293-7474*  
**Fax Phone** *202/293-8811*

**CC:**

**REMARKS:**  *Urgent*  *For your review*  *Reply ASAP*  *Please Comment*

Attached is a copy of the amendment adopted by the House Commerce Committee and filed with the Senate Finance Committee by Senator Bob Graham. Also attached is a copy of talking points which we provided Sen. Graham and a one page statement of facts. If you are able to communicate the position of the Administration, please call either Ken Klein, the Administrative Assistant to Sen. Graham at 224-1544 or Jenae Reiter, a Health staffperson to the Senator at 224-3041. Also, if you could call the Finance Committee Majority Staff, Dennis Smith at 224-4515, and/or the Minority Staff Director, Mark Patterson at 224-5315. The other Senators whom we look to for support include Sens. Chaffee, Hatch, Nickles, Gramm, Lott, Jeffords, Mack, Rockefeller, Breaux, and Moseley-Braun.

Thanks again for your help. Please leave me a message at 293-7474 if you are able to make a call -or even if you are unable.

*Chris -*  
*Have we taken a*  
*position on this?*  
*Elena*

## SEC. \_\_\_\_ . TREATMENT OF CERTAIN SETTLEMENT PAYMENTS.

Notwithstanding any other provision of law,

the payments made from any fund established pursuant to the settlement in the case of In re Factor VIII or IX Concentrate Blood Products Litigation, MDL-986, no. 93-C7452 (N.D. Ill.) shall not be considered income or resources in determining eligibility for, or the amount of benefits under, a State plan of medical assistance approved under Section 1902(a) of the Social Security Act.

## STATEMENT OF FACTS

### Status of Class Action Lawsuit

On May 9, 1997, the U. S. District Court for the Northern District of Illinois approved a class settlement for HIV-infected persons with hemophilia and their families who were infected with HIV through their use of plasma-derived clotting factor concentrates between 1978 and 1985. The settlement, offered by the four companies who processed and distributed the concentrates during that period, has been overwhelmingly accepted by the hemophilia community. Approximately 6000 people have accepted the settlement while slightly over 550 have not.

Under the terms of the settlement, each claimant will receive \$100,000 free and clear from attorneys' fees and third-party health insurance claims that have been or could be asserted by the federal government, the states and private insurance carriers for HIV-related hemophilia care. To date, the companies have entered into separate settlement arrangements with most of the nation's private health insurers, the federal government and a majority of the states by which those entities have compromised their claims to the class settlement amount in return for payments made by the companies. These payments have been made over and above the fund of approximately \$600 million that has been established for the class members.

### Eligibility for Medicaid

Certain members of the settlement class who currently qualify for Medicaid may lose their eligibility if they accept the settlement amount, because receipt of the settlement will count against the Medicaid assets limit. The exact number of members of the settlement class in this circumstance is not known, although estimates range from several hundred to two thousand individuals. All alternative means of payments to the group of settlement class members that preserve eligibility for Medicaid are being explored, but legislation to exempt the settlement funds from Medicaid eligibility consideration is necessary to assure that persons otherwise eligible for Medicaid are not prevented from participation.

### Reasons for Change

The Federal District Court supervising the settlement has placed a high priority on assuring that each claimant will be free to accept his or her check for \$100,000 without jeopardizing eligibility for Medicaid assistance. Unfortunately, the loss of Medicaid eligibility will discourage some members of the class from accepting the settlement payment to which they are otherwise entitled and will add yet another tragic chapter to this story. Carefully targeted Congressional action to preclude consideration of the settlement amount in determining Medicaid eligibility will permit virtually all members of the settlement class to make their decision based solely upon the facts of their individual case.

TALKING POINTS  
ON  
MEDICAID ELIGIBILITY FOR RECIPIENTS OF SETTLEMENTS  
IN FACTOR CONCENTRATE CLASS SETTLEMENT

- On May 9, 1997, the U.S. District Court for the Northern District of Illinois approved a class settlement for HIV-infected persons with hemophilia and their families who were infected with HIV through the use of plasma-derived clotting factor concentrates between 1978 and 1985.<sup>1</sup>
- Under the settlement each claimant will receive \$100,000 free and clear from attorney's fees and third-party health insurance claims that have been or could have been asserted by the federal government, state governments, and private insurance carriers for HIV-related care.<sup>2</sup>
- Approximately 6,000 people have accepted the settlement while approximately 550 people have declined.
- Certain members of the settlement class<sup>3</sup> who currently qualify for Medicaid may lose their eligibility if they accept the settlement amount, because it will cause them to exceed the Medicaid asset limit.
- The loss of Medicaid eligibility will discourage some members of the class from accepting the settlement payment to which they are otherwise entitled.
- The Federal District Court has asked the parties to the settlement to seek a means for assuring that each party is free to accept the settlement amount without jeopardizing their Medicaid eligibility.
- On Thursday, June 12, the House Commerce Committee adopted an amendment to the Medicaid reconciliation title excluding any settlement amounts received by an individual from the determination of Medicaid eligibility.
- To meet the Court's charge, and to provide a humanitarian outcome to those members of the class who would choose to accept the settlement if doing so did not jeopardize their Medicaid eligibility, carefully targeted Congressional action is necessary to preclude consideration of the settlement amount in determining Medicaid eligibility.

---

<sup>1</sup> One appeal was filed during the thirty day appeals period that ended on June 9, 1997.

<sup>2</sup> The Department of Justice negotiated the settlement of its potential subrogation claims on behalf of the entire federal government. Approximately one-half of the states – including the ten largest states – have negotiated similar agreements, and discussions are underway with the remainder. All of the largest private insurers have negotiated similar agreements.

<sup>3</sup> The exact number is unknown, but is estimated to be between several hundred and two thousand people.

Special Projects of  
National Significance

*A Program of the Ryan White C.A.R.E. Act*

SPNS

**GRANTEE  
DIRECTORY**

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# INTRODUCTION

## PROGRAM AUTHORITY

The SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE (SPNS) PROGRAM is authorized by Section 2691 of the Public Health Service Act, as amended by the Ryan White CARE Act Amendments of 1996, Public Law 104-146, dated May 20, 1996. The SPNS Program is administered by the Health Resources and Services Administration, Bureau of Health Resources Development.

## PURPOSE

The primary purpose of the SPNS Program is to demonstrate and evaluate innovative and potentially replicable HIV service delivery models. The authorizing legislation specifies three SPNS Program objectives: (1) to assess the effectiveness of particular models of care; (2) to support innovative program design; and (3) to promote replication of effective models.

## SPECIAL PROJECT CATEGORIES

In establishing Special Project Categories, 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." That document, commissioned by the SPNS Program, was developed through interviews and written comments from key HRSA staff and federal and non-federal experts in the field of HIV/AIDS.

