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THE WHITE HOUSE
Office of National AIDS Policy

FOR IMMEDIATE RELEASE

April 21, 1994

**GEBBIE HOLDS DISCUSSION AT HOWARD UNIVERSITY ON
HIV/AIDS AND HEALTH CARE REFORM**

Today, Kristine M. Gebbie RN, MN, National AIDS Policy Coordinator, spoke with an audience of Howard University students from various health disciplines, community HIV/AIDS advocates, those infected and affected with HIV/AIDS and answered very spirited, pointed questions about the impact of HIV/AIDS on the African American community.

This forum was moderated by Belma Johnson, Host and Producer of Black Entertainment Television's "TEEN SUMMIT."

The discussions centered around the many of the following issues: implications of the disproportionate spread of HIV/AIDS among African Americans; efficacy of AZT for this population; concern about the possible deliberate creation of this disease; the need for HIV/AIDS care for women, men and children of color; the need for media images that are consistent with the culture of this community in prevention messages; the effectiveness of needle exchange in communities of color.

"The African American community faces many unique challenges and is disproportionately affected by this epidemic" Gebbie said. "I enjoyed speaking at Howard University today and listening to the concerns of those present. I look forward to continuing work with the African American community to help improve their situations that relate to HIV/AIDS."

Ms. Gebbie also stressed the importance of the President's Health Security Act and emphasized its importance to all people living with HIV and to the African American community as a whole.

Co-sponsors included the D.C. Public Schools, Comprehensive School Health Program and the Howard University Department of Physical Education and Recreation.

A Bill to Strengthen and Improve the Public Health System

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Schools 1
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I. Public health dollars have been decreasing over the last decade, in spite of the increased threats to public health and safety and accounted for 0.9% of total national health expenditures last year. As a result of the increasing numbers of uninsured, state and local health departments have become the primary providers for millions of Americans and provided personal care services. An estimated 40 million people received personal health care services through local health departments last year. The shrinking pot of money for public health departments has meant, in many jurisdictions, that the core functions of public health have been greatly reduced or eliminated. In any type of health care environment, it is the public health system which is responsible for community assessment of needed services, assurance that groups of providers are available to meet community needs, and the administration of disease prevention and health promotion programs.

II. Strengthening the public health system is important for the following reasons:

A. Without universal coverage, the burden of health care delivery to the uninsured will continue to fall on local and state health departments, as the provider of last resort. Decreasing their capacity to respond to personal care services will increase the burden on hospitals (very costly and inappropriate care); and exacerbate existing public health problems, i.e. spread of TB, spread of STD's, low immunization rates, low birth weight babies, spread of HIV, etc. Public health issues know no boundaries, therefore the inability of one jurisdiction to adequately address public health threats has the potential to affect contiguous jurisdictions as well as far away states.

B. Risks to public health have increased and health departments have not had the resources to respond appropriately as the majority of resources have been diverted to personal care services. Examples include the high cost of violence, STD's and HIV, teenage pregnancies, environmental threats such as radon, and the contamination of drinking water; alcohol and substance abuse; and the re-emergence of TB.

C. Public health departments safeguard the public's health, not just that of the poor and uninsured. It is the job of the public health departments to identify and monitor emerging patterns of illness, injury and disease in localities as well as within and across regions of the country; identify the etiology of the illness, injury or disease(s); educate the public about any known risks, preventive measures, and available services; and collaborate with community health providers to develop effective clinical, educational and outreach programs.

D. Adolescents have high rates of preventable health problems and unacceptably high rates of mortality. Adolescents are likely to experience poverty and violence in their daily lives. And they often do not have accessible, appropriate and

affordable health care. Adolescents have the lowest utilization rates of health care services of any age group and they are the least likely to seek care through traditional office-based settings, despite the range of serious threats to their health and well-being. Adolescents need broad community and school-based clinical services and preventive strategies that promote healthy lifestyles. School-based clinics and non-traditional sites for adolescent health care are currently limited in both scope and availability. Yet, they have the potential to be the linchpin in combatting high rates of adolescent morbidity and mortality.

E. The HHS Secretary's Report to Congress on Health Personnel in 1991 stated that personnel shortages in public health occupations have severely impeded the ability of state and local health departments to effectively identify and address public health problems. While health professional trained to handle the unique demands of rural and inner city public health issues are in the shortest supply, even the health departments of Alexandria, Arlington and Fairfax cite the lack of expertise in public health impedes effective planning, implementation and evaluation of health programs.

F. Much of the emphasis of health reform is on institutionalizing preventive health care through appropriate clinical services and changes in individual behaviors. This is the mandate of population-based health programs, which attempt to protect the public from threats to their health. Including clinical preventive services in a uniform benefit package is critical but not enough. For example, TB screening might be included, but community surveillance, follow-up, and education and risk reduction efforts are public health responsibilities that will not be undertaken by an individual health plan.

G. The overarching goal of health care reform is cost-containment. The only way to realize this goal over the long term is by improving the overall health status of the population through prevention, and early detection and treatment of disease, injury and illness. It is the job of the public health system to lead community-based health promotion and disease prevention activities. Therefore, strengthening the public health system is critical to achieving long term health care cost containment.

III. With the exception of the President's Health Security Act, no bill has a provision to strengthen the public health system as part of national health reform. This bill could serve as a stand alone or as an amendment to any of the reform bills under consideration.

IV. The Public Health Infrastructure Improvement Act

A. Objectives

1. To expand the capacity of the public health system at the federal, state and local levels to undertake all of the core public health functions in a comprehensive manner. This

bill must designate a secure funding source for core public health functions, rather than leaving funding decisions to the annual appropriations process.

2. To expand and secure funding for the training of (new and existing) public health professionals in settings and institutions approved by the Council for Education for Public Health. A critical mass of public health disciplines of epidemiology, biostatistics, environmental health, health services administration, behavioral and social sciences are needed to build a prevention capacity.

3. To ensure a complementary relationship of community-based public health programs with delivery networks, alliances and health plans must be coordinated in each state by the official state health agency.

a. Networks, alliances, and/or health plans should be required to assess the health status of the communities which they insure. This would necessitate attention to public health problems and priorities. Outcome reporting should reflect personal and public health services relative to the objectives established in Health People 2000.

b. Both the medical care delivery system and the public health system collect data. The medical care system reflects individual encounter data, while public health data reflects community wide health indicators. Both are important in assessing community health and must be integrated.

4. To aggressively promote disease prevention, health education and some clinical services through the schools, with an emphasis on high risk children and adolescents.

5. To assure continuity of care for indigent and low income persons by securing funding for public clinics, local and state health departments, community, migrant and homeless health centers, and continue existing categorical grants, at least during the transition period for health reform legislation.

B. Mechanisms:

1. Establish a Public Health Infrastructure Fund approximating 2.7% of national health expenditures, \$25 billion. Last year, the US spent 0.9% of national health expenditures, \$8.4 billion, on public health, down from 1.2% in 1981.

A. Part of the Public Health Infrastructure Fund would be designated for Core Public Health Functions, to be managed and monitored by the CDC and planned and implemented by the states and local health departments. The following core functions would be required to be fully operational in all states:

1. Monitor and protect the health of communities from communicable diseases and exposure to toxic environmental pollutants, occupational hazards, harmful products and poor quality health care;

a. Data collection and analysis activities related to assessing community health status and outcomes reporting;

b. Activities to protect the environment and assure the safety of housing, workplaces, food and water;

2. Identify and control outbreaks of infectious disease, patterns of chronic disease and injury and adverse health conditions, including cooperative activities to reduce violence levels;

3. Develop, provide and disseminate information, education and communication about health promotion and disease prevention; appropriate and timely use of medical services;

4. Develop, test, evaluate and publish results of new prevention and public health control interventions, including assessment of the impact of health reform on quality of services and access to appropriate health services;

a. Internal and external evaluation of all public health programs annually against measurable targets, using process and outcome indicators

b. Formal communications linkage between state and local health departments across the country to ensure accessibility to data

c. Core public health functions should be evaluated against the objectives defined in Healthy People 2000 at state and local levels.

5. Provision of public health laboratory services to complement private clinical laboratory services; including screening tests for metabolic diseases in newborns, toxicology assessments of blood lead levels and other environmental toxins, tuberculosis and other diseases requiring partner notification, test for infectious and food-borne diseases;

6. Policy development and formulation of public health priorities at the state level after consultation and coordination with local health departments. This process should reflect the priorities in Healthy People 2000. Development of community public health coalitions to support and carry out these priorities are an essential component of core

functions;

7. Co-ordination of professional training at the state and local levels; technical assistance to state local health departments to undertake training

B. CDC Role

1. CDC would receive 5% of the total cost of the core functions program in order to plan, manage and evaluate...also to link together the states in an accessible communications network.

2. Assist in developing state, regional and national public health priorities

C. State Compliance:

1. Each state must develop a detailed analysis on the current public health problems, health status indicators, current public health responsibilities and develop plans for activities to address the core functions shortfall. The CDC will distribute grant money to each state, based on a FORMULA grant, reflecting health status indicators, demographic characteristics; epidemiologic data; and income levels. This is in contrast to a competitively bid grant (in the President's plan), which would mean that states would receive money for public health based on grant writing ability, rather than on need.

2. States would be required to document their activities, using both utilization and outcome indicators. States would be held accountable for achieving health outcome targets based on Healthy People 2000. For example, a utilization indicator would indicate number of contacts with health care system; outcome indicators would reveal the health status consequences of those contacts. States would be required to continue their current level of funding. CDC would monitor these activities and would provide technical assistance to those states not currently active in the core public health functions.

D. Expand training of public health professionals through the National Health Service Corps. This program is presently limited to physicians, nurses, and physician assistants and should be expanded to include professionals in the planning, implementation and evaluation of public health programs. The structure of the program would be expanded to include pay back through service in public health agencies, alliances, and purchasing cooperatives. The numbers of professionals trained through the National Health Service Corps should reflect the assessment of Phase I, see

E. Expand the community health improvement initiatives undertaken by states and localities, by supporting pilot projects and encouraging findings to be published and

circulated through the existing networks of state and local health departments. The Community Health Advisor Act, introduced by Rep. Sanders would fall into this category.

F. Establish grants to states for development of community-based provider networks, formation of health plans and service expansion which include local health departments as essential community providers.

1. All health plans would be required to offer contracts to all essential community providers in the health plans' service area. Essential community providers would include: Hospitals that would qualify for a Medicare disproportionate share adjustment under section 1886 (d) (5) (F) (i) (II) or 1886 (d) (5) (f) (vii) (I) of the Social Security Act; FQHC's, except that the governance requirements need not be met with respect to membership of the Board of Directors if the facility provides assurances of significant community input; local health departments; sole community hospitals; rural health clinics; Hospitals that would qualify as a Medicare-Dependent Hospital under Section 188(d)(5)(G)(i) of the Social Security Act; and individual health providers who serve more than one medically underserved area 20 hours /week, are licensed to practice in that jurisdiction, and hold hospital staff privileges or has a consultation and referral arrangement with one or more physicians who hold hospital staff privileges. Payment to essential community providers must be commensurate with payment to other providers participating in an area health plan.

2. Enabling services such as transportation, child care, translation services, outreach and public nursing visits to the home must be included.

3. Also included should be plans for shared public health data through electronic data systems. Safe harbors for Federally Qualified Health Centers and Rural Health Centers to allow participation in networking to improve services to medically underserved populations.

4. FQHC's and RHC's should receive Medicare Graduate Medical Education (GME) payments commensurate with direct and indirect teaching costs for those who actively participate in approved training programs.

G. Expand Migrant and Community Health centers. This should include funds for capital development, facility and equipment rehabilitation; and modernization of facilities to eliminate safety hazards. \$400,000,000

2. Formation of Public Health Advisory Board (PHAB)

A. PHAB should include, but is not limited to, eight professionals with expertise in the areas of planning,

implementation, management and evaluation of public health programs; medicine, public health nursing; environmental and sanitary engineering.

1. Advises the Secretary of HHS in conjunction with the Secretary of the Public Health Service; appointed by the Secretary of HHS.

2. Develops guidelines, in conjunction with CDC, for states to assess the existing status and effectiveness of public health programs, with respect to the epidemiological profile of their communities.

3. PHAB will monitor states' activities and effectiveness in carrying out core functions program and other new initiatives.

4. Will assist the Secretary of HHS and PHS in developing national public health priorities.

5. Will develop in conjunction with CDC, guidelines for evaluation of public health initiatives at the federal and state level.

B. States will undertake an 18 month evaluation, based on the guidelines established above, with technical assistance from CDC and the PHS, and submit findings and recommendations for public health funding to the PHAB. PHAB will analyze the state findings, hold a public comment period, and then make recommendations to Congress for five year funding of : core functions, training, migrant and community health centers, etc. \$12 million for planning stage.

1. This phase I assessment is critical in assessing the existing capability of state and local health departments to carry out core public health functions.

2. Congress would appropriate money from the Public Health Infrastructure Trust Fund, after a period of public comment, based on the final recommendations of the PHAB.

C. Retain categorical funding for five years.

3. Establish a School-based Health Education and Outreach Program, designated as "essential community providers" if they meet standards of quality adopted by the Secretary of HHS. This is well organized in the Clinton health plan and should be included here.

4. Financing for the Public Health Infrastructure Fund: 1-2% assessment on gross premiums of accountable health plans; an excise tax on firearms and ammunition; an assessment on all non-

profit hospitals and HMO's; continued funding from general revenues.

THE WHITE HOUSE
WASHINGTON

**Health Care Reform and the HIV Epidemic
Top Ten Issues**

For those infected with HIV, the assurance of comprehensive health insurance is an essential public health goal.

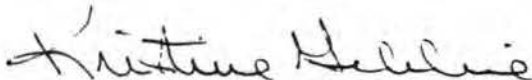
The Office of the National AIDS Policy Coordinator has provided advice on policy formulation during the development of the Health Security Act (HSA). These efforts were directed towards assuring adequate care and services for people with HIV/AIDS. As the Congress now debates the HSA, the Administration is making every effort to assure that modifications to the President's proposal maintain equity and sensitivity to the special needs of HIV-infected individuals.

Private insurance companies, like other businesses, seek to maximize profits by choosing only "acceptable" insurance risks. Under the HSA, universal coverage is guaranteed. Universal means everyone! What does Health Security mean to you?:

- * **Universal coverage - HIV status or other health conditions do not prevent you from getting coverage.**
- * **Community ratings prevent persons with HIV infection from being charged more for premiums.**
- * **Prescription drugs will be covered.**
- * **Ryan White CARE Act services will not be lost.**
- * **Any form of discrimination is prohibited.**
- * **Essential providers - specialists in treating HIV and AIDS will be available to all people who need them.**

Based on a series of focus groups with people with AIDS and HIV/AIDS service organizations, a list of "top ten" concerns for the HIV community were identified. Information regarding these concerns is attached for your review.

I hope this information will be helpful to you. If I can be of further assistance or provide any additional information, please contact me or Andrew E. Barrer, Ph.D. at (202) 632-1090. Thank you.



Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

Top Ten Issues

- 1. Premium Financing and Risk Adjustment**
- 2. Availability of and Assured Access to "Essential Providers"**
- 3. Long-term and Home Care Coverage**
- 4. Availability of Mental Health and Substance Abuse Services**
- 5. Impact of the HSA on the Ryan White CARE Act**
- 6. Medicaid and Medicare Funding and Program Transition Issues, especially as related to the Medicare and Medicaid programs**
- 7. Confidentiality**
- 8. Grievance Procedures**
- 9. Effects of "State Options" on the HSA package of benefits**
- 10. Funding for Public Health System Core Functions (e.g. Behavioral Research, Prevention Services, etc.)**

1. Premium Financing and Risk Adjustment

Issue: Will the risk adjustment mechanism prevent "redlining" for persons with HIV/AIDS or other life threatening illnesses?

Summary: Yes. Redlining, or any attempts to limit access to people with HIV or AIDS is clearly prohibited. The HSA provides mechanisms which require states to spread the financial risks associated with special communities by adjustments which would take into account such factors known to affect utilization of services, such as age, sex, health status and services to disadvantaged populations. The health plans have to meet specific rules on enrollment, community rating, information, and grievance procedures.