Currently, the SPNS Program is supporting grants in the following project categories:

- **Adolescent Care Demonstration and Evaluation** -- This category was initiated in FY 1993 with 10 projects funded. This initiative targets adolescents (ranging in age from 10 to 24) at high risk of HIV infection or who are already infected. These projects are participating in a national, cross-cutting evaluation study.
- **Dissemination and Refinement of the Model** -- This category was initiated in FY 1994 with 9 projects funded. This initiative focuses on the dissemination, refinement, and replication of previously evaluated models of care.
- **HIV Service Delivery Models and Evaluation & Dissemination Center** -- This category was initiated in FY 1994 with 27 projects funded in four different subcategories that focus on-- 1) comprehensive primary care (including managed care); 2) reduction of cultural, linguistic, and organizational barriers of care; 3) provider training and education in rural, correctional, or mental health settings; and 4) a national, cross-cutting evaluation study and dissemination plan.

## Adolescent Care Demonstration and Evaluation Grantees

### **Bay Area Young Positives, Inc.**

518 Waller Street  
San Francisco, CA 94117  
OFC: (415) 487-1616  
FAX: (415) 487-1617  
eMail: N/A

#### **Contact Person:**

Antigone Hodgins

**Project Period:** 12/93-11/96

This project uses a staff of full-time, paid young people and volunteers to provide support services for youth with HIV who are under 26 years of age. These services include recreational and social activities, peer counseling, advocacy education, practical support services, and information on youth-sensitive care providers.

### **Children's Hospital, Boston**

#### **Boston Happens**

Division of Adolescent/Young Adult  
Medicine

Boston Adolescent HIV Network Program

300 Longwood Avenue

Boston, MA 02115

OFC: (617) 355-6495 or

Clinic: (617) 355-7181

FAX: (617) 730-0442

eMail: WOODS@a1.tch.harvard.edu or  
HN5400@handsnet.org

#### **Contact Person:**

Elizabeth Woods, M.D., M.P.H.

**Project Period:** 12/93-11/96

This program provides outreach to HIV positive, high risk, homeless, and street youth through a diverse and comprehensive network of primary care service providers. Its network model facilitates an integrated service referral program among the principal adolescent service providers in the Boston area.

### **Children's Hospital, Los Angeles**

Division of Adolescent Medicine

P.O. Box 54700, Mailstop #2

Los Angeles, CA 90054-0700

OFC: (213) 669-4604

FAX: (213) 664-8365

eMail: N/A

#### **Contact Persons:**

Michele Kipke, Ph.D.

Arlene Schneir

**Project Period:** 12/93-11/96

This project disseminates HIV prevention and early intervention information, provides risk reduction counseling, and initiates case management services for youth at high risk for HIV who are also runaway, homeless, and/or injecting drug users. A wide range of medical and psychosocial services is provided including HIV testing and counseling, mental health screening and crisis intervention, and substance abuse services.

**Greater Bridgeport Adolescent  
Pregnancy Program/TOPS Project**

200 Mill Hill Avenue  
Bridgeport, CT 06610  
OFC: (203) 384-3629  
FAX: (203) 384-4034  
eMail: HN5490@handsnet.org

**Contact Persons:**

Rudy Feudo, Ph.D.  
Sandra Vining-Bethea

**Project Period:** 12/93-11/96

This program provides outreach, HIV prevention and early intervention, case management, and referral services for underserved minority adolescents, ages 15 to 24, who are HIV+ or at high risk for HIV. Program staff provide intensive supervision and support for ten peer-youth street outreach educators.

**Health Initiatives for Youth**

**Youth Services**

1242 Market Street, 3rd floor  
San Francisco, CA 94102  
OFC: (415) 487-5777  
FAX: (415) 487-5771  
eMail: HYHI@HYHI.COM

**Contact Persons:**

Ron Henderson  
Joanne Lothrop

**Project Period:** 12/93-11/96

This initiative is providing a comprehensive array of youth-centered services, self-help resources, and skills-training for young people with HIV, age 25 years and under.

**Indiana State Department of Health**

Division of HIV/STD Services  
2 North Meridian Street, Suite 600  
Indianapolis, IN 46202  
OFC: (317) 233-7867  
FAX: (317) 233-7663  
eMail: N/A

**Contact Persons:**

Michael Wallace  
Diane May

**Project Period:** 12/93-11/96

This is a peer-based model that addresses access to health and support services for underserved gay, lesbian, and bisexual adolescents who are HIV+ or at risk for HIV. The project focuses on peer counseling, risk reduction and assessment, health evaluations, street outreach, and an HIV prevention case management model in central Indiana.

**Project Site:**

**Indiana Youth Access Project**

Indiana Youth Group  
P.O. Box 20716  
Indianapolis, IN 46220  
OFC: (317) 541-8726  
FAX: (317) 545-8594  
eMail: HN5849@handsnet.org

**Contact Person:**

Jeff Werner

**University of Alabama at  
Birmingham**

School of Medicine  
Department of Pediatrics/Teenage Access  
Project (TAP)

1630 Sixth Avenue, South  
CHOB-basement

Birmingham, AL 35233

OFC: (205) 934-5262 or 5252

FAX: (205) 975-7307

eMail: pedp044@uabdpo.dpo.uab.edu

**Contact Persons:**

Marsha S. Sturdevant, M.D.

Pernell Brown, R.N.C.

**Project Period:** 10/93-09/96

The TAP model provides HIV outreach, education, testing and counseling, and case management for disadvantaged, high risk females between the ages of 10 to 24 years. It seeks to improve access to medical and psychosocial services through family-centered case management and to identify HIV+ female youth through early intervention, outreach, and testing.

**University of Minnesota  
Youth and AIDS Project**

Adolescent Early Intervention Project

428 Oak Grove Street

Minneapolis, MN 55403

OFC: (612) 627-6824

FAX: (612) 627-6819

eMail: HN5416@handsnet.org

**Contact Persons:**

Gary Remafedi, M.D., M.P.H.

Kathleen Roach, M.P.H., M.B.A.

**Project Period:** 12/93-11/96

This project is developing and evaluating a model of outreach, early intervention, and service delivery for adolescents ages 13-23 living with HIV in Minnesota. It provides outreach and comprehensive, coordinated, and family-centered care to Minnesota youth who are HIV+.

**Walden House, Inc.**

214 Haight Street

San Francisco, CA 94102

OFC: (415) 554-1480

FAX: (415) 241-5599

eMail: www.sfo.com/~walden\

**Contact Persons:**

Brian Greenberg, Ph.D.

Rob Burch, Ph.D.

Chris Sayer, M.S.W.