2. Availability of HIV Specialist, "Essential Providers"

Issue: Will HIV positive persons be able to continue using their local HIV medical specialist?

Summary: The Health Security Act establishes a special category of health care provider which is referred to as an "essential provider". Any health care provider or organization can make application to be certified as an essential provider. Within the HSA, a Ryan White grantee or subgrantee can be automatically certified as an essential provider. Each health plan must enter into a written agreement with each essential provider located within its service area.

3. Long-term Care and Home Health Care

Issue: Persons with HIV/AIDS often need home health care and long-term care services. Will the Health Security Act provide those needed services?

Summary: Home health care is included in the nationally guaranteed comprehensive benefits package. A new long-term care initiative will expand coverage of home and community-based care. This will make it possible for more elderly and disabled persons, including persons living with HIV/AIDS to live in their homes and communities while receiving long-term care. The Act will improve

Medicaid coverage for persons in nursing homes.

The HSA will improve the quality and reliability of private long-term care insurance and provide tax incentives for persons to buy it; and tax incentives to help individuals with disabilities work.

4. Availability of Mental Health and Substance Abuse Services

Issue: Mental health needs in the HIV/AIDS community tend to be greater than the average. What will HSA do to provide these services? Injecting drug users, at high risk of HIV infection and transmission, currently have inadequate treatment and preventive services available to them. Will adequate services be available to treat these individuals in order to ameliorate their additive disease and halt the epidemic?

Summary: A base level of mental health services will be provided to all persons through the Health Security Act. We know that viable mental health services are part of a good program of health care and especially beneficial to HIV infected persons.

In order to make a significant difference in the rate of new infections in the injecting drug use population and their sexual partners, the HSA will provide substance abuse treatment to everyone.

5. Health Care Reform and the Ryan White CARE Act

Issue: Will the financial restructuring of the health care system assure the delivery of health care services appropriate to the needs of vulnerable populations whose access problems go beyond lack of insurance?

Summary: The comprehensive benefits package provided by the HSA may not provide all essential services for persons with HIV/AIDS. Conversely, a variety of services currently provided by the CARE Act would be covered under the HSA benefits package. These would include primary care services, medications, assistance for health insurance coverage, home-based services, case management,

transportation, and outreach. It may be necessary to utilize Ryan White CARE Act funds "freed up" by the provision of these services under HSA to subsidize the supplemental and client's share of insurance premiums, co-payments, deductibles, and expenditures that exceed spending caps.

The CARE Act is not a "band-aid" that can be discarded after health care reform. The Act will serve as a critical resource to sustain health care delivery systems and insure the continued delivery of essential and comprehensive health and support services to those infected with HIV.

6. Medicaid and Medicare Funding and Program Transition Issues

Issue: What impact will the HSA have on funding for the Medicaid and Medicare programs? What programs will be available during the transition from the old system to the one provided under the HSA?

Summary: Under the HSA adult Medicaid recipients who now receive cash supplements (currently 9 million beneficiaries) would be enrolled in the new system, but would not have to pay premiums. Further, they would be entitled to join a new state and federally-matched program providing wrap-around services similar to those now available under the Medicaid program. Children less than 18 years of age who are currently eligible or would be Medicaid recipients, with eligibility for wrap-around services (primarily based on poverty level), would be provided those services through a new federally funded (but state administered) program, *regardless of their cash assistance status.*

The Medicare program will be preserved and strengthened under the HSA, which will add new coverage for prescription drugs and expanded coverage of home and community-based care.

7. Health Security Act (HSA) and Confidentiality Issues

Issue: What safeguards are envisioned for the handling of health information on HIV affected persons under the Health Security Act ?

Summary: The HSA addresses the issue of how information will be handled and what penalties will be imposed for misusing information. The HSA will provide guidance level information on creation of the oversight board, users and uses of information, privacy standards, enrollee rights, outright prohibitions, training of information handlers, and comprehensive health information privacy protection. The development of the Comprehensive Health Information Privacy Protection Act will be implemented within two years from the date of passage.

8. Grievance Procedures

Issue: How can individuals ensure that their health plan will provide the health benefits and services they require?

Summary: The HSA is intended to provide adequate health care coverage for all citizens and legal residents of the United States. The Act requires States to approve each health plan before it can engage in providing health care under the Act. The law prohibits exclusions because of pre-existing conditions or through "red-lining," the practice of excluding a particular group of individuals because of perceived high risk.

The Health Security Act includes a comprehensive grievance process for any person aggrieved by acts or practices which result in denial or delay of benefits or payments. Individuals must work within the individual plan's grievance process before going to adjudication through the Complaint Review Offices set up in each state. If there is a question as to an individual's eligibility for a plan, subsidies or cost sharing, the individual may go directly to court and all costs can be reimbursed if the court finds for the individual.

The complaint office must rule in under 30 days, although a 24 hour appeal is available in cases of emergency. Appeals must be processed within 60 days. There are means of appealing, with the national board being the ultimate administrative appeal.

9. "State Options"

Issue: What impact will "State Options" have on coverage under the HSA? What impact will it have on services, availability, and affordability?

Summary: Some states cover additional services under federally matched Medicaid programs. Under the HSA, a number of programs will become available at each state's option. To assure that there is not a loss of services to the person with AIDS, Ryan White will continue to act as the safety net to assure needed services reach all people in need. The expanded use of case management, will help follow individual needs and assure services are provided.

10. Public Health System Core Functions

Issue: What is the nature of the funding for research on behavior, health services and Core Functions of Public Health Programs?

Summary: The Health Security Act will provide funding for AIDS specific research and public health initiatives that will have to be provided under the authority of the Public Health System. Behavioral research into those behaviors that may cause or contribute to disease will be conducted by the National Institutes of Health. The Act will also provide funding for strengthening the public health core function of states, including those components related to diseases of public health significance. This support will allow communities to maintain strong programs to prevent the spread of HIV, tuberculosis, and other conditions of public health importance.

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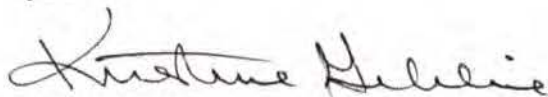
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Issue: How can individuals ensure that their health plan will provide the health benefits and services they require?

Summary: The HSA is intended to provide adequate health care coverage for all citizens and legal residents of the United States. The Act requires States to approve each health plan before it can engage in providing health care under the Act. The law prohibits exclusions because of pre-existing conditions or through "red-lining," the practice of excluding a particular group of individuals because of perceived high risk.

The Health Security Act includes a comprehensive grievance process for any person aggrieved by acts or practices which result in denial or delay of benefits or payments. Individuals must work within the individual plan's grievance process before going to adjudication through the Complaint Review Offices set up in each state. If there is a question as to an individual's eligibility for a plan, subsidies or cost sharing, the individual may go directly to court and all costs can be reimbursed if the court finds for the individual.

The complaint office must rule in under 30 days, although a 24 hour appeal is available in cases of emergency. Appeals must be processed within 60 days. There are means of appealing, with the national board being the ultimate administrative appeal.

9. "State Options"

Issue: What impact will "State Options" have on coverage under the HSA? What impact will it have on services, availability, and affordability?

Summary: Some states cover additional services under federally matched Medicaid programs. Under the HSA, a number of programs will become available at each state's option. To assure that there is not a loss of services to the person with AIDS, Ryan White will continue to act as the safety net to assure needed services reach all people in need. The expanded use of case management, will help follow individual needs and assure services are provided.

10. Public Health System Core Functions

Issue: What is the nature of the funding for research on behavior, health services and Core Functions of Public Health Programs?

Summary: The Health Security Act will provide funding for AIDS specific research and public health initiatives that will have to be provided under the authority of the Public Health System. Behavioral research into those behaviors that may cause or contribute to disease will be conducted by the National Institutes of Health. The Act will also provide funding for strengthening the public health core function of states, including those components related to diseases of public health significance. This support will allow communities to maintain strong programs to prevent the spread of HIV, tuberculosis, and other conditions of public health importance.

1/11/92

Health Care Reform and the HIV Epidemic Issues of Concern

Introduction: The National AIDS Policy Coordinator and staff have provided advice on policy formulation during the development of the Health Security Act (HSA). These efforts were directed towards assuring adequate care and services. As the Congress now deliberates the HSA, the Administration is making every effort to assure that modifications to the President's proposal maintain equity and sensitivity to the special needs of HIV infected individuals.

While the HIV epidemic has been thought of by the general public as an upper middle class, white gay male disease, legislators should not lose sight of the fact that the HIV epidemic has had a disproportionate impact in the inner cities where the HIV epidemic has devastated communities of color and people of limited socio-economic status. These populations are also at high risk for the many other epidemics raging in their communities: high infant mortality, substance abuse, sexually transmitted diseases, tuberculosis, multi-resistant tuberculosis, HIV infection, violence, crime, unemployment, low educational attainment, and poverty.

The socioeconomic and health conditions which fuel these epidemics contribute to health outcomes which are financially and personally catastrophic, such as: addictions, low birth weight babies, tuberculosis, violence-related injuries, and HIV and AIDS. The high cost associated with these outcomes will be a great incentive for most health plans to find ways *not to enroll individuals from communities where these epidemics might be present.*

The practice of "cherry picking" and "red-lining" historically have been practiced in the U.S; in fact, HIV infected individuals are considered "uninsurable" today. The insurance company today is a business and like any business is driven by the profit motive. Our health care system tries to balance the insurance principles of risk and equity. The private insurance company assumes risk and attempts to maximize profits by wisely choosing only acceptable risks.

Under the HSA, the health plans will be mostly run by insurance companies whose corporate motives will be directed in large part by profits. It is with great interest than that the HIV community has raised many concerns about their future health care benefits.

Background: The provisions of universal coverage, non-exclusion of pre-existing health conditions, and guaranteed lifetime coverage regardless of income represent major advances and security for all Americans. While these tenets have been put forward in the Senate Bill 1757 and House Bill 3600, the provisions of these bills will be deliberated by the 103D Congress. The details written into any new

legislation will structure the various national and state mechanism which will determine the equity and risks for both individuals and health plans.

Under the Health Security Act, all American citizens and legal residents will be guaranteed a comprehensive package of health benefits that can never be taken away. They will receive a Health Security Card entitling them to enroll in a plan. Everyone will have a choice of at least three - and in most communities, many more - health plans. And no matter which plan people choose, they will receive the comprehensive benefits package. Benefits covered under the nationally guaranteed comprehensive package carry no lifetime limits.

The package covers the following health services when they are medically necessary or appropriate including: hospital services, emergency services, services of health professionals, clinical preventive services, mental health and substance abuse services, family planning services, pregnancy-related services, hospice care (during the last six months of life), home health care, extended-care services, ambulance services, outpatient laboratory services, outpatient prescription drugs, outpatient rehabilitation services, durable medical equipment, routine ear and eye examinations (every two years) and eyeglasses and dental care for children under eighteen.

In addition, the HSA will preserve and strengthen Medicare, adding new coverage for prescription drugs. A new long-term care initiative will expand coverage of home and community-based care. This will make it possible for more elderly and disabled Americans to live in their homes and communities while receiving long-term care. The HSA will improve Medicaid coverage for people in nursing homes. It will improve the quality and reliability of private long-term care insurance and provide tax incentives for persons to buy it; and tax incentives to help individuals with disabilities work.

Community ratings, risk adjustment, re-insurance, and essential community providers are components of the HSA designed to assure services to underserved communities, and to compensate health plans for excessive health care cost. These mechanisms which are intended to guarantee equity to the most disadvantaged citizens must be carefully crafted such that they do not, in reality, create undue financial burdens which may in turn might cause health plans to promote exclusion of high risk groups as opposed to inclusion.

ONAP staff conducted a series of focus groups with PWA's and HIV organizations to ascertain their concerns related to the proposed HSA. The staff also undertook an analysis of it and identified 10 issues which related to the concerns which PWA's felt could adversely affect the HIV community: 1) Financial workings, 2) essential community provider, 3) grievance procedures, 4) long-term and home care, 4) substance abuse and Mental health, 5) equity of benefits (current Medicaid

benefits), 6) public health functions, and 7) impact on Ryan White CARE Act.

Premium Financing and Risk

Issue: Will the risk adjustment mechanism prevent "redlining" for persons with HIV/AIDS or other life threatening illnesses?

Summary: The HSA provides mechanisms which require states to spread the financial risk associated communities by adjustments which would take into account such factors, known to affect utilization of services, such as age, sex, health status and services to disadvantaged populations. The health plans have to meet specific rules on enrollment, community rating, information, grievance procedures, arrangements with providers and additional arrangements established by the National Board.

Premiums have to be community rated, that is adjusted, adjusted for individual verses family status based on the projected cost of providing the comprehensive benefits to a plans enrollees. The alliance will then risk adjust the premiums paid to each plan to account for the level of risk associate with the individuals enrolled in each plan. A plan could purchase reinsurance to cover cost beyond those covered by the risk adjustment.

By setting a rate which includes a much higher percentage of healthy people, over a larger geographical area, the rates for the less healthy will be averaged with those of the healthy. In order to assure that persons requiring greater medical care receive the necessary services without placing health plans in fiscal jeopardy, states will payer higher premiums to health plans for treating those persons. To assure that these "sicker" individuals do not cost health plans more than they can finance, the plan can purchase insurance from a national pool to further limit financial risk.

Discussion: Under the Health Security Act most of the population would obtain coverage through a regional alliance, a State-established intermediary between insurers and insurance purchasers in a defined geographic area. The alliance would contract with several plans, including managed care plans and conventional fee-for-service plans, to offer a comprehensive benefit package defined by the Act. Health plans are defined as those plans providing the comprehensive benefit package. Only State-certified health plans would provide coverage through the regional alliances. The plans would have to meet specific rules on enrollment, community rating, information, grievance procedures, arrangements with participating providers and additional requirements established by the National Health Board.

Premiums would have to be community rated, that is, adjusted for individual versus family status based on the projected cost of providing the comprehensive benefits to a plan's enrollees. The alliances would then risk-adjust the premiums paid to

each plan to account for the level of risk associated with the individuals enrolled in the plan. A plan could purchase reinsurance to cover costs beyond those protected by the risk adjustment. The following are detailed explanations:

Risk Adjustment: Alliances would risk adjust premiums to account for variations in enrollment across health plans. Any adjustment made to the premium through this process would not affect the amount paid by consumers. They would pay the premium amounts quoted at the time they chose their health plans. It would, however, affect the payments made to the plans by the alliance. The goal of risk adjustment would be to adjust a plan's premium to reflect the level of risk assumed in covering its enrolled individuals in comparison to the average population of the area. The adjustment would take into account such factors, known to affect utilization of services, such as age, sex, health status and services to disadvantaged populations. It would use the system developed by the National Health Board unless it obtained a waiver from the Board. In the early years of the alliance system, it is expected that alliances would use a reinsurance mechanism to compensate for the lack of an adequate risk adjustment methodology.

The National Board must develop a risk adjustment and reinsurance methodology by April 1, 1995.¹ The Board can make improvements to the standard methodology in order to provide for the adjustment of payments to regional alliance health plans to: 1) assure that payments to plans reflect the expected relative utilization and expenditures for services by each plan's enrollees compared to the average utilization and expenditures for regional alliance eligible individuals; and 2) protect health plans that enroll a disproportionate share of regional alliance eligible individuals whose expected utilization of health care services and expenditures for these services are greater than the average level of utilization and expenditures for regional alliance eligible individuals.²

Section 1541(a)(2) lists the factors the National Health Board must consider in developing the methodology, including: demographic characteristics, health status, geographic area of residence, socio-economic status, the proportion of enrollees who are SSI and AFDC recipients and any other factors the Board determines. There is a "zero sum" requirement in Section 1541(a)(3) which requires an assurance that the total payments to health plans by the regional alliance after application of the methodology are the same as the amount of payments that would have been made without application of the methodology.

¹ Title I, Health Care Security, Subtitle F, Federal Responsibilities; Part 1, National Board; Subpart E, Risk Adjustment and Reinsurance Methodology for Payment of Plans.

² Section 1542(b).

Section 1541(a)(4) allows for the prospective adjustment of payments to health plans. The Board does not specifically have to take into account AFDC/SSI recipients if it determines that the application of other risk adjustment factors is sufficient to adjust premiums to take into account the enrollment into plans (Section 1541(a)(5)). Special consideration can be given for adjustment for individuals with mental illness, veterans, military and Indian health plans (Sections 1541(a)(6), (a)(7) and (a)(8)). If the total payments made by a regional alliance to all regional alliance health plans in a year exceeds or is less than, the total estimated by the alliance, because of differences in the estimate and the actual distribution, the methodology must be adjusted to reduce or increase payments made by the alliance to all plans. Mandatory reinsurance is presented in Section 1541(b). If a Board determines an adequate system of prospective payment cannot be developed by an implementation date established by the National Health Board, the Board can include a mandatory reinsurance system as a component of the methodology.

Mandatory Reinsurance Mechanisms: The National Health Board (NHB) is mandated to develop risk-adjustment and reinsurance methodology by April 1, 1995. The primary purpose of both mechanisms is to protect health plans that may have a disproportionate number of "high-cost" enrollees relative to other plans; this would allow the plans to meet their higher level of expenditure with appropriately increased funding. The Mandatory reinsurance requirement³ is included as it may be necessary for states using the NHB methodology to mandate non-voluntary "transfer payments" between health plans that are within alliances, if risk-adjustment methodology cannot be developed and implemented prospectively in time to adequately control for the expected cost differentials among different enrollees within the plans. The NHB is required under the proposal to determine the type and level of coverage and operation of a mandatory reinsurance system for each state, taking into account privacy standards in order to minimize identification of individuals.

Each state that participates in the new system is required to establish a mandatory reinsurance system utilizing NHB standards. Finally, the NHB may reduce or eliminate the mandatory reinsurance system in the future if it determines that a prospective risk-adjustment methodology can be implemented successfully.

Implications for Persons with HIV/AIDS State utilization of mandatory reinsurance will probably be necessary as the methodology to do the required level of risk-adjustment is only now under development. Establishment of this provision, then, is very important for those concerned with HIV/AIDS, because the epidemiologic trend in AIDS is shifting toward the inner-city populations. Without reinsurance

³ Title I, Subtitle F, Section 1541 (c)

mechanisms, plans will be more likely to avoid "high-cost" areas such as the inner cities with greater proportion of AIDS, TB, low-birthweight babies, etc. so as not to be saddled with those higher costs during the interim period. The American Academy of Actuaries has stated that there are "tremendous" financial incentives for risk-avoidance behavior by plans in serving geographic areas within states until risk-adjustment is fully implemented, which may take, "several years".

Recommendation: Support vigorously the concept of mandatory reinsurance as laid out in the Administration plan, as a means of ensuring that "redlining" in any form (temporary or permanent) does not occur; i.e., that PWA's will not be discriminated against by health plans' avoiding places that they may live and have the best access to clinical care. This provision is the best method to make sure that plans which choose to serve PWA's are not going to suffer financially and disproportionately for that decision.

Availability of HIV Specialist, "Essential Providers"

Issue: Will HIV positive persons be able to continue using their local HIV medical specialist.

Summary: The Health Security Act establishes a special category of health care provider which is referred to as an "essential provider". Any health care provider or organization can make application to the Secretary to be certified as an essential provider. Within the HSA, a Ryan White grantee or subrecipient can be automatically certified as an essential provider. Each health plan shall enter into a written agreement with each essential provider located within its service area. The health plan shall make payment to the provider in accordance with the appropriate subsection of the HSA.

Discussion:

The Health Security Act establishes a special category of health care provider which is referred to as an "essential provider". Any health care provider or organization can make application to the Secretary to be certified as an essential provider. Within the HSA a list of organizations which can be automatically certified is included. This list consist principally of Public Health Service funded programs. One of major interest to this Office includes the AIDS providers under the Ryan White Act. Which is defined as a public or private nonprofit health care provider that is a recipient or subrecipient of a grant under Title XXVI of the Public Health Service Act.

Each health plan shall, with respect to each electing essential community provider located within the plan's service area, either (1) enter into a written provider participation agreement (described in subsection (b)) with the provider, or (2) enter into a written agreement under which the plan shall make payment to the provider in accordance with subsection (c).⁴

Under subsection (b) Participation Agreements, the health plan agrees to treat the provider in accordance with terms and conditions at least as favorable as those that are applicable to other providers participating in the health plan with respect to the following: 1) scope of services, 2) rate of payment, 3) financial incentives, 4) limits on financial risk, 5) assignment of enrollees, and 6) access to subspecialist within the plan.

⁴ Title I - HEALTH SECURITY ACT, Subtitle E - Health Plans, Part 3 - Requirements Relating to Essential Community Providers, Sec.1431 - Health Plan Requirements.

Under subsection (c) Payments for Providers Without Participation Agreements, a provider may elect to be paid at the rate as established by the regional alliance/State or by methodologies established by the Secretary which closely approximate those of Medicare. Additionally, "No application of gate-keeper limitations" may be imposed. Payment in accordance with this subsection may be subject to utilization review, but may not be subject to otherwise applicable gate-keeper requirements under the plan.

With respect to establishing a time limitation on the mandated provisions of the "Essential Provider", SEC. 1432. SUNSET OF REQUIREMENT, shall only apply to health plans offered by a health alliance during the 5-year period beginning with the first year in which any health plan is offered by the alliance.

An electing essential community provider who is aggrieved by the failure of a health plan to fulfill a duty imposed on the plan by section 1431 may commence a civil action against the plan in an appropriate State court or district court of the United States. If the court finds that the health plan has failed to fulfill a duty imposed, the electing essential community provider may recover compensatory damages and the court may order any other appropriate relief. The court, in its discretion, may allow the prevailing party, other than the United States, a reasonable attorney's fee (including expert fees) as part of the costs, and the United States shall be liable for costs the same as a private person.⁵

The HSA requires each health plan to enter into agreements with each essential provider practicing within the health plans service area. The essential providers given the option of electing one of two payment mechanisms. While it is unclear as to how these mechanisms will be implemented, there is much to be said for, "No application of gate-keeper limitations." This would be an important element in the multi-specialty requirements for an AIDS practice.

A major point of concern in the HSA is that while a Ryan White recipient (State or City) or subrecipient (community based organization) is automatically certified, the standards for certification for individual providers will be established after the passage of the HSA by the Secretary. Adequate provisions have been made in the HSA for an essential provider to seek relief in the courts.

Recommendation: That the Administration work with the Congressional liaison to include specific language defining the standard for certification of an individual as an essential AIDS provider.

⁵ TITLE V - QUALITY AND CONSUMER PROTECTION, Subtitle C - Remedies and Enforcement, Part 2 - Additional Remedies and Enforcement Provisions, Sec. 5240. CIVIL ACTION BY ESSENTIAL PROVIDERS.

Grievance Procedures

Issue: How can individuals ensure that their health plan will provide the health benefits and services they require?

Summary: The HSA is intended to provide adequate health care coverage for all citizens and residents of the United States. The Act requires States to establish health alliances which will approve each health plan before it can engage in providing health care under the Act. The law prohibits exclusions because of pre-existing conditions or through "red-lining," the practice of excluding a particular group of individuals because of perceived high risk.

The Health Security Act includes a comprehensive grievance process for any person aggrieved by acts or practices which result in denial or delay of benefits, payments. Individuals must work within the individual plan's grievance process before going to adjudication through the Complaint Review Offices set up in each state. If there is a question as to an individual's eligibility for a plan, subsidies or cost sharing, the individual may go directly to court and all costs can be reimbursed if the court finds for the individual.

The complaint office must rule in under 30 days, although a 24 hour appeal is available in cases of emergency. Appeals must be processed within 60 days. There are means of appealing, with the national board being the ultimate administrative appeal. The DHHS Secretary can also make a determination of whether a particular plan fulfills the legal requirements.

Discussion: The grievance process of the Health Security Act⁶ states that all claimants must use the plans claims process and all recourse must be exhausted before they go on to the complaint process.⁷ The plan provides for individuals to submit claims to the regional Complaint Review Offices for adjudication within 30 days. Appeals to these decisions can also be made to the regional claims office and adjudication will be made within 60 days.⁸ The regional claims office must be established by all the states that set up alliances. The Department of Labor will issue regulations for the operations of these offices.⁹ For alliances not set up by the state (i.e., corporate alliances [corporations with more than 5,000 employees]), the Department of Health and Human Services will run the claims office based on

⁶ TITLE V, Subtitle C, Remedies and Enforcement.

⁷ Section 5202(c)

⁸ Section 5201(1) and (2).

⁹ Section 5202 (a)(1).

the DOL regulations.

The HSA also provides for expedited review within 24 hrs. of claims in situations where grievous harm will occur to the claimant or the provider.¹⁰ The determinations by the claims office must specify the grounds upon which the action will be taken.¹¹ All complaints must be in writing with a sworn statement and must give notice of the nature of the complaint.¹² All claims must be filed within one year of the event that causes the claim.¹³ Individual claimants can forego the complaint process and go directly to court, can elect to participate in the Early Resolution Program¹⁴ or can obtain a hearing in the Complaint Review Office. To participate in the Early Resolution Program, the dispute must be over payment or the rendition of services and the election must be made within 15 days of the submission of the complaint.

Adjudications can be enforced by the courts. In addition to the awarded damages, the complainant will receive attorneys and other reasonable costs.¹⁵ The Secretary of Labor may impose civil penalties based on the findings of the hearing.¹⁶ In order to enforce the particular requirements of the plan, individuals must exhaust administrative remedies as described above¹⁷ or may go directly to court to obtain a ruling on issues of eligibility.¹⁸ Cases of civil rights violations can be adjudicated directly by the courts.¹⁹ The claimant can receive court costs at the discretion of the court. The HHS Secretary may make a finding that a particular plan does not comply and can ask DOJ to file suit.²⁰

¹⁰ Section 5202(c)(2).

¹¹ Section 5201(e).

¹² Section 5202(e).

¹³ Section 5202(f).

¹⁴ Section 5211.

¹⁵ Section 5202(g).

¹⁶ Section 5206.

¹⁷ Section 5237.

¹⁸ Section 5237(b)(2).

¹⁹ Section 5238.

²⁰ Section 5238(c).

Implications: The grievance procedure will be important to persons with HIV, which may be excluded from coverage by various plans. Making the grievance procedure accessible will be critical to persons living with HIV/AIDS.

Recommendation: During the implementation phase, persons requesting redress under the grievance process may not receive service as soon as necessary. For people living with HIV/AIDS, the expedited process may be necessary in all instances.

Long-term care and Home Health Care

Issue: Persons with HIV/AIDS often need home health care and long-term care services, will the Health Security Act provide those needed services?

Summary:

Home health care is included in the nationally guaranteed comprehensive package as a medically necessary or appropriate service. A new long-term care initiative will expand coverage of home and community-based care. This will make it possible for more elderly and disabled persons, including persons living with HIV/AIDS to live in their homes and communities while receiving long-term care. The Act will improve Medicaid coverage for persons in nursing homes.

The HSA will improve the quality and reliability of private long-term care insurance and provide tax incentives for persons to buy it; and tax incentives to help individuals with disabilities work.

Discussion:

Home Health Care:

Under the HSA, home health care, including skilled nursing care, physical, occupational and speech therapy, prescribed social services and home-infusion therapy after an acute illness will be covered to prevent institutionalization. Under the HSA²¹, home health care is a skilled nursing care and therapeutic services benefit. Services must be provided under the supervision of a physician or registered nurse. It would not include what is usually called "custodial care," that is, care that could be safely rendered safely and reasonably by a person not medically skilled, and that are designed mainly to help a person with daily living activities. These activities could include (not exhaustive) and would *NOT* be covered: 1) personal care such as help in walking, getting in and out of bed, bathing, eating by spoon, tube or gastrostomy, exercising, dressing; 2) homemaking, such as preparing meals or special diets; 3) moving the person; 4) acting as companion or sitter; 5) supervising medication that can be self-administered; or 6) treatment or services that any person may be able to perform with minimal instruction included but not limited to recording temperature,

²¹ Title I, Health Care Security ; Subtitle B - Benefits; Part 2 - Description of Items of Service Covered; Section 1118, Home Care defines this benefit as the items described in Section 1861 (m) of the Social Security Act (under Medicare statute) and home infusion drug therapy services described in Section 1861(II) of the Social Security Act (as added by Section 2005.)

pulse, and respirations, or administration and monitoring of feeding systems.

The "custodial care" definition is as described in the Federal Employee Health Benefit brochure (December 1993), but is generally indicative of what is not considered "skilled" care. It should also be noted that as described in the Plan, this benefit is not the same as Medicaid home health or Ryan White home services as defined in statute.

Long-term care:

Beginning in 1996, a new home and community-based care program will enable Americans with severe disabilities to remain in their own homes or with family, yet still receive the care and assistance they need.²² The HSA²³ requires States to have a plan for the home and community-based services to individuals with disabilities submitted and approved by the Secretary. No individual entitlement is established (Section 2101).

Basically, the HSA would establish a new Federal-State long-term care program for disabled persons of all ages and income levels and includes a variety of other changes in long-term care policy. The HSA would establish a new grant program to States to provide home and community-based long-term care services to the severely disabled (persons requiring assistance in three or more activities of daily living, or ADLs, such as dressing or eating), the severely mentally ill or mentally retarded, and technology-dependent children. Participation would be open to all persons meeting the disability criteria, regardless of age or income.

Low income persons not meeting the criteria but currently eligible for home and community-based services under Medicaid would continue to receive Medicaid services. However, Federal funding for these services might be limited. The program would not be an individual entitlement, like Medicare and Medicaid, under which anyone meeting eligibility criteria has a right to benefits. Instead, it would be a "capped" entitlement, with the number of participant limited to the number that could be served within the program's budget. Federal funding would be subject to an annual limit, updated for inflation and growth in the disabled population.

The formula for allocation of funds to the States would take into account the State's share of the disabled population, the State's low-income population, State

²² Title II, New Benefits; Subtitle B - Long -Term Care.

²³ Title II, Subtitle B; Section 2101, State Programs for Home and Community-Based Services for Individuals with Disabilities.

wage levels and required State contribution levels. State contributions for services could range from 5 to 22 percent of the costs of services, with higher shares paid by States with above-average per capita income. Individuals would pay coinsurance on an income-based scale. Program funding would be phased in over a 7 year period, beginning with \$4.5 billion in FY 1996 and reaching \$38.3 billion in FY 2003.

States could offer more limited services during phase-in than would be available later on; however, they could not impose means tests for eligibility. All eligible persons would receive an individual assessment and plan of care. Services would be defined by the State, but would have to include personal assistance services.

State Medicaid programs would continue to provide home and community-based services -- either additional services for persons served under the new Federal program, or services to persons not eligible under the program (because of capacity limits or because they do not meet the disability criteria). States would have the option of integrating community and institutional long-term care with fixed limits on Federal funding in place of open-ended matching funds.

The HSA would establish a system of Federal regulation of private long-term care insurance policies (including requirements that policies include inflation protection and nonforfeiture provisions) and would provide the same tax preferences for these policies that are available for regular health insurance. A new tax credit would be established to pay as much as 50 percent of costs (up to \$15,000) for personal care services for employed persons with disabilities.

Implications: The new long-term care program is the first major federal support for home care services (other than Medicaid for very low-income persons). The program is likely to be popular with the elderly, who have a strong preference for home care services. While the funding for the program is quite substantial, persons with HIV/AIDS are concerned that it raises expectations it cannot meet. In addition, the requirement that participants require assistance with three ADLs would disqualify many disabled persons who also need assistance, including persons with HIV/AIDS. A person living with HIV/AIDS would still have to impoverish themselves to obtain such services through Medicaid. In addition, there is a possibility that expenditures for the mentally retarded and developmentally disabled could potentially consume a large share of the funds. Members of Congress against the Clinton plan have specifically cited this benefit as one with great potential to become another "entitlement."

Further, the HSA measures to promote private long-term care insurance raise some concerns. The requirement that all policies include nonforfeiture provisions and offer inflation protection could significantly raise the cost over coverage. It would then not be affordable except to the wealthy.

Availability of Mental Health and Substance Abuse Services

Issue: Injecting users, a major transmission mode of HIV infection, currently have inadequate treatment and preventive services available to them, will adequate services be available to treat these individuals in order to ameliorate their additive disease and halt the epidemic?