**Project Period:** 10/93-09/96

Walden House provides a multi-disciplinary approach to the substance abuse treatment, psychiatric, and medical needs of dually diagnosed youth. The program combines long-term residential treatment with clinical and medical services specifically designed for adolescents living with HIV and those at risk.

**YouthCare**

Project for Street Involved, Homeless and  
Sexual Minority Youth

P.O. Box 9130

Seattle, WA 98109

OFC: (206) 282-9907

FAX: (206) 282-6463

eMail: a10er@sswgate

**Contact Person:**

Adam Tenner

**Project Period:** 12/93-11/96

This project combines HIV testing and counseling with early intervention and prevention case management services to develop a continuum of care for youth who are living with HIV.

## Dissemination and Refinement of the Model Grantees

### **Children's Hospital of New Orleans**

Pediatric AIDS Program  
200 Henry Clay Avenue  
New Orleans, LA 70118  
OFC: (504) 524-4611  
FAX: (504) 523-2084  
eMail: HN5420@handsnet.org

#### **Contact Persons:**

Michael Kaiser, M.D.  
DeAnn Gruber, B.C.S.W.  
Project Period: 09/94-08/96

This program is focusing on assuring the availability of comprehensive, family-centered, community-based services for HIV-infected women, children, adolescents, and their families in Baton Rouge and Monroe, Louisiana. This is being accomplished by replicating the model of care utilized by the Pediatric AIDS Program (PAP) and the Resources for Adolescents Program (RAP) of the Children's Hospital of New Orleans through the provision of technical assistance and support to Friends For Life in Baton Rouge and GO CARE in Monroe. Both process and impact evaluation.

### **Children's National Medical Center**

Project CHAMP  
111 Michigan Avenue, N.W.  
Washington, D.C. 20010-2970  
OFC: (202) 884-4004 or 5451  
FAX: (202) 884-3711  
eMail: N/A

#### **Contact Persons:**

Robert H. Parrott, M.D.  
Mary Rathlev, M.S.N.  
Project Period: 09/94-08/96

The Children's National Medical Center's Project CHAMP (Children's HIV/AIDS Model Program) is collaborating with the Pediatric AIDS Health Care Demonstration Project and the Synergy Project to adapt its model community education program to target youth service providers. The youth service provider project will develop educational programs specific to the learning needs of a variety of community-based professional and alternative caregivers. This community educational program is being refined and replicated in another urban area.

### **Family Planning Council of SE Pennsylvania**

260 South Broad Street, Suite 1000  
Philadelphia, PA 19102-3865  
OFC: (215) 985-2657  
FAX: (215) 732-0916  
eMail: N/A

#### **Contact Persons:**

Alicia Beatty  
M. Delores Vera  
Project Period: 09/94-08/96

This project will refine the homemaker position to meet some of the in-home medical as well as practical needs of medically fragile families as the HIV-infected member(s) becomes increasingly ill. The goal of this project is to reduce emergency room visits and hospitalizations, to increase the sense of well-being, and to help the families remain intact and in their homes for as long as possible. The project will be comparing the effectiveness of enhanced, skilled homeworkers (medically trained) vs. families without homeworkers or traditional homeworkers from the perspective of the family and the provider.

**Fortune Society, Inc.**  
39 West 19th Street  
New York, NY 10011  
OFC: (212) 206-7070  
FAX: (212) 366-6323  
eMail: JPFORTUNE@aol.com  
**Contact Person:**  
JoAnne Page, J.D.  
**Project Period:** 09/94-08/96

This project expanded the availability of effective counseling, case management and other services for HIV+ ex-prisoners by training other organizations to provide these services. They implemented the ETHICS (Empowerment Through HIV Information and Community Services) model of HIV intervention, which was developed by Fortune Society, Inc. This model utilizes a holistic approach to meet a broad range of needs critical to client stabilization and health preservation while supporting clients effectively to avoid relapse into substance abuse and high risk behaviors associated with substance abuse.

**Indiana State Department of Health**  
Division of HIV/STD Services  
2 North Meridian Street, Suite 600  
Indianapolis, IN 46202  
OFC: (317) 233-7867  
FAX: (317) 233-7663  
eMail: N/A  
**Contact Persons:**  
Michael Wallace  
Diane May  
**Project Period:** 09/94-08/96

This project's model is refining a statewide integration of well-informed and accessible community-based mental health services into the primary health care of those affected by HIV/AIDS. Timely intervention is designed to increase the capacity for informed decision making and self-management of the individual's well-being. Mental health services are further integrated into a statewide system of HIV care coordination. The primary mechanism for system integration is referral and care delivery network development and maintenance.

**Project Site:**

**Indiana Integration of Care  
Project**

I. Michael Schuff, Ph.D.  
OFC: (812) 237-3910  
FAX: (812) 237-3613  
eMail: N/A

**Montefiore Medical Center**

Albert Einstein College of Medicine  
Belfer Building, Suite 906  
1300 Morris Park Avenue  
Bronx, NY 10461

OFC: (718) 430-2154

FAX: (718) 430-8645

eMail: Mulvihill@aecom.yu.edu

**Contact Persons:**

Michael Mulvihill, Dr.P.H. or

Mark Winiarski, Ph.D. at

OFC: (718) 405-4133

FAX: (718) 405-4148

eMail: HN5471@handsnet.org or

Sister Rosemary Moynihan, L.C.S.W. at  
St. Joseph's Hospital and Medical Center

OFC: (201) 754-4767

FAX: (201) 754-4777

eMail: N/A

**Project Period:** 09/94-08/96

**Multnomah County Health  
Department**

426 SW Stark Street, 4th Floor  
Portland, OR 97204

OFC: (503) 248-5020 x 2290

FAX: (503) 248-5022

eMail: HN5519@handsnet.org

**Contact Person:**

John Dougherty, Ph.D.

**Project Period:** 09/94-08/96

**National Native American AIDS  
Prevention Center (NNAAPC)**

2100 Lakeshore Avenue, Suite A  
Oakland, CA 94606

OFC: (510) 444-2051

FAX: (510) 444-1593

eMail: nnaapc@aol.com

**Contact Person:**

Ron Rowell, M.P.H.

**Project Period:** 09/94-08/96

**Project Management Site:****Ahalaya Project--NNAAPC**

5350 South Western, Suite 500  
Oklahoma City, OK 73109

OFC: (405) 631-9988

FAX: (405) 631-9989

eMail: bettyd2702@aol.com

**Contact Person:**

Betty Duran, M.S.W.

This is a quasi-experimental evaluation project that is evaluating two refined models of integrating HIV/AIDS mental health services with primary care: a hospital-based HIV primary care model at St. Joseph's Hospital and Medical Center in Paterson, NJ and a community health center model with several sites at Montefiore Medical Center in Bronx, NY. This assessment will be used to determine whether this integration of mental health services has a positive effect on the providers working within the system as well as to determine if the increased use of mental health services improves the psychosocial well-being of the targeted patients.

This project is replicating the NOAH (No One Alone with HIV) model developed by Boston City Hospital. The primary goal of the project is to increase mental health and substance abuse assessment, intervention, and referral skills/resources of primary care staff, thereby increasing the number of clinic clients who receive these services.

This project is refining the Oklahoma-based, culturally relevant "Ahalaya Case Management" model to further improve the quality of life for HIV-infected Native Americans and to improve access to needed health and social services. The target population includes American Indians, Alaska Natives, and Native Hawaiians who are HIV infected. The essential components of the model are traditional healing, referral services, essentials of life, health-oriented case management, secondary prevention services, and social and psychological support. A rigorous evaluation is being conducted on data collected from all 10 sites nationwide.

**Protection and Advocacy System,  
Inc.**

1720 Louisiana N.E., Suite 204  
Albuquerque, NM 87110  
OFC: (505) 256-3100  
FAX: (505) 256-3184  
eMail: HN5412@handsnet.org

**Contact Persons:**

James Jackson

Susan Boettger

**Project Period:** 09/94-08/96

The goals of this project are to replicate the previously developed New Mexico model of protection and advocacy programs for persons with HIV/AIDS in three western states through a combination of training, technical assistance, and support strategies. Through educational efforts, technical assistance, and related dissemination strategies, the project aims to build the service capacity of the national network of Protection and Advocacy Systems by encouraging these systems to adopt or adapt one or more key model elements. Program evaluation will consist of process and outcome measures.

## HIV Service Delivery Model Grantees

### Primary Care Service Delivery

#### Capitated Reimbursement System

**AIDS Healthcare Foundation**

6255 W. Sunset Blvd., 16th Floor  
Los Angeles, CA 90028  
OFC: (213) 462-2273 or 468-1353  
FAX: (213) 962-8513  
eMail: N/A

**Contact Persons:**

Michael Weinstein

Craig Thompson, J.D., M.B.A.

Peter Reis

**Project Period:** 10/94-09/99

The objective of this project is to test the feasibility of providing comprehensive HIV services under a capitated reimbursement system utilizing an established pilot project. This pilot project offers a comprehensive managed healthcare program to Medi-Cal-eligible AIDS patients in Los Angeles County and was established through the State of California's Department of Health Services. The AHF Clinic patients will have access to a full continuum of medical and social services. An intended outcome of this project is to demonstrate that an enhanced, capitated, managed healthcare approach to providing HIV/AIDS care will produce fewer opportunistic infections, fewer and shorter hospitalizations, better compliance with medical treatment, and an overall longer lifespan including a better quality of life for HIV/AIDS diagnosed populations.

**East Boston Neighborhood Health Center**

10 Gove Street  
East Boston, MA 02128  
OFC: (617) 568-4755 or 4452  
FAX: (617) 539-5025  
eMail: N/A  
**Contact Persons:**  
James Taylor, M.D.  
Judy Steinberg, M.D.  
**Project Period:** 10/94-09/99

This project is developing an expanded, capitated reimbursement system for providing a cost-efficient, community-based HIV/AIDS care plan. They will explore the feasibility of developing three separate, capitated reimbursement rates for patients who will be appropriately grouped according to clinical diagnosis--HIV+ asymptomatic, HIV+ symptomatic, and CDC AIDS. This system of care will provide appropriate and comprehensive services from the time of seroconversion through terminal care.

**Johns Hopkins University School of Medicine**

720 Rutland Avenue, Ross 1159  
Baltimore, MD 21205  
OFC: (410) 955-7634, (410) 614-3631  
FAX: (410) 955-7889  
eMail: [jb@welchlink.welchijhu.edu](mailto:jb@welchlink.welchijhu.edu)  
**Contact Person:**  
John Bartlett, M.D.  
**Project Period:** 10/94-09/99

This activity involves three major entities--Johns Hopkins Health Systems, the Hopkins HIV Care Program, and the Maryland Medicaid Program. The goal of this project is to reduce the financial barriers to adequate care for AIDS patients and to improve the comprehensiveness of their care while containing costs to the insurer and reducing uncompensated costs to the provider. The evaluation analysis will include: 1) cost-effectiveness, 2) rate of clinical progression, and 3) quality of life assessment.

**New York State Department of Health/Health Research**

Division of HIV Health Care/  
AIDS Institute  
Empire State Plaza  
Corning Tower, Room 327  
Albany, NY 12237  
OFC: (518) 473-7781  
FAX: (518) 474-0419  
eMail: [hxc01@health.state.ny.us](mailto:hxc01@health.state.ny.us)  
**Contact Person:**  
Humberto Cruz  
**Project Period:** 10/94-09/98

This project involves a dynamic data collection effort to generate information related to cost, utilization, and access to care as persons with HIV/AIDS transition from fee-for-service to a managed care environment. Cost and utilization data collected will be used to validate risk-adjusted payment rates for HIV/AIDS and to develop accurate cost estimates that will be used in structuring HIV Special Needs Plans. Access to care will be evaluated through a representative survey of the experiences of persons with HIV and AIDS as they seek and use services during the period of transition to Medicaid managed care. Financial, administrative, and organizational information necessary to develop managed care Special Needs Plans that ensure appropriate access to and quality of care will be collected from organizations awarded HIV Special Needs Plans planning grants.

**Visiting Nurses Association of  
Los Angeles**

520 S. LaFayette Park Place, Suite 500  
Los Angeles, CA 90057  
OFC: (213) 386-7200  
FAX: (213) 386-9072  
eMail: cherin@chaph.usc.edu

**Contact Persons:**

David Cherin, M.S.W.  
Kristine Hillary, M.S.N., R.N.  
**Project Period:** 10/94-09/97

This project focuses on AIDS patients. A database program is being developed which will test the feasibility of providing a comprehensive, capitated reimbursement system. This system will compare service utilization, costs of care, quality of life, and patient outcomes of approximately 1,000 AIDS-infected clients under a fee-for-service Medicare/Medicaid reimbursement system and a condition-based Medicare/Medicaid capitated hospice. The project will also provide a fuller continuum of care and test the model on a broader population base. To accomplish this, an effort will be made to remove barriers to hospice utilization by AIDS patients through patient and physician education as well as broadening AIDS hospice eligibility requirements.