Summary: HSA would provide some treatment for those injection drug users not now covered by any insurance. However, because of the limitations on coverage over the first years, the recidivism rate for addicts would probably remain high and the need for more intensive, prolonged treatment simply postponed. In order to make a significant difference in the rate of new infections in the injecting drug use population and their sexual partners, the public health infra-structure and funding for drug and alcohol abuse would need to be increased greatly to fill the gaps during the phase in period. The cost saving effects of limited coverage would be offset by the cost of treating more HIV infected persons and by eventually having to provide additional treatment for addictions.

Discussion: Health insurance plans which currently provide mental health and substance abuse benefits provide substantially limited services. Over the the past 10 years efforts to curtail healthcare costs have almost universally begun with cut-backs in mental health and substance abuse services. Current health plans limit benefits in a number of ways: inpatient limits, outpatient limits, dollar caps, inordinately high copayments, and denial of benefits.

Inpatient benefits are usually capped with a maximum of 30 -60 days for which benefits will be paid, copayments may range from 10-50%, and outpatient benefits are limited approximately 50% of the daily fee. It is not uncommon for the benefits to be further limited by selective payment for some of the services (i.e. payment for group therapy but not for individual counseling, etc.). Some current policies limit their payment for these services by simply placing a dollar limit on the total amount that will be paid out for services in this category. Copayments for mental health and substance abuse benefits are usually much higher than for medical benefits and many policies simply do not cover these services.

In past years , many companies, also, initiated managed care contracts which provided the same psychiatric and substance abuse benefits which are proposed in the HSA. Unfortunately, managed care companies, in order to be succesful must establish and effectively operated utilization review programs that monitor the quality of treatment and identify and minimize inappropriate use of medical services and facilities. Utilization review in many cases have meant denying the patients the type of care recommended, authorizing only a lesser intensity of care, or cutting off care before the patient had been able to obtain the maximum benefit. The result, too often being, inadequate treatment and return to disability.

The publicly funded mental health and substance abuse treatment programs that are now in place are inadequate. The quality of treatment is less than ideal, the recidivism rates are high, and the number of programs available are not adequate to provide "treatment on demand" for those who wish to access such programs. Those States with the largest number of injecting drug users who are infected or at risk of becoming infected with HIV are having the greatest difficulty adequately funding treatment programs.²⁴ The Public Health Service estimates that there are over 2 million (does not include persons with alcoholism) persons who would enter treatment if slots were available. The Nation Commission on AIDS states that every assessment of the epidemic has identified the urgent need to make treatment of addiction the highest priority in an effective public health to curtail further spread of HIV.

Using Methadone as an interim treatment for injecting drug users is controversial and only postpones the need for quality, long term treatment. Alcoholism is another disease which contributes to unsafe high-risk sexual activities that can spread HIV. Publically funded, community mental health centers do not exist in most areas where they are most needed. In addition, homeless persons and others in most need are prevented by their illness from seeking treatment. Mental illnesses which contribute to injecting and other illicit drug use, as well as alcoholism, are seldom treated.

The comprehensive benefit package describes²⁵ the following services for mental health and substance abuse illnesses: 1) inpatient and residential treatment, 2) intensive nonresidential treatment, 3) outpatient services including case management, screening and assessment, crisis services, and collateral services.

Before January 2001, 30 days of inpatient treatment is covered. A maximum of 30 additional days may be authorized if a health professional designated by a health plan determines it meets the criteria.²⁶ For every two days of intensive non residential treatment received, inpatient care is reduced by one day.²⁷ Sixty days of addition intensive treatment may be covered, cost sharing for these 60 days is

²⁴ Department of Health and Human Services, Public Health Service, PHS Response to the Nation Commission on AIDS Recommendation.

²⁵ Title I - Health Care Security, Subtitle B - Benefits, Part 2 - Description of Items and Services Covered, Section 1114. Mental Health and Substance Abuse Services.

²⁶ Section 1115 (c) (2) (D) .

²⁷ Section 1115 (d) (2) (C) .

25% in lower costing sharing plan and 50% in higher cost sharing plans.²⁸

Treatment for substance abuse counseling and relapse prevention is covered if a health professional designated by a health plan authorizes. Inpatient and residential days are reduced one day for every 4 days of substance abuse counseling and relapse prevention; detoxification as an out patient treatment is covered only in the context of a treatment program.²⁹

In addition to the treatment benefits appropriations for mental health and substance abuse benefits are requested in the HSA.³⁰ Authorization for appropriations are \$100M FY 1995, \$150M FY1996, and \$250M FY 1997-2000. In addition to these sums the Secretary shall establish pilot programs to demonstrate models of integrating mental health and substance abuse programs with benefits covered in Title I.³¹

Implications: The earliest description of the Health Security Act included coverage for mental health and substance abuse services which would be the equivalent of services for other medical services. As the benefit package evolved it was very quickly realized that the proposed program was going to be too

²⁸ section 1115(2)(C).

²⁹ Section 1115 (e)(2)(B,C and D).

³⁰ Title III - Public Health Initiative, Subpart F - Mental Health and Substance Abuse, Part 1 - Financial Assistance, Section 3501.

³¹ Title III, Subpart B, Section 3521.

expensive to pass Congress. Consequently, the mental health and substance abuse services are limited to the same levels as most currently available health plans for the first few years. These limits will be removed as managed care assumed responsibility for these services. This sounds like evolution in the right direction. Managed care, however, has been around in the behavioral care areas for a number of years and it has not improved access to care and has had a definitely deleterious effect on the quality of care.

The current limitations are major barriers to care for most patients with psychiatric and substance abuse illnesses. These patients are frequently in financial trouble or employment trouble at the point when they are considering treatment. These same barriers will be present under the Health Security Act. The only limited improvement in the situation will be for the individual who has no current coverage who moves into a situation where they will have extremely limited coverage.

Active addictive disease (or mental illness) because of the poor judgement involved, inability or unwillingness to practice safe sex, and the direct risk from needle use places one at higher risk of HIV infection and may well also reduce ones resistance to active disease once infected. One of the limited ways in which risk to HIV can be reduced is to identify at an early stage those who are in this high risk category and do everything possible to reduce barriers and maximize incentives to obtain competent and effective treatment. Unfortunately there is very little in the current Health Security Act which will accomplish or even move us toward this goal.

Recommendation: Work with Congress to increase substance abuse treatment and outreach preventive services for the populations at high risk for HIV infection.

Health Security Act (HSA) and Confidentiality Issues

Issue: What safeguards are envisioned for the handling of health information on HIV affected persons under the Health Security Act of 1993.

Summary: The HSA addresses the issue of how information will be handled and what penalties will be imposed for misusing information. The structure of the information sections are well thought out; however, there is a lack of specific guidelines and standards. It provide guidance level information on creation of the oversight board, users and uses of information, privacy standards, enrollee rights, outright prohibitions, training of information handlers, and comprehensive health information privacy protection. The development of the Comprehensive Health Information Privacy Protection Act does not have to be implemented until three years from the date of passage.

Discussion: The confidentiality of the information obtained by the providers and entered into a national data base under the HSA, is of great concern to all individuals. All anyone needs to do to confirm their concerns is to look at the history of surrounding the HIV epidemic. As we know, HIV status has been misused by employers, medical providers, landlords, and others and has led to a reluctance to share such information on an other than "need to know" basis.

Those familiar with the medical community, know that there is little "confidentiality" within the medical providing community, and that HIV infected patients are well known to personnel in medical settings. To compound that, the HSA now proposes to collect information on all American's enrolled in the plan, and to provide that information across state lines to any provider with whom the person will be enrolled. This, of course, raises new issues of information handling among HIV sensitive communities.

A cursory overview of the Administration's legislation follows:

Information Systems, Privacy, and Administrative Simplification is the title of Title V, Subtitle B of the HSA.³² These parts address the issue of how information will be handled, and how and with what penalty, any mishandling will be dealt.

³²Beginning as Part 1 - HEALTH INFORMATION SYSTEMS, Section 5101. Establishment of Health Information System and continuing through Part 2 - PRIVACY OF INFORMATION Section 5120. Health Information System Privacy Standards; Section 5121. Other Duties with Respect to Privacy; Section 5122. Comprehensive Health Information privacy Protection Act; and Section 5140. National Privacy and Health Data Advisory Council.

Creation of an oversight board. Within two years of passage of the HSA, the National Health Board (NHB) is to develop and implement a health information system (HIS) by which the Board shall collect, report, and regulate the collection and handling of information collected under the Act.³³ The HIS system is to be developed by the NHB and is to be consistent with the National Information Infrastructure Act of 1993 and with standards established under section 5120 of the HSA.

Users and uses of information Information collected under the HIS is to be used for planning, policy development and evaluation and for research.³⁴ Entities having access to it are Federal, State and local governments and regional and corporate alliances.³⁵

Privacy Standards. The National Health Board is to promulgate health information system privacy standards.³⁶ The NHB is to design a "unique identifier number" (UIN) as a part of the HIS³⁷, but other than a general prohibition of general access to information compiled for each holder of a UIN, there is no general guidance as to what information is to be collected or what the permissible uses of the information are to be allowed.³⁸ The most striking prohibition set forth in the principles is that no "individually identifiable health information may be provided by a health plan to a regional alliance or a corporate alliance for the purpose of setting premiums based on risk adjustment factors."³⁹ And, anyone who maintains uses or disseminates individually identifiable health information must have "administrative, technical and physical safeguards for the security of such information."⁴⁰

³³S.B.1757, hereinafter referred to as the Health Security Act or HSA at Title V, Subtitle B, Part 1, Sec. 5101 (a).

³⁴HSA at sec. 5101(d)(1).

³⁵HSA at section 5101(d)(1).

³⁶HSA at section 5103 (d).

³⁷HSA at section 5104 (a)-(c).

³⁸Section 5120 of the HSA provides for the promulgation of privacy standards. There are broadly proposed principles for such standards including unauthorized disclosure and limited disclosure to local law enforcement agencies. See HSA Title V subtitle B section 5120 (c)(1).

³⁹HSA at section 5120(c)(3).

⁴⁰HSA at section 5120(c)(4).

Enrollee rights. All enrollees have a "right to know" (a) if an individual or entity uses or maintains information on the enrollee and (b) what purposes the information is used for or may be maintained for;⁴¹ a "right to access" such information, copy such information and to correct such information⁴² and a "right to notice" ⁴³ of the purposes for which any information is provided and further underscoring the right of access set forth in paragraph (6) of the section.

Outright Prohibitions. In addition to prohibiting the use of the information for purposes of setting premiums, no information collected on the HIS can be used by a employer or prospective employer with regard to "making employment decisions."⁴⁴ Indeed, if a person were to deny or discourage employment based upon such information, might face civil penalties of up to \$50,000 per incident.⁴⁵

Training Information Handlers. The NHB is obligated under the Act to establish education and awareness programs which are designed to (a) foster adequate security practices⁴⁶; train personnel handling such information as to their duties under the Act ⁴⁷ and of informing individuals and their employers regarding their rights with respect to such information.⁴⁸ Since violations of the HSA have sanctions of up to \$10,000 per violation⁴⁹, it is assumed that information handlers will be motivated to circumscribe the sharing of information.

Comprehensive Health Information Privacy Protection Act. Finally, the HSA requires legislation within three (3) years of enactment of the HSA for the NHB to submit to the President and the Congress a detailed proposal for legislation to provide a comprehensive scheme to protect individually identifiable health

⁴¹HSA at section 5120(c)(5)

⁴²HSA at section 5120(c)(6).

⁴³HSA at section 5120(c)(7).

⁴⁴HSA at section 5120(c)(9).

⁴⁵HSA at sections 5412(a)(3) and 5412(b)(1).

⁴⁶HSA at section 5121(c)(1).

⁴⁷HSA at section 5121(c)(2).

⁴⁸HSA at section 5121(c)(3).

⁴⁹HSA at section 5141(a)(3).

information.⁵⁰ The proposed legislation would cover information which is inappropriately shared whether verbally or written.⁵¹

Implications: With regard to the two years of delay between the passage of the HSA and the implementation of the health information system (HIS), there is a time-lag problem. The increasing number of HIV infected populations within the United States is concentrated in minority populations including women, children, the homeless and prison populations. Many of these individuals will be under-enrolled: i.e. they will not be caught up in the first rush to register. The homeless are often difficult to locate and their first "experience" of registration will probably be reserved for "emergency room" visits. Prison populations are not even being currently considered for coverage. They are, in fact, excluded under the Act. Thus, information may, or may not, be collected on these populations. If it is, the populations themselves may lack the will to challenge the mishandling of such information. They may not even be aware of a mechanism for redress of grievances under the Act.

Once collected, there should be serious concern as to the users of the information. Use of collected and reported data for health care planning, policy development, policy evaluation, and research are good public health functions and objectives in and of themselves. But users of the information are not just traditional users such as government suppliers of services (i.e. federal, state and local government entities) but also regional alliances and corporate alliances. This places information on people within the care, custody and control of private or quasi-private entities, which may or may not be monitored for information processing, handling, and disseminating. Having the information in their hands leads to questions of what is to be done with it once it is there.

Increased pressures for access to the information will be acute since one goal of collecting such information is the "managing and containing costs at the alliance and plan levels".⁵² Plans and alliances of Ryan White Title I cities will be particularly interested in such statistics for purposes of initially qualifying or continuing qualification for Title I funds. The key to information control may be limiting the access to such information by curbing who will have person-specific access and having all other uses be epidemiological (i.e. number counts as opposed to name counts).

The legislation contemplates "unique identifier numbers" for each enrollee of the

⁵⁰HSA at section 5122.

⁵¹HSA at section 5123(3).

⁵²HSA at section 5101(d)(8).

plan, much like the social security number provided to each American now. This does not mean that wanton misuse of the information will prevail. For example, no use is to be made of the information for denying benefits or by employers for denying jobs. This clearly addresses two grave concerns of HIV positive people: loss of coverage and loss of employment. Of more than general interest is the provisions within the Act to train information handlers as to their duties and responsibilities under the act as well as the provisions for actively educating enrollees as to what their rights are: rights of knowing, accessing, correcting and of being told when information is held on a person.

The chief weakness as the legislation currently stands is the lack of specific guidelines or standards of the types of information collected, restrictions on that information, and clearly articulated standards of who should receive such information and when they should receive it. The "heaven in the details" will evidently be at the guidance of the proposed Comprehensive Health Information Privacy Protection Act which is to come within three years of the Acts passage.

Recommendations: The following recommendations should be considered for tightening up the proposed legislation as it pertains to confidentiality issues:

- 1) There is no need to delay for three years of development from the date of passage a Comprehensive Health Information Privacy Protection Act as envisioned by the Act. The public, which will lack confidence in the accumulation of such information pools, let alone the experience-driven HIV populations, will be demanding privacy protection from the beginning. Such protection should be developed parallel to the refinements of the Act.
- 2) It is unclear whether the provisions of such an Act would be pre-emptive of State or local laws governing medical records. Would the Federal law be a floor, setting minimum standards of handling health care records; would it set a ceiling, or would it set exclusive standards that could not be modified by other entities. This point needs to be lobbied.
- 3) The intersection of "handicap" protection as allowed under the Americans With Disabilities Act for HIV sensitive communities and the Comprehensive Health Information Privacy Protection Act needs to be carefully reviewed. If someone mishandles information, does a private right of action spring into existence or is one relegated to a government forum for resolving the matter?
- 4) Conflict resolution mechanisms in HCR need to be carefully reviewed as to the timeliness of their resolution for fatally infected individuals. The two and three year judicial time lines of the past, which often lead to the plaintiff's death before resolution, Resolutions for such populations needs to be expedited by placement on fast-tracks for arbitration or judicial resolution. The conflict resolution sections of

HCR recognize these needs and provide for most resolution within 30 days⁵³ of complaints being filed, and in some cases, within 24 hours.⁵⁴ However, claimants must use the plan's claims process and all recourse must be exhausted before the claimant goes on to the complaint process. It is these kinds of requirements that need to be carefully reviewed since they will most often be the cause of delay.

5) Along with the rights to know, to have access and to obtain notice, a "right to treatment" might also be considered. This is much more political in scope, but many people who are turned away by medical providers now might be more willing to buy into the proposed legislation if they know that part and parcel of universal health care coverage is the assurance that they have a "right to treatment" which cannot be denied.