**Coordinated Care System (Managed Care Plan)**

**Missouri Department of Health**

Bureau of HIV/AIDS Care  
930 Wildwood  
Jefferson City, MO 65109  
OFC: (573) 751-6107  
FAX: (573) 751-6447  
eMail: N/A

**Contact Person:**

James Dempsey, M.A., M.S.W.  
**Project Period:** 10/94-09/97

The objective of this project is to develop and implement an "Integrated Model of Care" for patients with HIV that suffer from mental illness and/or have substance abuse problems in Kansas City, St. Louis, and outstate Missouri. An enhanced case management system (through collaborative efforts with the Department of Mental Health) is being developed which will simplify referral services for mental health and substance abuse treatment services.

**University of Nevada School of  
Medicine**

Department of Pediatrics  
411 W. Second Street  
Reno, NV 89503  
OFC: (702) 784-6170  
FAX: (702) 784-4828  
eMail: tal@med.unr.edu

**Contact Persons:**

Trudy Larson, M.D.  
Barbara Scott, MPH, RD  
**Project Period:** 10/94-09/98

The goal of this service delivery model is to provide comprehensive nutrition assessment and intervention services to relatively healthy individuals with HIV. Patients are from the Early Intervention Clinic of the Washoe County District Health Department and from private practitioners in the medical service area of Reno, Nevada. The program will-- 1) demonstrate the efficacy of nutritional services in preventing or delaying the onset of weight loss and wasting syndrome in individuals with HIV, 2) determine the most practical and cost effective system of incorporating nutrition screening and counseling in a clinic setting, and 3) develop an automated FAX-IN based system for recording, managing, and tracking data from physician and nursing interventions.

### **Intermediate Level of Care**

**Larkin Street Youth Center**

1044 Larkin Street  
San Francisco, CA 94109  
OFC: (415) 673-0911  
FAX: (415) 923-1378  
eMail: N/A

**Contact Persons:**

Anne Stanton, M.S.W., C.S.W.  
Michael Kennedy, M.S., M.F.C.C.  
**Project Period:** 10/94-09/99

There are two primary objectives for this project. First, the Larkin Street Youth Center (LSYC) will expand their existing "Aftercare" program services which provide emergency housing, comprehensive primary medical care and psychosocial support services for homeless youth living with HIV, to serve CDC-defined HIV symptomatic disease, or AIDS diagnosed youth. Secondly, they are establishing an "Assisted Care Facility"; this will consist of a 12-unit assisted living and long-term care facility. The permanent housing program will be a focal point for providing a coordinated service delivery model which manages medical, substance abuse, and mental health treatment needs of these young people.

### **Rural Continuum of Care**

**University of Vermont & State  
Agricultural College**

Medical Center Hospital of Vermont  
Dept. Of Family Practice  
235 Rowell Building  
Burlington, VT 05405  
OFC: (802) 656-4330  
FAX: (802) 656-3353  
eMail: cgrace@salus.uvm.edu,  
ksoons@salvs.uvm.edu

**Contact Person:**

Christopher Grace, M.D.  
Karen Richardson Soons, Ph.D  
**Project Period:** 10/94-09/98

This activity involves the development of three rural community HIV satellite clinics in Vermont to supplement services currently being provided by the state's only comprehensive HIV clinic located in Burlington. These satellite clinics are housed in regional hospitals. The clinics provide state-of-the-art medical care for people with all stages of HIV/AIDS, psychosocial case management, and education for rural primary care providers in diagnosis and treatment of people with HIV/AIDS.

## Service Delivery Models for Women

**Cook County Hospital/Hektoen  
Institute for Medical Research**  
CCSN-12th Floor  
1900 West Polk Street  
Chicago, IL 60612-3810  
OFC: (312) 633-8675  
FAX: (312) 633-4902  
eMail: dris101W@wonder.em.cdc.gov  
HN5391@handsnet.org

**Contact Person:**  
Mary Driscoll, R.N., M.P.H.  
**Project Period:** 10/94-09/99

**Research Foundation of SUNY**  
Health Sciences Center at Brooklyn  
450 Clarkson Avenue, Box 1240  
Brooklyn, NY 11203  
OFC: (718) 270-2690  
FAX: (718) 270-3386  
eMail: jrrips@netmail.hscbklyn.edu

**Contact Persons:**  
Howard Minkoff, M.D. or  
Jill Rips, M.A., M.Phil  
OFC: (718) 270-4737  
FAX: (718) 270-3386  
**Project Period:** 10/94-09/99

### **Washington University School of Medicine**

660 South Euclid Avenue  
Campus Box 8051  
St. Louis, MO 63110  
OFC: (314) 747-1026 or 362-4413  
FAX: (314) 362-5727  
eMail: kmeredit@imgate.wustl.edu

**Contact Persons:**  
Victoria Fraser, M.D.  
Karen Meredith, M.P.H., R.N.  
**Project Period:** 10/94-09/99

Cook County Hospital HIV Primary Care Center, Women and Children's HIV Program is developing the Maternal and Child Health (MCH) HIV Integration Project. The purpose of this project is to insure HIV education, counseling and testing by consent in all family planning and perinatal sites in Cook County. Additionally, the project will link the MCH service delivery sites and the Ryan White funded primary care agencies to guarantee on-going care for identified women living with HIV and their families. The project is also following HIV + pregnant women and their infants. The evaluation will assess the change in practice of MCH providers in providing HIV education counseling and testing by consent as a routine part of MCH care and the offering of ZDV to pregnant women.

The major objectives of this initiative are to develop systems which-- 1) reduce the frequency of perinatal transmission of HIV through increased counseling and testing of pregnant women and increased use of perinatal AZT protocols, 2) enhance access to care for women with HIV through provision of combined HIV primary and gynecologic care, and 3) disseminate successful systems models to the greater community of providers. Models are being developed at three sites--SUNY Health Science Center at Brooklyn, a tertiary care center; Kings County Hospital Center, a municipal hospital; and Luthern Medical Center, a community hospital.

This project is developing a special care unit for women with HIV to integrate services for women in a 12 county area around St. Louis. Early intervention and treatment would be promoted to involve women in the area who are not presently seeking services. The integrated services will include pediatric services. Case management will be used to coordinate all services and appointments while attempting to assure compliance with medication and medical regimens. The intended results are to identify women with HIV at an earlier stage, increase access to service and clinical trials, opportunistic infections and vertical HIV transmission and improve quality of life.

**Active Substance Abusers**

**Outreach, Inc.**

3030 Campbellton Road, SW

Atlanta, GA 30311

OFC: (404) 346-3922

FAX: (404) 346-3036

eMail: N/A

Contact Person:

Sandra McDonald

Project Period: 10/94-09/99

Outreach's project, **SAFE PLACE**, utilizes a peer counselor and street team model for service delivery using indigenous staff. They will expand enrollment and enhance retention of substance abusers with HIV in primary care by opening a satellite facility within an African-American neighborhood near downtown Atlanta. Activities will include assisting 75 substance abusing, HIV-infected adults in obtaining medical and substance abuse treatments. The project also addresses barriers to care by developing a training program for primary care and other service providers.

**PROTOTYPES**

5601 W. Slauson Avenue, Suite 200

Culver City, CA 90230

OFC: (310) 641-7795

FAX: (310) 649-3096

eMail: sarw23a@prodigy.com

Contact Person:

Vivian Brown, Ph.D.

Project Period: 10/94-09/99

PROTOTYPES heads a consortium of Los Angeles County agencies designed to be a community-based, outpatient model for delivering a comprehensive continuum of services for women with HIV/AIDS. Women are recruited throughout Los Angeles County in order to-- 1) provide a range of quality services to substance abusing women with HIV designed to increase their use of health care services and treatment compliance; 2) change risk behaviors with an array of services; 3) increase compliance with medical treatment and enhance access to existing services outreach to high need women; 4) improve the quality of life for women living with HIV through comprehensive case management; 5) increase provider's knowledge, receptiveness and skill in treatment of women substance abusers living with HIV; 6) to develop and evaluate models for replication and integration into HIV/AIDS delivery systems for women; and 7) disseminate information about successful service models.

**Well-Being Institute**  
216 South State Street, Suite 4  
Ann Arbor, MI 48104  
OFC: (313) 913-4300  
FAX: (313) 913-4306  
eMail: user6rm@mts.cc.wayne.edu  
**Contact Person:**  
Geoffrey Smereck, J.D.  
**Project Period:** 10/94-09/99

The Well-Being Institute Women's Intervention Program is a comprehensive, nursing-based intervention program designed for HIV positive women substance abusers who are not accessing existing health delivery systems. The program is three-tiered and will serve 32 women at any one time. Tier one services assists women in overcoming access barriers to primary health care services. Tier two services assist women to become drug free and provide temporary housing for the women and their children. Tier three services provide an opportunity for participation in a revenue-generating activity for the women.

### **Ethnic Group Facing Both Linguistic and Cultural Barriers**

**Center for Community Health,  
Education, and Research**  
(formerly Haitian Community AIDS  
Outreach)  
420 Washington Street  
Dorchester, MA 02124  
OFC: (617) 265-0628  
FAX: (617) 265-4134  
eMail: N/A  
**Contact Person:**  
Eustache Jean-Louis, M.D.  
**Project Period:** 10/94-09/97

The project is seeking to enhance its current community and hospital-based case management system. The enhancement will add one-on-one intensive counseling sessions and educational training. The grantee will develop a Haitian culturally competent risk reduction curriculum. Clients will be selected from the Haitian population residing in the Greater Boston Area who are HIV+ or have AIDS. The participants will sign a consent form and receive a stipend for complying with the guidelines and completing the program.

### **Special Populations Experiencing HIV-Based Discrimination**

**Indiana Community AIDS Action  
Network**  
3951 North Meridian Street, Suite 200  
Indianapolis, IN 46208  
OFC: (317) 920-3190  
FAX: (317) 920-3199  
eMail: HN3745@handsnet.org  
**Contact Person:**  
Paul Chase, J.D.  
Steve Johnson  
**Project Period:** 10/94-09/96

This program targets African-Americans and men who have sex with men to increase their utilization of advocacy services and, therefore, reduce barriers to health care access and discriminatory practices encountered in health care settings, employment, housing, public accommodations, governmental services, criminal justice, social/domestic relations, and insurance. The model provides education to reduce HIV discrimination by employers and health care providers, coupled with skills building to increase the capacity of consumers and consumer advocates to redress HIV-related bias. Primary objectives are assistance in enforcing state and federal anti-discrimination laws and development of a grass roots coalition through which to influence public policy decision-making. Increased utilization of these advocacy services will reduce barriers to health care access and financing.

**Michigan Protection and Advocacy Services**

29200 Vassar Blvd., Suite 501  
Livonia, MI 48152-2181  
OFC: (810) 473-2990  
FAX: (810) 473-4104  
eMail: HN5293@handsnet.org or  
HN5606@handsnet.org

**Contact Persons:**

Jay Kaplan, J.D.  
Laura Anderson, J.D.

**Project Period:** 10/94-09/96

This project is expanding its HIV/AIDS Advocacy Program to increase access to legal services and information on rights to HIV+ African-Americans, Latinos, gay men and lesbians throughout Michigan. The program trains volunteer community advocates on HIV-related laws, who will in turn provide legally-based advocacy services to clients within their own community. The program is also training attorneys, expanding an attorney referral network, and pursuing some impact litigation.

**Underserved Population Groups**

**Center for Women Policy Studies**

1211 Connecticut Avenue, NW - Suite 312  
Washington, D.C. 20036  
OFC: (202) 872-1770  
FAX: (202) 296-8962  
eMail: HN4066@handsnet.org

**Contact Persons:**

Leslie Wolfe  
Belinda Rochelle

**Project Period:** 10/94-09/99

The Center for Women Policy Studies project--the Metro DC Collaborative for Women with HIV--is designed to ameliorate organizational barriers to care for women with HIV through organizational collaboration and inclusion of women with HIV, their providers, and advocates in policy development. The project is conducted in collaboration with PROTOTYPES. The components of the model are-- 1) nurturing leadership among women with HIV in the policy arena and building a cadre of women with HIV who are policy advocates and influencers; 2) for educating policy makers about the needs of women with HIV; 3) capacity building through training, technical assistance, and organizational development; and 4) process and outcome evaluation consisting of a needs assessment instrument of service barriers, a longitudinal client-participation instrument, a training and technical assistance evaluation form, and a fax-in data system maintained by TMG, as well as qualitative data gathering.

**Health Initiatives for Youth**

1242 Market Street, 3rd Floor  
San Francisco, CA 94102  
OFC: (415) 487-5777  
FAX: (415) 487-5771  
eMail: HN5409@handsnet.org

**Contact Persons:**

Ron Henderson

**Project Period:** 10/94-09/99

This project helps health and human service providers offer developmentally and culturally appropriate care for HIV-affected youth and young adults ages 12 to 25. This project offers a variety of experiential trainings on health and psychosocial topics related to youth; informational resources including a quarterly newsletter, a directory of providers, and information on packets; and technical assistance through in-person, written,

*Health Initiatives for Youth cont'd*

**Interamerican College of Physicians and Surgeons**

NYU School of Medicine  
915 Broadway, Suite 1105  
New York, NY 10010-7108  
OFC: (212) 777-3642  
FAX: (212) 505-7984  
eMail: [icps@iia.org](mailto:icps@iia.org)

**Contact Persons:**

James P. Tierney  
Larua Zizic

**Project Period:** 10/94-09/97

and telephone consultation. In addition, the project encourages networking and collaboration among providers so that youth receive better coordinated care for HIV and health-related concerns.