⁵³HCR section 5202(c).

⁵⁴HSA section 5201(c)(2).

Health Care Reform and the Ryan White CARE Act

Issue: Will the financial restructuring of the health care system assure the delivery of health care services appropriate to the needs of vulnerable populations whose access problems go beyond lack of insurance.

Summary: to be written

Discussion: In August of 1990, Congress passed the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. The purpose of the CARE Act was to provide emergency assistance to States and localities for the delivery of essential services to individuals and families affected by HIV disease. Further, the CARE Act was created to establish services for persons with HIV/AIDS who would otherwise have no access to care. Finally, it was intended to provide emergency relief funding to communities with the highest number of reported AIDS cases.

Congress funded the CARE Act at \$221 million in fiscal year (FY) 1991, \$276 million for FY 1992, \$338 million for FY 1993, and \$579 million for FY 1994. As health care reform is undertaken, its affect on clients served by the CARE Act must be assessed. Several key issues such as guaranteed benefits and wrap-around services, financing mechanisms, essential providers, and access to specialty services must be explored.

Persons living with HIV have special needs often exacerbated by other physical, social and economic factors, e.g. substance abuse and homelessness. Needs that are best served by the provision of a complex array of social as well as preventive and primary care services. Further, these individuals often require extensive outreach and efforts to modify the behaviors that both put them and others at risk and make them averse to seeking care in a timely manner.

The Administration is currently stating that federal categorical such as the CARE Act will be "offset" by the cost of services estimated to be provided in guaranteed benefits in the health care reform package. The comprehensive benefit package may not provide many essential services for persons with HIV/AIDS. These supportive and enabling services, and their cost, must be identified to ensure that comprehensive care for persons with HIV/AIDS is sustained with CARE Act dollars. Conversely, a variety of services currently provided by the CARE Act would be covered by a comprehensive benefits package. These would include primary care services, medications, assistance for health insurance coverage, home-based services, and case management.

An evaluation of CARE Act expenditures for these categories is necessary to determine CARE Act funds "freed" as a result of health care reform. These funds might be utilized to support HIV-specific supplemental insurance for wrap-around

services, "infrastructure" grants for coinsurance, copayment, etc., other health care reform provisions or the deficit.

It may be necessary to utilize CARE Act funds to subsidize the supplemental and client's share of insurance premiums, co-payments, deductibles, and expenditures that exceed spending caps. With health care reform there will be a need for persons living with HIV to have access to specialty HIV care that may only be provided outside a health alliance. This need may be met with the designation of all providers under the CARE Act as "essential providers." However, questions remain about: 1) what defines essential community providers, e.g. primary medical, social service provider, etc.; 2) whether there are gatekeepers that would limit access to essential providers; and 3) how this provision would play out in rural or low-incidence HIV communities.

Recommendation: 1) To work through the Administration to assure that the CARE Act is not discarded after health care reform; and that it continues to serve as a critical resource to sustain health care delivery systems, comprehensive health and support services those infected with HIV.

2) To work through the Administration to assure that any "savings" of CARE Act funds which may be realized as a result of services provided under the HSA not be used as an "off-set" but used to provide grants to additional eligible metropolitan areas.

Public Health Core Functions/Research

Issue: What is the nature of the funding for research on behavior, health services and Core Functions of Public Health Programs?

Summary: Although the Health Security Act will provide funding for health care for all Americans, there are research and public health initiatives that will have to be provided by the Public Health System. Behavioral research into those behaviors that may cause or contribute to disease will be conducted by the National Institutes of Health. The Act will also provide funding for strengthening the public health core function of states, including those components related to diseases of public health significance.

Discussion: The Act includes coverage for all individuals for medical services and prevention. The Act also makes provisions for improving the quality of services provided by the states and for public health initiatives that constitute primary prevention. These functions are reinforced with behavioral and health promotion research.

The Act provides for additional biomedical and behavioral research on prevention and health promotion at NIH and for research on the impact of health care reform. In addition, the Act provides for grants to states to improve the core function of the public health system and grants to state/local governments, non-profits and public/private partnerships to conduct national prevention programs. Funding for all these initiatives is in addition to other funding that may be provided for these activities through other appropriations.

These programs are included under Title III, Subtitle C, Health Research Initiatives. NIH will conduct biomedical and behavioral research. Sec. 3201, amending Section 402(f) of the Public Health Service Act. Research will consist of child and adolescent health, chronic and recurrent health conditions, reproductive health, mental health, elderly health...infectious diseases... and to resource development related to such research. NIH will receive \$400M in FY95, \$500M in FY96-2000. Sec. 3211(a).

Research on the impact of Health Care Reform shall be conducted by the Administrator of Agency for Health Care Research. Sec. 3202, amending section 902 of the Public Health Service Act. This research will be conducted under the direction of the National Board. Research will concentrate on the quality of care, consumer choice, health delivery, risk adjustment, access to health care and others. The PHS Initiatives Fund will receive \$150M in FY95, \$400 in FY96, \$500 in FY97 and \$600 for FY98-2000.

Core functions of Public Health Programs: funding will be given to the states to improve the following: communicable disease prevention, accident prevention, toxic hazard exposure, identify and control outbreaks of infectious diseases, public information campaigns, develop new prevention strategies. Sec. 3311. Funding will consist of \$12M in FY95, \$325 in FY 96, \$450 for FY97, \$550 for FY98, \$650 for FY99 and \$750 for FY2000. Sec. 3301(a). Grants will go to states to improve data collection, to protect the environment, investigation and control of health conditions, public information campaigns, evaluation, public health laboratory services, training and education, policy development and administration. Sec. 3312(b)(1-8).

National Initiatives Regarding Health Promotion and Disease Prevention: Grants will go to state/local governments, non-profits and public/private partnerships to carry out projects to provide health promotion and disease prevention. Sec. 3331. Priorities will be set by the DHHS Secretary once a year. Sec.3332(a). The grants will be made by DHHS based on the following: programs must take into account the needs of the affected populations, are targeted to the most needy population, examine links between preventable diseases and increase links between agencies rendering programs. Sec. 3331. Grant applications must be submitted to DHHS. Sec. 3333.

Implications: Although the Health Security Act will provide for primary care, there are research and public health core functions that must be supported with continued funding. These will not be funded through reimbursement mechanisms that will be used for HSA. The behavioral research component will be instrumental in impacting behaviors that put persons at risk for HIV, enhance survivability and improve quality of life. The core function funding will enhance the public health structure to better deal with illnesses of public health significance.

Recommendations: These provisions must be supported. Whenever possible, this funding must be maintained or increased. HSA will not be able to provide sufficient funding for the public health functions that are necessary to support the general welfare.

Supplemental Services under Medicaid and the New Health System: Implications for HIV/AIDS Populations

Discussion: Optional services under Medicaid are those which directly or indirectly allow access of patients to the health care system or are certain patient care services which are not required under the standard Medicaid insurance plan. There are 33 different services that states may opt to provide, including transportation, social work, child care, case management, hospice and home health. These are provided by seven states (medical social worker and christian science nurse services) to 50 states (optometric, clinic, prescription drug, prosthetic, and nursing facilities for the mentally retarded). These are provided in all states. Numbers of services per state range from 14 (Louisiana and Wyoming) to 30 (Minnesota, New Jersey and Wisconsin).

This optional services are supported by federal matching funds ranging from 50-80% (inversely related to state per capita income) for any of the 33 services states opt to elect (Federal Financial Participation [FFP]). These services are mandated for many of the 16 million Medicaid-eligible children regardless of state option (enforced match). Medicaid is currently estimated to provide coverage of direct and indirect services for approximately 90% of children with HIV/AIDS. In addition, significant, though smaller, amounts of supplemental services are currently funded through other non-Medicaid means (federal grants [e.g. Ryan-White], state, third-party and out-of-pocket funds).

Under the Administration's Health Security Act adult Medicaid beneficiaries who receive cash assistance (9 million beneficiaries) would be main streamed into the new system, but would not have to pay premiums. Further, they would be entitled to join a new state and federally-matched program providing wrap-around services similar to those listed above. Children less than 18 years old who are currently or would be Medicaid beneficiaries, with eligibility for wrap-around services (primarily based on poverty level), would be provided those services through a new fully federally funded, state-administered program, regardless of their cash assistance status.

However, adult Medicaid beneficiaries who are not on cash assistance and the estimated 37 million currently uninsured would only be able to receive supplemental services at state option, without federal entitlement support. In FY92, there are an estimated 6 million Medicaid adult non-cash beneficiaries with an annual total (direct/indirect services) payout of at least \$25 billion.

A proposal for funding enabling services through federal grant mechanisms is mentioned in the Public Health Initiative part of the HSA, and would be authorized for \$200 million in FY 96, \$300 million in FY97-99, and \$100 million in FY 2000.

Categorical grant programs (e.g., Ryan-White) would continue under the proposal, funding "essential community providers", so that there would still be provision of significant support from PHS for enabling services in states and localities. However, there would likely be an "offset" (latest percentage quoted for Ryan-White is 25%) reduction of funds to account for the clinical services portion that would instead be provided through the benefits package.

Implications on access to care

More children/adolescents who are in need of financial assistance will have greater (more nationally uniform and easily obtained) access to supplemental services under the new proposals than under the current system. Given Medicaid's current coverage of almost all (90%) children with HIV/AIDS, this proposal would continue to allow that high level of support for enabling services.

Adults on cash assistance (9 million), who require significant support services in order to successfully access the health care system, will continue to have these paid for by state and federally matched entitlement funds. This plan will continue entitlement support for access services in those groups where there is a high rate of increase of HIV/AIDS.

Adults who are NOT on cash assistance (including the 6 million from Medicaid as well as those from the estimated 37 million uninsured), however, will be provided only those supplemental services that states choose to continue in the face of being unable to receive matching federal entitlement funds. A significant financial burden may therefore be placed on states that wish to (continue to) provide wrap-around services to these adults.

The impact on HIV/AIDS populations could be very significant, as adults in this group who are financially strapped but not on welfare could potentially lose, let alone not gain, additional services that give them access to the care provided by the plan. The Public Health enabling services initiative and the proposed continuation of the categorical grant programs (especially Ryan-White) would assist in lessening the financial predicament described above. However, they are not even authorized at levels to supplant the potential loss of benefits that may result due to the Medicaid modifications. Further, as these are categorized as discretionary spending, they may be subject to significant budget constraints in future years, due to deficit-reduction initiatives.

Policy Options: A. OPTIMAL Support the Administration proposal to establish broader medical coverage for children and continued coverage for cash-assisted adults under the Medicaid program, due to the significant concerns regarding increasing HIV rates in these age and risk groups. Advocate that

requirements for provision of federal entitlement matching funds for supplemental services be established for all formerly Medicaid AND uninsured adults, whether on cash assistance or not, in order to assure appropriate access to care for these individuals.

The major difficulty with this approach is that a very significant (potentially multi-billion dollar) increase in federal financing would be required for the additional millions of formerly uninsured who could need (and definitely use if available) these services.

B. OPTIMAL/REALISTIC Support the Administration proposal to establish broader medical coverage for children and continued coverage for cash-assisted adults under the Medicaid program, due to the significant concerns regarding increasing HIV rates in these age and risk groups. Advocate that the Public Health enabling services initiative be legislated as entitlement spending in order to prevent it from being subject to the annual appropriations process, which could very likely result in its being less than fully funded. Advocate the same policy for categorical grant programs of particular relevance to HIV/AIDS (inc. Ryan-White, up for reauthorization).

However, given the federal government's experience with the increasing mandatory financial obligations of entitlement programs, it is unlikely that it would want to establish new ones, particularly with deficit-reduction as a prioritizing principle.

C. REALISTIC Support the Administration proposal to establish broader medical coverage for children and continued coverage for cash-assisted adults under the Medicaid program, due to the significant concerns regarding increasing HIV rates in these age and risk groups. Support within the Administration and in Congressional hearings establishment of, and promises of full funding for, the Public Health enabling service initiative and categorical grant programs like Ryan-White that financially support provision of the supplemental services that PWA's particularly require for care. Advocate funding equivalency at least between the gain expected through the public health initiatives and the loss encumbered through the Medicaid program revisions. As a previous step, support the prioritization by the Department's analytic group of conducting a study on determining the financial gains/losses on supplemental services under health reform. Evaluation of supplemental services need by the currently uninsured could be advocated as an additional step.

THE WHITE HOUSE
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NOTE TO KRISTINE M. GEBBIE

Through: George Walter *aw*

Subject: Health Care Reform Hearing -- UPDATE

- o As reported at the staff meeting on Monday, we have continued to actively monitor health care reform activities and wanted to provide you with additional summaries of Congressional hearings.
 - o The three great problems of health care reform that have emerged are: How to finance universal coverage? How to contain costs? How to spread costs equitably so that sick and poor citizens aren't left out of any new system?
 - o Eight members of the House plan to go to the floor tonight to debate the statement: "Resolved: The Clinton health-care plan best represents the elements that should be included in health-care reform." Representatives Gephardt (MO), Waxman (CA), Stark (CA) and DeLauro (CT) will argue in support of the statement. Arguing against the plan will be Representatives Gingrich (GA), Bliley (VA), Thomas (CA) and Johnson (CT). The debate will be covered on C-SPAN and on National Public Radio, is the first in what is supposed to be a series of debates on major policies facing Congress.
 - o Yesterday the Ways and Means Subcommittee on Health voted to keep a provision requiring that employers pay for 80 per cent of the cost of health care for their employees. The amendment to strip the provision is one of the key issues in the debate - whether universal health-care coverage should be made possible largely by requiring employers to pay for health care coverage for their employees.
 - o We have attached summaries for your review and circulated them among staff.
- Tab A: The Clinton Health Plan and Public Health,
Consumer Protection and Civil and Privacy Rights
- Tab B: Health Care Reform: Issues Relating to Inner-City
and Rural Communities

Page 2 - Note to Kristine M. Gebbie

Tab C: Health Care Reform: HR1200, The American Health Security Act of 1993; HR 2610, The Mediplan Act of 1993; and Other Single-Payer Options
Tab D: Hearing to Examine Health Care Coverage for Americans with Disabilities
Tab E: Benefits Package Health Care Reform
Tab F: Women's Health Care in the President's Health Care Plan

Should you have any questions or comments, we are available at your convenience to discuss.

Alice M. Litwinowicz
Alice M. Litwinowicz

TAB A

Hearing Summary
House Subcommittee on Health and Education
The Clinton Plan and Public Health, Consumer Protection and Civil
and Privacy Rights
January 31, 1994

Members list:

Democrats: Waxman (CH-CA), Cooper (TN)

Witnesses:

Philip R. Lee, M.D., Assistant Secretary for
Health, PHS
Nan Hunter, Deputy General Counsel, HHS
Panel 1: John Lumpkin, M.D., Director Illinois Dept. of Health
Fernando M. Trevino, Ph.D., M.P.H., Exec. Director
American Public Health Association
Panel 2: Brian Lindley, National Consumers League (replaced
Linda Goldoner from the National Consumers League)
Panel 3: Dr. William Gibson, CH. of National Board of Directors
NAACP
Marcia Greenberger, Co-President National Women's Law
Center
Tim McFeely, Exec. Dir., Human Rights Campaign Fund
Kathleen Frawley, J.D., M.S., R.R.A., Director
Washington D.C. Office of American Health Information
Management Association

Rep. Waxman opened the hearing by saying that the current public health policy on AIDS is unsuccessful. He also expressed concern over individuals rights to privacy as well as whether or not the Health Security Card will be a civil rights violation to over one third of the Latinos within the U.S..