This project is a collaborative effort between the Interamerican College of Physicians and Surgeons (ICPS), Bellevue Hospital Medical Center, and the Department of Dermatology at NYU School of Medicine. ICPS is expanding access to health care services for HIV-infected Hispanic populations by increasing, through training, the number of Hispanic health care providers active in screening, testing, counseling, and managing their patients at risk or already HIV infected. Individualized training will be provided to each of the 90 physician trainees in their private offices and an in-hospital training session will be held at Bellevue Hospital Medical Center. Physicians will be assigned to intervention and control groups in a randomized research trial with a post-test intervention and a case study design involving 5% of randomly selected subjects.

**University of Texas Health Science Center at San Antonio**

Community Pediatrics Division  
7703 Floyd Curl Drive  
San Antonio, TX 78284-7818  
OFC: (210) 567-7400  
FAX: (210) 567-7443  
eMail: [german@uthscsa.edu](mailto:german@uthscsa.edu)

**Contact Persons:**

Victor German, M.D., Ph.D.  
Selina Catala, M.S., L.C.D.C.

**Project Period:** 10/94-09/97

The "Salud y Unidad en la Familia/Health and Unity in the Family" ("SALUD") project targets the health and human services delivery system for women, children, and their families with HIV in South Texas. Project "SALUD" is a collaborative effort involving the Texas Department of Protective and Regulatory Services (TDPRS) and four Ryan White service providers who have been seminal organizations in the development and delivery of HIV/AIDS services in San Antonio, Corpus Christi and the Lower Rio Grande Valley. This project is designed to provide a mechanism for urban and rural communities to build upon existing strengths and capacities for continued development of a comprehensive, family-centered continuum of care for HIV/AIDS women, children, and their families. Project "SALUD's" goal is to bring about system assessment and system change. System assessment objectives include: child and family-focused needs assessment and organizational and systems resource assessment. System change objectives include: dissemination activities at the local and state levels, cross-training of staff, caregiver training and curricula development.

**Provider Training and Educational Models in Rural, Correctional, or  
Mental Health Settings**

**Correctional**

**Emory University**  
Southeast AIDS Training and Education  
Center  
735 Gatewood Road, NE  
Atlanta, GA 30322  
OFC: (404) 727-2929  
FAX: (404) 727-4562  
eMail: rswift@emory.edu  
**Contact Persons:**  
Ira Schwartz, M.D.  
Jacqueline Zalumas, Ph.D., R.N., FNP  
**Project Period:** 10/94-09/97

This project is developing, testing, and evaluating educational models for increasing, improving, and updating knowledge about HIV infection and treatment for Georgia's correctional health care providers. Using a quasi-experimental design, Emory will compare the impact of three different levels/intensities of training and three different training strategies. The project is utilizing interviews and chart audits to examine the following variables: knowledge and attitudinal changes, trainees' assessments, and observed change over time.

**The Fortune Society, Inc.**  
39 West 19th Street  
New York, NY 10011  
OFC: (212) 206-7070  
FAX: (212) 366-6323  
eMail: JPFORTUNE@aol.com  
**Contact Persons:**  
JoAnne Page, J.D.  
Tracey Gallagher  
**Project Period:** 10/94-09/99

The Fortune Society's Latino Discharge Planning (LDP) program delivers culturally and linguistically appropriate services to Hispanic women and men prisoners and releasees who are HIV+ and symptomatic in New York City jails and New York state prisons. This project focuses on discharge planning for prisoners, case management referrals with follow up, and intensive case management post release. This innovative approach entails identification of and consistent contact with clients prior to release.

**Mental Health**

**University of Washington**  
AIDS Education and Training Center  
1001 Broadway, Suite 217  
Seattle, WA 98122  
OFC: (206) 720-4250  
FAX: (206) 720-4218  
eMail: keegan@u.washington.edu  
**Contact Person:**  
Karina Uldall, M.D.  
**Project Period:** 10/94-09/97

The University of Washington Center for AIDS and STDs is working with the School of Medicine, Department of Psychiatry and Behavioral Science to train primary care providers, mental health staff, and volunteers at four sites: Harborview Medical Center, Swedish Medical Center AIDS Unit, Bailey Boushay House and Rosehedge. The training and education model will develop, test, and evaluate strategies for increasing, improving, and updating

*University of Washington cont'd*

knowledge about HIV neuropsychiatric illness with specific emphasis on delirium and its treatment. Program goals include enhancing current service delivery and standardizing assessment and treatment across providers in the project.

**Rural Areas**

**University of Colorado Health Sciences Center**

4200 E. Ninth Avenue, Box A-089  
Denver, CO 80262  
OFC: (303) 315-2516  
FAX: (303) 315-2514  
eMail: andersod@essex.hsc.colorado.edu

**Contact Persons:**

Donna Anderson, Ph.D., M.P.H.  
Sara Martin

**Project Period:** 10/94-09/97

This project is evaluating the impact and cost effectiveness of three educational methodologies designed to increase service delivery to individuals in rural areas. The methodologies are self-study modules, two-way interactive audio/visual teleconferencing, and experiential programs delivered by rural outreach teams. The project focuses on physicians, physician assistants, and nurses to examine whether improvements in knowledge, attitudes, and willingness translate into increased services for at-risk and seropositive individuals.

**University of Mississippi Medical Center**

Division of Infectious Diseases  
2500 N. State Street  
Jackson, MS 39216  
OFC: (601) 984-5556  
FAX: (601) 984-5565  
eMail: harold@fiona.umsmed.edu

**Contact Person:**

Harold Henderson, M.D.

**Project Period:** 10/94-09/99

This project is enhancing the capacity of health care providers in rural clinics to diagnose and treat asymptomatic HIV disease. This occurs by expanding the Delta AIDS Education and Training Center's (DAETC) ability to provide clinical training for those providers with a computer-based distance learning system and building on the existing preceptorship provided by DAETC. Physicians, nurse practitioners, and dentists at targeted clinics are being provided with updated medical references, access to sources of additional HIV funding, and a means for interactive training supervised by HIV specialists at University of Mississippi Medical Center. Providers and community health centers in areas of highest HIV prevalence are being targeted.

## Evaluation and Dissemination Center (EDC)

### **The Measurement Group/PROTOTYPES Consortium**

c/o The Measurement Group  
5811A Uplander Way  
Culver City, CA 90230  
OFC: (310) 216-1051

FAX: (310) 670-7735  
eMail: ghuba@prodigy.com  
lmelchior@prodigy.com

#### **Contact Persons:**

George Huba, Ph.D.

Lisa Melchior, Ph.D.

**Project Period:** 10/94-09/99

The Measurement Group/PROTOTYPES consortium provides consultation and technical support services to grantees which include components of centralized data entry/management, statistics and management information reports, and information dissemination functions. Some specific activities that the Center provides to HRSA as well as the HIV Service Delivery grantees include review and assess evaluation plans; provide technical assistance to refine and implement evaluations; conduct an evaluation workshop; provide on-going support for data collection and analysis of site-specific data; monitor the quality of data and provide feedback; establish and maintain a computerized data repository; provide writing and editing support; provide logistical support for meetings; and work with HRSA and grantees to produce journal articles and policy program reports. The EDC is a consortium headed by The Measurement Group and also includes PROTOTYPES. The Measurement Group provides overall management for the EDC and is responsible for the evaluation and some dissemination activities. PROTOTYPES is responsible for logistical support of the Steering Committee meetings and dissemination activities.

## Special Projects of National Significance (SPNS) Program Grantees

<i>Adolescent Care Demonstration and Evaluation</i>	<i>Dissemination and Refinement of the Model</i>	<i>HIV Service Delivery Models</i>
<p>Bay Area Young Positives, Inc. Children's Hospital, Boston (Boston Happens) Children's Hospital, Los Angeles Greater Bridgeport Adolescent Pregnancy Program, TOPS Program Health Initiatives for Youth Indiana Youth Access Project (ISHD) University of Alabama at Birmingham University of Minnesota, Youth, and AIDS Project Walden House, Inc. YouthCare</p>	<p>Children's Hospital, New Orleans Children's National Medical Center Family Planning Council of SE Pennsylvania Fortune Society, Inc. Indiana Integration of Care Project (ISHD) Montefiore Medical Center Multnomah County Health Department National Native American AIDS Prevention Center (NNAAPC) Protection &amp; Advocacy System, Inc. (New Mexico)</p>	<p>AIDS Healthcare Foundation Center for Community Health, Education, and Research Center for Women Policy Studies Cook County Hospital/Hektoen East Boston Neighborhood Health Center Emory University Fortune Society Health Initiatives for Youth Indiana Community AIDS Action Network Interamerican College of Physicians &amp; Surgeons Johns Hopkins University School of Medicine Larkin Street Youth Center Michigan Protection &amp; Advocacy Services Missouri Department of Health New York State Department of Health/Health Resources Outreach, Inc. PROTOTYPES (includes TMG/PROTOTYPES EDC) Research Foundation of SUNY University of Colorado Health Sciences Center University of Mississippi Medical Center University of Nevada at Reno University of Texas Health Science Center at San Antonio University of Vermont &amp; State Agricultural College University of Washington Visiting Nurses Association of Los Angeles Washington University School of Medicine Well-Being Institute</p>

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### **AIDS Healthcare Foundation**

Los Angeles, CA  
OFC: (213) 462-2273  
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Atlanta, GA

OFC: (404) 727-2929  
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### **Bay Area Young Positives, Inc.**

San Francisco, CA  
OFC: (415) 487-1616  
Page: 2

### **Family Planning Council of S.E. Pennsylvania**

Philadelphia, PA  
OFC: (215) 985-2657  
Page: 5

### **Center for Women's Policy Studies**

Washington, D.C.  
OFC: (202) 872-1770  
Page: 15

### **Fortune Society, Inc.**

New York, NY  
OFC: (212) 206-7070  
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### **Children's Hospital, Boston Boston Happens**

Boston, MA  
OFC: (617) 355-6495 or 735-7131  
Page: 2

### **Greater Bridgeport Adolescent Pregnancy Program – TOPS Project**

Bridgeport, CT  
OFC: (203) 384-3629  
Page: 3

### **Children's Hospital, Los Angeles**

Los Angeles, CA  
OFC: (213) 669-4604  
Page: 2

### **Center for Community Health, Education, and Research (formerly Haitian Community AIDS Outreach)**

Dorchester, MA  
OFC: (617) 265-0628  
Page: 14

### **Children's Hospital, New Orleans**

New Orleans, LA  
OFC: (504) 524-4611  
Page: 5

### **Health Initiatives for Youth**

San Francisco, CA  
OFC: (415) 487-5777  
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### **Children's National Medical Center**

Washington, D.C.  
OFC: (202) 884-4004 or 5451  
Page: 5

### **Indiana Community AIDS Action Network**

Indianapolis, IN  
OFC: (317) 920-3190  
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### **Cook County Hospital/Hektoen**

Chicago, IL  
OFC: (312) 633-8675  
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### **Indiana Integration of Care Project (ISHD)**

Indianapolis, IN  
OFC: (317) 233-7867  
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### **East Boston Neighborhood Health Center**

Boston, MA  
OFC: (617) 568-4755 or 4452  
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### **Indiana Youth Access Project (ISHD)**

Indianapolis, IN

### **Emory University**

OFC: (317) 541-8726

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**Interamerican College of Physicians and Surgeons**

New York, NY

OFC: (212) 777-3642

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**Johns Hopkins University School of Medicine**

Baltimore, MD

OFC: (410) 955-7634

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**Larkin Street Youth Center**

San Francisco, CA

OFC: (415) 673-0911

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**Michigan Protection and Advocacy Services**

Livonia, MI

OFC: (810) 473-2990

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**Missouri Department of Health**

Independence, MO

OFC: (816) 325-6140

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**Montefiore Medical Center**

Bronx, NY

OFC: (718) 430-2154

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**Multnomah County Health Department**

Portland, OR

OFC: (503) 248-5020 x 2290

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**National Native American AIDS Prevention Center (NNAAPC)**

Oakland, CA/Oklahoma City, OK

OFC: (510) 444-2051/(405) 631-9988

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**New York State Department of Health/Health Resources**

Albany, NY

OFC: (518) 473-7781

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**Outreach, Inc.**

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OFC: (404) 346-3922

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**Protection and Advocacy System, Inc.**

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**PROTOTYPES**

Culver City, CA

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**Research Foundation of SUNY**

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**The TMG/PROTOTYPES Consortium**

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**University of Alabama at Birmingham**

Birmingham, AL

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Denver, CO

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**University of Minnesota, Youth, and AIDS Project**

Minneapolis, MN

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Jackson, MS

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**University of Nevada School of Medicine**

Reno, NV  
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San Antonio**

San Antonio, TX  
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College**

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**University of Washington**

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**Visiting Nurses Association of Los Angeles**

Los Angeles, CA  
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**Walden House, Inc.**

San Francisco, CA  
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**Washington University School of Medicine**

St. Louis, MO  
OFC: (314) 747-1026 or 362-4413  
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**Well-Being Institute**

Ann Arbor, MI  
OFC: (313) 913-4300  
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**YouthCare**

Seattle, WA  
OFC: (206) 282-9907  
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