Following the opening remarks, Dr. Philip Lee testified that the President's plan will improve the health of Americans and also reduce health disparities. The plan, according to Dr. Lee, emphasizes personal accountability, disease prevention and a close relationship between the personal care and public health systems. Under the plan, all Americans will have comprehensive benefits including clinical preventive services. Dr. Lee stressed that the President's plan focuses on keeping individuals healthy. Dr. Lee stressed that there is a real need for public health care reform. He exemplified this point by saying that "substance abusers are the fastest growing segment of the HIV/AIDS population, and substance abusers with AIDS are a major factor in the spread of multi-drug resistant tuberculosis." Dr. Lee told the subcommittee that the President's plan has three specific Public Health initiatives. They are to "strengthen the capabilities of communities to protect the health of their populations and address high-priority local health problems; improve the knowledge base for preventing disease and providing medical care; and assure access to necessary health services for all Americans." By improving the health of communities, it will strengthen the government's capacity to provide population-based health activities. The President's plan allows for a national prevention initiation program and a core health program that will support such functions as the surveillance of communicable and

chronic disease, control of communicable diseases and injuries, environmental protection, public education and community mobilization, accountability and quality assurance, public laboratory services and education of public health professionals. The Public Health initiative provides for new prevention resources and expanded health services. Dr. Lee told the subcommittee that AIDS/HIV infection still poses the top prevention challenge. Dr. Lee also explained to the subcommittee that the Health Security plan will improve quality care six ways. They include national quality measures, quality report cards, expansion of research outcomes and the development of clinical practice guidelines, the placement of regional professional foundations at the center of continuing education within the health care field, the state establishment of quality criteria and the simplification of paperwork for providers. Dr. Lee also informed the subcommittee that consumer protection would be monitored under the President's plan. The final area that Dr. Lee discussed was that of privacy under the health plan. He explained to the subcommittee that there are three core principles under the President's plan. They include any disclosure that is permitted by law will be minimal, every patient shall have the right to know where individual identifiable information may be located, and every patient shall have a right of access to individual identifiable information to copy or correct such records.

The subcommittee asked Dr. Lee where the appropriations would be found for his plan. Dr. Lee told the subcommittee that the administration would be willing to work with Congress to find the money for the initiatives. Dr. Lee also explained to the subcommittee that the administration was willing to work with the committee to set proper standards for the alliances. Rep. Waxman told the panel that there was a need for the continuation of the Public Health Service and that the infrastructure within must be geared towards targeted objectives. The subcommittee expressed concern on how the individual state health plans would be evaluated. Dr. Lee explained that each plan would be looked at to see if it has met the set goals, what treatments are offered and other pertinent standards as set by Congress. Dr. Lee said that plans will be monitored by the alliances, Public Health Service agencies, and by the consumer (quality report cards). Dr. Lee told the subcommittee that the administration would work closely with Congress to prohibit any sexual discrimination.

Dr. John Lumpkin applauded the President's proposal and strongly supports the eight core functions. He believes they are critical to the population and should not be funded through competitive means or at the discretion of the Secretary of Health and Human Services. Dr. Lumpkin believes that states must have a designated, predictable source of funding for core public health programs. He would like to see increased accountability within states, increased data collection for research, and the inclusion of public health professionals in the development and implementation of a reformed health care system within a health care plan.

Dr. Fernando Trevino testified in support of a health care

reform bill that offers universal coverage while removing financial, organizational, and social impediments. He strongly supports the President's core public health functions. Dr. Trevino also approves of a national initiative regarding health promotion and disease prevention programs, but he says that the programs are far too vague as presented in the President's plan. He believes that the plan should support the training of public health workers so that they may respond effectively to public health problems including AIDS.

Brian Lindley testified in support of the President's plan and applauded the attention given to data collection, analysis, and dissemination. He told the subcommittee that individuals would need to be able to obtain unbiased information concerning plans, options, and providers, as well as an advocate and a grievance procedure for patient complaints. Mr. Lindley stressed that the incorporation of comparative information, plan-specific information, and condition specific information was necessary. He also supported the administrations establishment of ombudsman offices, but called for more detail concerning how this program will be designed.

Dr. William Gibson testified on behalf of the NAACP. He explained to the subcommittee that the NAACP wants a health plan that addresses both the racial and socio-economic realities that currently exist in the country. The NAACP supports many parts of the Clinton proposal, yet they are concerned that the plan may be too vague and ambiguous in addressing certain issues. The NAACP also supports the inclusion of an anti-discrimination provision. They would like to see protection against redlining and other possible civil rights violations, possibly through the use of a "preclearance mechanism."

Marcia Greenberger testified before the subcommittee on behalf of the National Women's Law Center. Ms. Greenberger stressed that there are many significant barriers that inhibit women from obtaining adequate health care. Ms. Greenberger explained to the subcommittee that AIDS has been affecting women in increased numbers, particularly among young women of color.

Mr. Timothy McFeely testified on behalf of four national lesbian and gay rights groups, including the Human Rights Campaign Fund. He told the committee that many of the health concerns of lesbians and gay men remain extensive and unmet. He explained that the gay and lesbian community desired an investment in an aggressive national program of biomedical research. Mr. McFeely also told the subcommittee that the protection against discrimination for disabled persons must also extend to those in the gay and lesbian community who are infected by HIV/AIDS. He stressed that "lesbians and gay men must have the right to full health coverage free of bias on the part of health alliances, plans, or providers." Mr. McFeely testified that no plan should allow a health care provider to refuse services that are included in the benefits package. McFeely also stressed the need for the recognition of non-traditional families, confidentiality, early intervention services and a comprehensive benefits package that promotes prevention, primary care, long-term care, home and community-based health care,

prescription drug coverage and medical education.

Prepared by:CHarrington:ONAP:March 7, 1994:690-5560.

TAB B

Hearing Summary
House Subcommittee on Health
Health Care Reform: Issues Relating to Inner City
and Rural Communities
February 7, 1994

Members Present:

Democrats: Stark(CH-CA), McDermott(WA)

Republicans: Thomas(CA), McCreery(LA)

Witnesses:

Honorable Charles Stenholm, M.C., Texas

Honorable Pat Roberts, M.C., Kansas

Honorable Craig Thomas, M.C., Wyoming

Honorable Philip Lee, M.D., Assistant Secretary for Health, HHS

Panel 1:

Sara Rosenbaum, Center for Health Policy and Research, George Washington University

James D. Bernstein, President-Elect, National Rural Health Association

Larry Gage, President, National Association of Public Hospitals

John M. Silva, President, National Association of Community Health Centers, Inc.

Panel 2:

Honorable Jim Moody, Visiting Professor, Wisconsin Medical College

Jon E. Vice, President, Children's Hospital of Wisconsin

Barbara Staggers, M.D., Director of Adolescent Medicine, Children's Hospital Oakland

Martin Goldsmith, President and CEO, California Children's Hospital Association

Honorable Edward H. McNamara, County Executive, Wayne County, Michigan

- * This office covered panel one, the additional information is taken from written testimony.

Senator Charles Stenholm testified before the subcommittee on behalf of the House Rural Health Care Coalition. He explained that financial incentives are found within the Clinton Bill, H.R. 3600, for primary care providers to locate in rural areas, yet these financial incentives are not enough. He encouraged the subcommittee to look at incentives that would build integrated health care delivery and communications systems. Sen. Stenholm also urged the subcommittee to "consider options to help communities in the planning and implementation of delivery networks." The Senator was concerned about the effects of health care reform upon small businesses.

Senator Pat Roberts also testified on behalf of the House Rural Health Care Coalition. He supports the efforts made in the Health Security Act to invest in the expansion of primary care services in undeserved areas, although he was concerned about the funding and the administration of funds for these programs. He also expressed concerns for the funding of educational and prevention programs. Sen. Roberts was anxious about the regional

alliance caps that may be developed based on historical data, rationing, and in the formation of adequate delivery systems. Sen. Roberts stressed the importance of giving rural communities adequate time to build funds for electronic information systems.

Senator Craig Thomas testified on behalf of the House Rural Health Care Coalition Task Force on Hospitals and Clinics. He explained to the subcommittee that no matter what plan is adopted, rural people must have the same benefits, access and treatment as those who live in urban areas. He told the subcommittee that the President's plan does not necessarily fit all communities, especially those that are rural or urban. Sen. Thomas expressed concern over the slashing of Medicare reimbursement funds, and the delivery system as prescribed under the President's plan.

Dr. Philip Lee testified before the subcommittee on behalf of the Department of Health and Human Services. He explained that the plan would provide health security to all Americans including those living in rural areas and urban cities. In his written testimony, Dr. Lee informed the subcommittee that HIV/AIDS is a serious problem in both inner cities and rural areas. For each HIV/AIDS case that is prevented, approximately \$102,000 will be saved in health care costs. Under the President's plan, all Americans will receive a comprehensive benefits package including preventive services, mental health and substance abuse services. Under the Health Security Act, health care alliances will provide consumers with purchasing power, indigent populations will receive subsidies, practitioners providing care in underserved areas will be eligible for tax credits, and safeguards will be implemented to prevent discrimination based on race, ethnicity, age, or gender. Dr. Lee told the subcommittee that the Ryan White Act will be maintained and strengthened under reform. He also stressed that the National Health Service Corps will be expanded and inner city and rural areas will be supported by new competitive grant and loan programs. Dr. Lee informed the subcommittee that through the Access Initiatives found within the plan, outreach and enabling services will be increased, mental health and substance abuse initiatives will be expanded, and two new programs will be instituted to reach out to school-age youth. Dr. Lee explained to the subcommittee the President's proposal concerning core public health functions as well as prevention initiatives.

Sara Rosenbaum stressed to the subcommittee that persons with HIV and other communicable diseases are at a particularly high need of comprehensive health services. She said that those with particularly high health risks are often found in underserved communities. She explained to the subcommittee the need for the removal of access barriers for underserved populations, as well as making insurance affordable, accessible, and of good quality. She also stressed the need for the direct financing of health providers and the adaption of health services to those within underserved populations.

James Bernstein, in his testimony to the subcommittee expressed support towards a health care plan that would provide universal access, health care training programs, the retainment

of health care services for rural areas, and graduate medical reimbursements. He expressed concern over the use of historical data to determine the level of reimbursements for rural providers.

Larry Gage stressed to the subcommittee the need for "substantial safeguards," including mandatory open enrollment, limitations on advertising, and mandatory random assignment of "high risk" patients. He also wanted to see that urban safety net hospitals be maintained.

Martin Goldsmith testified before the subcommittee that there are three major problems within the Clinton Health Security Act. He is concerned about the proposed cuts in Medicare, the way the plan addresses the uncompensated care issue, and the potential side effects of how the plan would serve Medicaid recipients.

Dr. Martin Staggers emphasized the need for the designation of Children's Hospitals as essential providers. She told the subcommittee that there was a need for the preservation of disproportionate share payments to supplement the Medicaid program or a new fund that would ensure coverage for vulnerable populations. Dr. Staggers also stressed the need for the preservation of Title V programs for children with special needs.

Jon E. Vice told the subcommittee that the reform plan "should designate not only publicly primary care clinics but also public hospitals and children's hospitals serving the mentally underserved as "essential providers." He also explained to the subcommittee that there was a need for financing of graduate medical education, the assurance of access by children to designated pediatric centers of excellence, and that reform should address the needs of children with special care needs.

All members of the panels expressed support for provisions in the Health Security Act that would recognize those who currently care for the underserved as "essential community providers."

Prepared by:CHarrington:ONAP:March 8, 1994:690-5560

TAB C

Hearing Summary
Committee on Ways and Means: Subcommittee on Health
Health Care Reform: H.R.1200, The American Health
Security Act of 1993; H.R.2610, The Mediplan Act of
1993; and Other Single Payer Options
February 9, 1994

Members Present:

Democrats Stark (CH-CA), Cardin (MD), Kleczka (WI), Lewis (GA)
Republicans Thomas (CA), McCrery (LA)

Witnesses:

Panel 1

The Honorable Jim McDermott, M.C. Washington
The Honorable John Conyers, M.C. Michigan
The Honorable George Miller, M.C. California

* Additional Panels were not covered by this office.

Following opening statements, Rep. Jim McDermott testified before the panel as a co-sponsor of H.R. 1200, the American Health Security Act (AHSA). He explained to the committee that the single payer plan guarantees universal coverage while maintaining the best aspects of the current delivery system. Rep. McDermott told the committee that under the AHSA every American will know exactly how much their health insurance will cost them in the future. He also explained that under the single payer plan, seventy-five percent of Americans will pay less than what they are currently paying, for a comprehensive benefits package that will include home, community-based, and nursing home long-term care, prescription drugs, comprehensive mental health and substance abuse benefits as well as a variety of preventive and acute care services.

Rep. John Conyers explained to the subcommittee that he was in support of the single payer health care plan. He told the members that the plan offered universal coverage, comprehensive benefits and strong cost containment. Rep. Conyers explained that the single payer plan offered the consumer free choice of provider and targeted medical assistance. He stressed to the subcommittee that this plan was not socialized medicine and was overwhelmingly supported by the Congressional Black Caucus.

Rep. George Miller informed the subcommittee that according to the Congressional Budget Office, H.R. 1200 would reduce national health care spending by between \$114 billion and \$175 billion per year starting in the year 2003 and that the plan would offer the benefits prescribed based on the financing method. He testified that the single payer plan will offer better benefits, maintain long term care and does not require co-payments and deductibles in addition to the premiums.

Following testimony, the panel answered questions. The panel explained that there were no out-of-pocket payments for acute care or preventive services. The subcommittee expressed concern over redlining, Medicare, and rationing.

TAB D

Hearing Summary
House Subcommittee on Social Security
Hearing to Examine Health Care Coverage for
Americans With Disabilities
February 23, 1994

Members present:

Democrats: Jacobs (CH-IN)

Republicans: Bunning (KY), Houghton (NY)

Witnesses:

Panel 1:

Judith Feder, Ph.D, Principal Deputy Assistant
Secretary for Planning and Evaluation, HHS

Helen Smits, M.D., Deputy Administrator, Health Care
Financing Administration

Allan Bergman, Chair, Long-term Services and Support Task
Force

Rebecca Ogle, Washington D.C.

Karen Vaughn, Indianapolis, Indiana

Panel 2: Linda Weindruch, Esq., Des Moines, Iowa

Chester Helms, National Council on Independent Living

Jodie Wildy, National Rehabilitation Caucus

Jerry L. Mashaw, Ph.D., National Academy of Social Insurance

Panel 3: Lawrence J. Gorski, Director Chicago's Mayor's Office
for People with Disabilities

Paula Malek, American Disabled for Attendant Programs Today

Gerben DeJong, Ph.D., National Rehabilitation Research
Center

Dr. Judith Feder testified before the subcommittee that the President's Health Security Act (HSA) is distinguished from other plans because of its long-term care benefits that it offers. The long term care benefits gives care to all those with disabilities through federal funding. The benefits set forth in the plan would be designed by consumers to be responsive to their needs.

Dr. Helen Smits testified that the HSA would guarantee services and protect against discrimination while offering recipients choices. The HSA requires all health plans to have contacts with academic health centers and to maintain essential community providers.

Allan Bergman testified before the subcommittee that 81 million people with disabilities would gain from the President's Health Security Act. He explained that under the HSA new work incentives would be implemented that would help individuals currently on Social Security Disability Insurance (SSDI) move into the mainstream. He informed the subcommittee that the HSA offers a tax credit for working age adults. He urged them to pass health care reform.

Following testimony the panel answered questions. The subcommittee asked how the plan would affect Social Security beneficiaries who are currently disabled. The panel informed them that the Social Security beneficiaries would be provided primary coverage through the alliances and that they had the option of buying supplemental coverage, although full scale

coverage would be offered in the alliances. The panel explained to the subcommittee that if an individual is working part time, the question of health care coverage would depend on the individual's income. If an individual's employment ends, that person would return to the Medicare system.

Ms. Rebecca Ogle testified before the subcommittee concerning her personal journey with a disability and the current health care system. Ms. Ogle is living with spina bifida. She urges the members of Congress to pass legislation that guarantees universal health care coverage for all Americans.

Karen Vaughn testified before the subcommittee about her experiences with paralysis, employment, and the Social Security Disability Program. Ms. Vaughn asked the members to "pass national health care reform consistent with the principles embodied in the President's Health Security Act."

Ms. Linda Weindruch testified about her personal experience with multiple sclerosis. She also testified in support of the HSA.

Mr. Chester Helms stressed that the current Medicare plan is inadequate. Mr. Helms explained that President Clinton's plan allows for Medicare coverage for prescription drugs, choices concerning home health care and the option to obtain insurance without two year waiting period. He informed the subcommittee that the HSA allows for "true equality for people in the arena of health care."

Ms. Jodie Wildy testified that rehabilitation must be an integral part of tomorrow's health care system. She urged Congress to specify covered services and also made some recommendations for the President's plan. She stressed that provisions for orthotic and prosthetic devices should be consistent, language should refer directly to rehabilitation, the definition of rehabilitation hospitals and units must be amended, the definition of qualified facilities should be updated, specific therapies should be covered, community based residential treatment programs should be included as an additional site for rehabilitation services, and the state financing for rehabilitation services needs to be readdressed. Ms. Wildy also recommended changes in the administrative structure of the plan.

Ms. Virginia Reno testified on behalf of Dr. Jerry L. Mashaw. Ms. Reno testified that the current Medicare system is inadequate. She explained to the subcommittee that his panel uncovered three findings. They are that universal coverage would be a major breakthrough for those living with disabilities, universal coverage would "foster early intervention to prevent diseases or impairments from becoming permanent work disabilities", and that health care coverage would offer prescription coverage, medical equipment, personal assistance services, and rehabilitation services.

Mr. Lawrence J. Gorski explained to the subcommittee that there are four key areas that are essential to health care legislation. They include universal access, no exclusions based on pre-existing conditions, long-term care options including home services, and funding for personal assistance services.

Ms. Paula Malek testified that currently there is not enough

money being spent on community-based attendant services. She stressed that under the health care plan, there should be standards set for attendant services community based standards, availability, maximum control placed in individual providers situation, provisions for emergency services, cost sharing, and the allowance of health related tasks to be performed by unlicensed yet qualified personnel.

Dr. Gerben DeJong testified that the President's Plan takes great steps in helping those with disabilities. These areas include, tax benefits, long-term and community based services and community ratings.

Prepared by: CHarrington:ONAP:March 14, 1994:690-5560

TAB E

United States Senate Committee on Finance
Hearing on a "Benefits Package" Under Health Care Reform
Thursday, March 3, 1994

Members Present:

Democrats: Moynihan (Ch-NY), Baucus (MT), Rockefeller (WV)
Republicans: Packwood (OR), Dole (KA), Danforth (MS), Chafee
(RI), Durenberger (MN)

Witness List:

Panel I: Judith Feder, Ph.D., Principal Deputy Assistant
Secretary, Office of the Assistant Secretary for
Planning and Evaluation, Department of Health and
Human Services
Roger C. Herdman, M.D., Director, Office of
Technology Assessment

Panel II: Susan Gleeson, Executive Director, Medical and
Quality Management, Blue Cross and Blue Shield
Association
Rhoda H. Karparkin, J.D., President, Consumers Union
of the United States, Inc.
Frank B. McArdle, Ph.D., Manager, Washington
Research Office, Hewitt Associates LLC
Paige R. Sipes-Metzler, D.P.A. Executive Director,
Health Services Commission, Oregon Department of
Human Resources
William H. Straub, M.D., Senior Health Policy
Analyst, Jackson Hole Group

Each Senator opened the hearing by making a few brief remarks. Senator Packwood opened by saying there was no way that a benefits package could provide "all things to all people." Senator Moynihan talked about the decisions made by the public about these matters. Senator Danforth said that the important question was: how does one say no? Senator Rockefeller asked the same thing adding that the Clinton plan wasn't a Cadillac plan that doesn't make false promises to the American people showing exactly what they will receive.

Judith Feder testified that the benefits question was one of importance, however, it is only one of the issues that need to be addressed. Dr. Feder gave various reasons about the need to specify a benefits packages: for fiscal responsibility, to provide security to purchasers of the benefits package by specifying a standard package of benefits, etc. She said with this done, choices among plans would be facilitated for consumers. The President's plan, she said, achieves these specifications. It provides a comprehensive benefit package, much like an average set of benefits that people are able to purchase today: "It [the Clinton plan] is comparable to the average coverage enjoyed by individuals with employment based private health insurance." She said that the Clinton plan provides many services including mental health and substance abuse treatments without lifetime limits on such benefits. She

also made a special point to mention the special need of people with disabilities as well as children and their need for long-term care being covered by a benefits package.

Roger C. Herdman said that "the public will judge reform based on the services received and what they pay." He then pointed to a chart which shows a box titled "Benefit Package." From the benefit package, the chart works through two "filters" where various influences come into play such as payment, expenditure caps, etc., leading finally to what the patient actually gets. Mr. Herdman spent some time explaining what the chart meant before speaking on how the way benefits are financed may effect not only the costs but also the benefits package as well. He ended his testimony by saying that there was "no completely scientific way to design benefits."

After the first two panelists finished, the Senators began asked questions about the general theme of whether or not it would be possible to say no to some things because, as Senator Packwood pointed out, not everything can be covered and a decision would have to be made about what was going to be in any list of benefits package. There was no decision as to what was going to be in such a package, only a reiteration of what wasn't going to be in President Clinton's plan. Senator Danforth led this line of questioning by asking Dr. Feder if she could "say no to certain kinds of benefits?" Dr. Feder tried to reiterate the administration's view that the Clinton plan does indeed say no to some benefits as well as leaving doctors with enough autonomy to be able to decided which procedures are necessary and should be covered on a case by case basis. There were also questions over having a 'standard plan' and a 'catastrophic plan.' During his allotted time, Senator Durenberger pointed out three basic functions of any benefit package. These functions were dealt with in one way or another by the five panelists of the second panel. They were 1) making markets work, 2) equity, the universal coverage issue, and 3) value judgements, what are we getting for our money

The first witness in the second panel was Ms. Sipes-Metzler, who addressed certain aspects of the Oregon system and pointed out some basic features of the Oregon Commission that decides which procedures are covered. Some of the points were that the commission needs to be neutral politically and the need for financial freedom. She closed by saying that in Oregon, the commission "blends public values with scientific findings." The second panelist, Susan Gleeson, gave a short history of Blue Cross and Blue Shield. One of the most interesting points about the organization was the fact that Blue Cross leaves to an extended panel of various people including members from the Kaiser Permanente firm, which Blue Cross is affiliated, the decisions of what is covered in their benefits package.

Rhoda H. Karpatkin, President of the organization that publishes Consumer Reports Magazine, summarized various points taken out of

the ten in her written testimony. The first was that consumers want comprehensive benefits. The second was that the private market has proven incapable of providing this. The third was that Cadillac coverage is a myth. The fourth was Congress shouldn't leave the benefits package to a benefits commission. Frank B. McArdle also gave nine issues, this time, however, sharing the microlevel experience of his office. Some of the issues were that planned designs change every year. Another idea was that the edge of major change was in the idea of benefit design. Another issue was that there is no 'one' plan design that will serve everyone well. There will have to be many different designs to take into account the differences throughout the nation. William Straub in his testimony said that a standard plan of benefits would be fundamental for "a seamless plan" meaning any health care reform initiative. He went on to say that, as Senator Durenberger said, standardization would facilitate in comparing different plans. He also said that Senator Durenberger touched on three points (mentioned above) that were addressed in his written testimony.

Prepared by Lord: ONAP: 690-5560: March 3, 1994.

TAB F

Hearing Summary
Senate Subcommittee on Aging
Women's Health Care in the President's Health Care Plan
March 9, 1994

Members Present:

Democrats	Mikulski (CH-MD), Kennedy (MA), Pell (RI), Wofford (PA), Moseley-Braun (IL), Murray (WA), Feinstein (CA)
Republicans	Hutchinson (TX)

Witnesses

Panel 1 Dr. Phil Lee, Asst. Secretary of Health, HHS
Dr. Susan Blumenthal, Deputy Asst. of Women's Health,
HHS (Accompanied Dr. Phil Lee)
Dr. Samuel Broder, Director, National Cancer Institute

***Additional panels were not covered by this office, although testimony is available.**

There was no testimony covered by this office although the question period following panel one was covered.

The questions following the testimony of panel one primarily dealt with the issues of breast cancer and mammogram. Dr. Blumenthal informed the subcommittee that she would have a breast cancer strategy prepared by April 18, 1994 for their review. The panel informed the senators that the benefits package would be decided upon by Congress and would be an evolving package. The panel told the subcommittee that there would be increased graduate medical education as well as the establishment of a women's health issues curriculum. They also informed the panel that education for counseling of risks behaviors and chronic diseases would be implemented. The subcommittee was concerned over why the baseline for mammogram was over age 50 and not under age 40. The subcommittee found this very frustrating since in the past women have been instructed to have a mammogram every year as of age 40. The panel informed the subcommittee that recent evidence has shown that the need for a mammogram test has been reduced. The senators said that they have been witnessing a declining budget go to women's health care research and asked the panel whether or not the President's plan would hurt this particular area. The panel responded that it would not be hurt, but rather there would be increased funding for women's research within the NIH.

All the Senators were in support of coverage for women's health care issues.

Prepared by:CHarrington:ONAP:March 14, 1994:690-5560

THE WHITE HOUSE

WASHINGTON

MAR 23 1994

NOTE TO KRISTINE M. GEBBIE

Through: George Walter *Amf for*

Subject: Health Care Reform Hearing -- UPDATE

- o The House Veterans Affairs Hospitals and Health Subcommittee held a hearing on the VA's plans to implement national health care reform. From coverage of the hearing today, we understand that the VA is in the process of doing a plan, but it has not been cleared by the Secretary and is not expected to be completed for approximately two months (see attached summary).
- o The Congress leaves for a two week spring break starting March 25 and will return on April 11. We plan to cover the hearing on Medicaid scheduled for tomorrow, March 24.

Alice M. Litwinowicz
Alice M. Litwinowicz

Hearing Summary
House Veterans Affairs Committee: Subcommittee
on Hospitals and Health Care
Hearing on Health Care Reform Implementation by
the Veterans Administration
March 23, 1994

Members Present:

Democrats: Rowland(CH-GA), Long(IN), Edwards C.(TX),
Filner(CA), Kreidler(WA)

Republicans: Smith, C.(NJ), Bilirakis(FL), Linder(CA),
Everett(AL), Buyer(TN)

Witnesses: Dr. Elwood J, Headley, Acting Deputy Under Secretary
for Health Department of Veterans Affairs
Accompanied by: Mr. Keiner, Veterans
Administration's General Counsel; Mr. Walters,
Legislative Office Health Care Reform Office; Dr.
Milbrant, Resource Manager; Ms. Neary, Construction
Planning; Ms. Kirks, Construction Planning

Rep. Rowland opened the hearing by saying that the Hospitals and Health Care Subcommittee wanted to build upon H.R. 3600, the Health Security Act. The subcommittee, according to Rep. Rowland is aiming to improve the bill and make it more applicable to veterans.

Following the opening statements, Dr. Elwood Headley testified on behalf of the Veterans Administration (VA). He informed the subcommittee that the VA has been working with the Clinton Administration to define and preserve an independent health care system for veterans. This system would offer choices to both the veterans and their dependents. He said "The Health Security Act... is the only health reform bill which we have seen which recognizes the unique health needs of veterans and the importance of the VA health system and would preserve and strengthen that system." The VA health plans would guarantee a comprehensive benefits package to all veterans and their dependents who are enrolled with the VA. This package would include inpatient and outpatient care, prosthetics, durable medical equipment, home health services, hospice care, and prescription drugs. He informed the subcommittee that last fall, the Health Care Reform Program Office was established to develop an implementation plan for the VA to make the transition to a competitive health care environment. This office is currently editing the initial draft of the proposed changes that the VA would have to make to adapt to the President's plan. Since this revision has not been submitted to the Secretary for his review, it is not available. There are two key changes that the VA will have to make. They are in the areas of customer service and the establishment of an "integrated managed care delivery system." The VA would like to see prompt and accessible primary care, including health promotion and disease prevention, acute chronic and specialty care, and health education. According to Dr. Headley, H.R. 3600 would grant "provide the VA with the authority to implement alternative personnel systems for the management of

VA health personnel." He stressed that the organizational, administrative, financial management and information resource decision making authority would be placed at the lowest possible level.

Following testimony, Dr. Headley and his panel answered questions. Rep. Rowland asked what the two key recommendations by the VA would be to the Secretary. Dr. Headley responded that they would be concerning customer service orientation and decision making planning. Dr. Headley explained that the customer service orientation would involve culture changes, personnel initiatives, work place initiatives, defining roles, defining benefits and the proper addressing of veterans issues. The VA would like to educate all employees on customer service standards. Dr. Headley informed the subcommittee that such items as spinal cord care, blindness rehabilitation, and care for homelessness would be covered under the current appropriations as supplemental benefits. The panel informed the subcommittee that the VA has not taken a position on the abortion issue, but will offer the benefits package as prescribed in H.R. 3600. The panel told the subcommittee that the Clinton plan would offer comparable prescription drug benefits, expanded prothesis, and durable medical equipment. The panel informed the members that the price tag for this endeavor was not available at this time. The panel also explained to the subcommittee that the ambulatory care program is not ready yet. They also said that there still would be a need for tertiary care. The Republican members of the subcommittee expressed concern over whether the VA would maintain its independence under the Clinton plan. They were concerned that the VA would lose its voice and the veterans would suffer. The subcommittee suggested that a survey of other veterans programs around the world be taken.

Prepared by:CHarrington:ONAP:March 23, 1994:690-5560

Hearing Summary
House Veterans Affairs Committee: Subcommittee
on Hospitals and Health Care
Hearing on Health Care Reform Implementation by
the Veterans Administration
March 23, 1994

Members Present:

Democrats: Rowland(CH-GA), Long(IN), Edwards C.(TX),
Filner(CA), Kreidler(WA)

Republicans: Smith, C.(NJ), Bilirakis(FL), Linder(CA),
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Witnesses: Dr. Elwood J, Headley, Acting Deputy Under Secretary
for Health Department of Veterans Affairs
Accompanied by: Mr. Keiner, Veterans
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Legislative Office Health Care Reform Office; Dr.
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Planning; Ms. Kirks, Construction Planning

Rep. Rowland opened the hearing by saying that the Hospitals and Health Care Subcommittee wanted to build upon H.R. 3600, the Health Security Act. The subcommittee, according to Rep. Rowland is aiming to improve the bill and make it more applicable to veterans.

Following the opening statements, Dr. Elwood Headley testified on behalf of the Veterans Administration (VA). He informed the subcommittee that the VA has been working with the Clinton Administration to define and preserve an independent health care system for veterans. This system would offer choices to both the veterans and their dependents. He said "The Health Security Act... is the only health reform bill which we have seen which recognizes the unique health needs of veterans and the importance of the VA health system and would preserve and strengthen that system." The VA health plans would guarantee a comprehensive benefits package to all veterans and their dependents who are enrolled with the VA. This package would include inpatient and outpatient care, prosthetics, durable medical equipment, home health services, hospice care, and prescription drugs. He informed the subcommittee that last fall, the Health Care Reform Program Office was established to develop an implementation plan for the VA to make the transition to a competitive health care environment. This office is currently editing the initial draft of the proposed changes that the VA would have to make to adapt to the President's plan. Since this revision has not been submitted to the Secretary for his review, it is not available. There are two key changes that the VA will have to make. They are in the areas of customer service and the establishment of an "integrated managed care delivery system." The VA would like to see prompt and accessible primary care, including health promotion and disease prevention, acute chronic and specialty care, and health education. According to Dr. Headley, H.R. 3600 would grant "provide the VA with the authority to implement alternative personnel systems for the management of

VA health personnel." He stressed that the organizational, administrative, financial management and information resource decision making authority would be placed at the lowest possible level.

Following testimony, Dr. Headley and his panel answered questions. Rep. Rowland asked what the two key recommendations by the VA would be to the Secretary. Dr. Headley responded that they would be concerning customer service orientation and decision making planning. Dr. Headley explained that the customer service orientation would involve culture changes, personnel initiatives, work place initiatives, defining roles, defining benefits and the proper addressing of veterans issues. The VA would like to educate all employees on customer service standards. Dr. Headley informed the subcommittee that such items as spinal cord care, blindness rehabilitation, and care for homelessness would be covered under the current appropriations as supplemental benefits. The panel informed the subcommittee that the VA has not taken a position on the abortion issue, but will offer the benefits package as prescribed in H.R. 3600. The panel told the subcommittee that the Clinton plan would offer comparable prescription drug benefits, expanded prothesis, and durable medical equipment. The panel informed the members that the price tag for this endeavor was not available at this time. The panel also explained to the subcommittee that the ambulatory care program is not ready yet. They also said that there still would be a need for tertiary care. The Republican members of the subcommittee expressed concern over whether the VA would maintain its independence under the Clinton plan. They were concerned that the VA would lose its voice and the veterans would suffer. The subcommittee suggested that a survey of other veterans programs around the world be taken.

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Nsg/
Health
reform file

WHAT ROLE FOR NURSE PRACTITIONERS IN PRIMARY CARE?

WHEN the call went out recently for an increase in the number of primary care providers, nurse practitioners were prominent among the many professional groups that stepped forward. Now approximately 50,000 strong, they claim that their skills suit them ideally to fill the gap created by the shortage of primary care providers and gatekeepers. Already, 25 states have legislation authorizing the reimbursement of nurse practitioners by private and commercial insurers^{1,2}; 21 states and the District of Columbia permit them to write prescriptions for drugs, and 15 of these give independent prescribing authority for controlled substances.³ Is expansion of the ranks of nurse practitioners the optimal solution to the shortage of primary care providers?

Nurse practitioners are "advanced-practice" nurses who are trained in patient interviewing, physical examination, diagnosis, and therapeutics.⁴ They receive considerably less training in these areas than physicians,⁵ yet many believe they should be permitted to practice "first contact" care, carry out diagnostic testing, plan and monitor treatment, prescribe medications, and provide long-term care.⁵⁻⁷ They assert that they can treat common acute illnesses and stable chronic illnesses and that they are particularly effective in promoting health, preventing disease, and achieving patient compliance.^{5,6,8} They want authority to manage obesity, hypertension, and diabetes mellitus.⁶ Many of their claims stem from a perception, advanced by some of their leaders, including Dr. Mundinger in this issue of the *Journal*,⁷ that primary care is much simpler now and that practicing it requires considerably less training than physicians receive.

Those who support an expanded role for nurses in primary care believe that in comparison to physicians, advanced-practice nurses would (1) provide care at least equal in quality, (2) employ more efficient diagnostic strategies, (3) practice more often in underserved areas, and (4) provide less expensive care. They have supported these claims by citing hundreds of published studies, a report in 1986 by the Office of Technology Assessment (OTA),⁹ and an extensive meta-analysis published recently by the American Nurses' Association.¹⁰ How persuasive are these claims?

The claim that nurse practitioners provide primary care equal in quality to that provided by physicians is based on weak data. Most of the relevant studies were performed nearly two decades ago, when health services research was in its infancy. By current standards the methods of nearly all the studies that supporters cite are seriously flawed. Though the OTA report concluded that these flaws were not important enough to alter the conclusion that within nurse practitioners' areas of expertise quality was equivalent,⁹ I believe that the OTA report did not apply a sufficiently high

standard to the evaluation of study design. Serious flaws include a lack of appropriate controls, heterogeneity of practice settings, small samples of nurse-practitioner subjects and patients, lack of random assignment of patients, failure to account for differences in the severity of illnesses, and a paucity of outcome events. I am not the first to point out these shortcomings. They are well described in the OTA report⁹ and by nurse researchers themselves, many of whom have called for better-designed studies on the practice performance of their colleagues.^{11,12}

Some even claim that nurse practitioners who practice without physician supervision provide care that is as good as or better than that provided by physicians,^{5,13} but I am more skeptical about this assertion. Common sense argues that the shorter training of nurse practitioners should limit their capacity to deal with diagnostic uncertainty and complexity. When a patient's clinical manifestations call for reasoning from first principles, causal (physiologic) reasoning, or probabilistic reasoning,¹⁴ nurses' limited exposure to these concepts is likely to find them unprepared for certain diagnostic and therapeutic tasks. Therefore, they may not always appreciate the seriousness of a clinical problem and may fail to refer the patient to someone more expert. Existing data on the performance of nurse practitioners as independent providers^{10,13,15,16} also fail to meet criteria for adequate study design. Thus, there is insufficient evidence that nurse practitioners who work without physician supervision are equivalent to physicians.

This is not to say that nurse practitioners cannot perform many tasks as well as physicians. They are now effectively managing a large number of common problems (such as sore throats and lower urinary tract infections), with and without physician supervision. In outcome measures of such tasks, nurses score consistently better in several areas, such as patient satisfaction, patient compliance, health promotion, and disease prevention. They also seem as capable as physicians of performing many specific procedures. Their skills in performing one of these, flexible sigmoidoscopy, are evaluated elsewhere in this issue of the *Journal*.¹⁷

What about the claim that nurse practitioners use less invasive technology?^{5,6} In most studies comparing their practices, the nurse practitioners have had less than 1/10 the experience of the physicians,¹⁰ and they have, of course, less intense training in the use of technology. If we posit that care by nurses and physicians is comparable, and if the nurse practitioners are using invasive diagnostic studies more efficiently with far less training and experience, what special strategies are they using and why are doctors unaware of them? Alternatively, nurse practitioners may be using less advanced strategies because they are unfamiliar with or uneasy recommending sophisticated diagnostic tests. If so, some patients under their care may be deprived of needed studies, such

as magnetic resonance imaging, electrocardiographic stress tests, and cardiac catheterizations.

The assumption that nurse practitioners will gravitate toward the inner city and rural sites is based on the observation that many practice in these areas now. In fact, less than one fifth of nurse practitioners are based in such locations,¹⁸ and many are there because those were the places where they could find work. If nurse practitioners were allowed to practice primary care without supervision, there is every reason to expect that, unless special incentives were offered for practice in underserved areas, their geographic distribution would be not much different from that of primary care physicians.

Some argue that billions of dollars would be saved every year if more nurse practitioners were employed in primary care.^{6,19} This assertion is based on the shorter time needed to train nurse practitioners and the premise that they are paid less for their services, as well as other assumptions.¹⁹ I believe that these estimates of cost savings are open to serious question. When nurse practitioners are paid on an hourly basis, their income for a comparable workweek is not much different from that of a primary care physician. We cannot expect nurse practitioners (mostly women) to do comparable work and yet be paid less than physicians (still mostly men). Indeed, many nurse practitioners are already calling for equal pay for equal work.^{5,6} Finally, if we add a cadre of nurse practitioners to primary care, either in collaborative or independent practices with physicians, costs may increase or decrease depending on the number of other primary care practitioners (especially physicians) in the system at that time. I do not think we can count on lowering our health care costs by such a plan.

Physicians have long opposed giving nurse practitioners a larger role in primary care, but they have often been motivated by considerations of turf. I am not concerned with turf, but I worry about the claim that primary care now requires less training.^{7,20} On the contrary, as medical science becomes more complex the task of the generalist becomes more difficult. Indeed, physicians' concern about the difficulty of dealing with the whole of medicine has been a stimulus for specialization. The development of sophisticated diagnostic tests has made primary care more complicated, because the physician must decide which of many difficult-to-interpret, invasive, and expensive tests to recommend. And increases in our knowledge of pathogenesis have in some cases added to the complexity of managing disease. For example, the observation that tight control of blood sugar reduces complications in patients with diabetes mellitus²¹ raises the question of whether such patients should be cared for by those with more, not less, expertise.

Primary care is an essential component of health care reform. Should the future work force of primary care providers consist of more internists, family practitioners, and pediatricians? A larger number of obstetrician-gynecologists? Specialists and subspecialists

retrained as generalists? How about nurse practitioners? It certainly would be reasonable, as Munding suggests, to use many more nurse practitioners in collaborative practice arrangements, especially if reform promotes large group practices.⁷ Yet many nurse practitioners are not content with this model. They argue that they should be allowed to practice primary care entirely independently, and they have pressed for expanded authority from federal and state governments to do so.^{5,22,23} Given the lack of evidence that this mode of practice is efficacious and safe, we should be cautious about this approach. Properly designed and executed studies of the performance of primary care providers are not easy to perform; yet until we have solid data from such studies, I worry that further expanding a fully independent role for nurse practitioners in primary care will be an irreversible step that we may regret.

JEROME P. KASSIRER, M.D.

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SOUNDING BOARD

ADVANCED-PRACTICE NURSING — GOOD MEDICINE FOR PHYSICIANS?

HEALTH care reform has engendered many debates. One that has captured the attention of physicians, nurses, and policy makers is the relation, and perhaps the competition, between physicians and advanced-practice nurses. Advanced-practice nurses are registered nurses with specialty training, usually at the master's-degree level, in primary care (i.e., nurse practitioners and nurse-midwives) or acute care of inpatients (i.e., clinical nurse specialists). The practice of nurse practitioners has been evaluated since 1965, when the role was developed by Henry Silver, M.D., and Loretta Ford, R.N. When measures of diagnostic certainty, management competence, or comprehensiveness, quality, and cost are used, virtually every study indicates that the primary care provided by nurse practitioners is equivalent or superior to that provided by physicians.¹⁻⁴

Over the past few years, state legislatures have broadened the authority of nurse practitioners to receive direct payment and write prescriptions, and the barriers to independence have fallen. As a result, nurse practitioners can establish independent practices that parallel those of primary care physicians (either solo or in health maintenance organizations), or they can establish collaborative practices in which doctors and nurses care for patients together. I advocate a collaborative-practice structure for two reasons clearly beneficial to physicians. First, collaborative practice is more comprehensive, more cost effective, and therefore more competitive than independent practice in the current environment of health care reform. Second, it provides a configuration of practice that is attractive to primary care physicians. Rather than battle for patients and turf, physicians and nurse practitioners can advance their practices and retain the rewards they value most by forming new teams — teams in which authority rests on competence, not historical medical dominance.¹⁻³

The studies cited in this paper, which are representative of the research comparing nurse practitioners with primary care physicians, all refer to initial, independent judgments made by nurse practitioners about diagnosis or treatment, even when the nurse practitioners worked in settings in which their decisions were confirmed by physicians before being implemented. Nurse practitioners work in a wide variety of structures, from settings in which they are supervised employees of physicians, to collaborative practices with other practitioners, to solo practices. In each of these structures the nurse practitioner sees a patient, elicits data, reaches diagnostic conclusions, and decides about treatment. It is with regard to this professional process that nurse practitioners and physicians are being compared.

Randomized populations of patients have been the basis of many studies comparing nurse practitioners with physicians as providers of care.^{2,5-8} When the research involved analyzing multiple studies, compari-

sons were stratified according to whether they were from a randomized study or some other methodologically sound type of study.^{1,4,9,10} Remarkably similar outcomes with regard to quality, competence, and cost savings were reached in all the studies, and there was close agreement between studies that randomized patients and those that did not.

In collaborative practice, a nurse practitioner and a physician provide primary health care to a group of patients, and the two professionals share authority equally for providing care within the scope of their practice. The nurse practitioner is not required to obtain the physician's approval to provide that care. When there are differences of opinion, the person with the greatest degree of professional competence holds authority; for complex diagnostic and treatment problems involving unstable and critically ill patients, this is the physician, and for prevention, access to community-based resources, health education, and counseling, it is the nurse practitioner. When there is a difference of opinion about a patient's direct medical care, the physician has final authority. This same process can work for a team that includes a physician and a clinical nurse specialist who both provide care for acutely ill hospitalized patients, although the very nature of inpatient care suggests that physicians will have a much higher degree of involvement in directing that care.

There are now approximately 100,000 advanced-practice nurses, half of them nurse practitioners and nurse-midwives, and half clinical nurse specialists.¹¹ Whereas nurses have been attracted to primary care in increasing numbers, physicians in training have become less interested in that field and more interested in specialty and subspecialty medicine. Nearly a third of physicians (perhaps 200,000) are primary care practitioners, but less than 15 percent of medical students (2800 a year) are now planning careers in primary care.¹² Conventional wisdom has set 50 percent as the proportion of physicians needed in primary care; more recently, extrapolations from ratios of managed-care providers suggest that a balance of two thirds primary care physicians and one third specialists is needed.¹³

Primary care holds relatively little allure for physicians, however. Specialists are paid better, have more manageable and intellectually more interesting practices, and retain a higher degree of esteem among their colleagues.^{12,14,15} I doubt that merely increasing the remuneration for primary care would attract more physicians.^{14,16,17} The features of a medical career that distinguish it from most other career choices make money a major determinant, but only one of many. The day-to-day commitment, the continual intense encounters with anxious or sick patients and their families, and the requirement to maintain highly technical skills and keep abreast of new knowledge and new techniques are the payment society extracts in exchange for the respect and high income it gives physicians. The required level of commitment is possible only if physicians find it deeply satisfying to spend 14-hour days in such pursuits. One may also

ask why the nation should spend more money to induce physicians to do what nurse practitioners would do gladly.

Primary care no longer requires the level of training that it once did. As biomedical knowledge has grown, basic medical education has been truncated. The gap in competence between the specialist and the primary care physician has increased, and the rewards associated with primary care medicine have shrunk proportionately. As the scope of medical care has grown, so has the scope of nursing care, and in primary care there is substantial overlap in practice between physicians and nurse practitioners. This overlap has been shown in numerous studies, including a randomized trial of 1598 families assigned to a nurse practitioner or a physician for treatment of a variety of conditions²; an analysis of 21 published studies, including 8 randomized trials comparing the practices of nurse practitioners and physicians¹; a randomized study of simulated diagnostic and treatment decisions about abdominal pain that compared 799 nurse practitioners and physicians⁶; a randomized trial comparing the care provided by nurse practitioners and physicians in 550 disease-specific encounters⁷; and three major reviews analyzing hundreds of published studies that were considered well conducted and methodologically strong.^{4,9,18} In all these studies, the independent judgments of nurse practitioners were compared with the judgments of physicians with regard to similar patients.

Although they are indistinguishable from their physician counterparts in making primary care decisions, nurse practitioners bring additional skills to the practice. Nurses are more likely to talk with patients and adapt medical regimens to a patient's preferences, family situation, and environment.^{7,10} They are also more likely to provide disease-prevention counseling, health education, and health-promotion activities,^{4,6,8} as well as to know about and use community resources,⁴ such as nutrition programs, self-help or group therapy, and parenting and stress-reduction programs. The training and perspective gained in nursing education account for the extra time nurses spend on these aspects of care. A practice focused on health is profoundly different from a practice focused on disease. A physician and a nurse practitioner may treat a specific acute illness in an identical manner, but nurse practitioners evaluate the illness differently, placing an emphasis on why a patient is at a specific risk. Once the illness is resolved, they intervene with counseling about health promotion or disease prevention to maintain the patient's health.^{4,6,7}

Many states are increasing the level of authority and reimbursement for nurse practitioners. Most private insurance companies and health maintenance organizations cover the services of nurse practitioners. Forty-six states now authorize nurse practitioners to write prescriptions, although they differ widely in the degree of autonomy they grant. Twenty-one states and the District of Columbia currently provide authority to write prescriptions independently, and 15 of

those include the authority to prescribe controlled substances. The remaining states require some form of oversight by a physician.¹⁹ Medicaid requires that states recognizing family nurse practitioners and pediatric nurse practitioners reimburse them directly for their services. Medicare allows direct reimbursement of nurse practitioners practicing in rural areas — a result of the scarcity of physicians in such areas.

Clinical nurse specialists are also demonstrating that cost-effective, high-quality care can substitute for some medical care of stable inpatients.^{20,21} The practice of a clinical nurse specialist overlaps with many of the areas of competence of a first-year medical resident. Much of what residents do as their training progresses pertains more to providing service to patients than it does to their own education. Medicare funds for graduate medical education now pay an average of \$70,000 a year per resident.²² When malpractice insurance and the other costs for a resident are included, a clinical nurse specialist, with salary and malpractice insurance costs less than half those of a resident,²³ can carry out most of the first-year resident's responsibilities under a physician's supervision and guidance. In such a configuration the clinical nurse specialist is more cost effective.

If the number of physicians in training decreases in the future, as nearly all estimates predict, then hospitals will need the clinical nurse specialist to provide services previously delivered by residents. Such substitution can also increase quality. Every July, novice residents go through several weeks of orientation and training to reach the level of competence that experienced clinical nurse specialists presumably have already achieved. In addition, one clinical nurse specialist can function for years in the role of a physician-associate, whereas residents rapidly join the ranks of specialists and enter practices competitive with those of their mentors.

Still, physicians are reluctant to support the increased use of advanced-practice nurses, and many worry about what will happen to displaced or excess physicians, particularly specialists. Should not the nation, which has subsidized their training and paid them high wages, now support retraining for primary care? Lundberg and Lamm have noted that retraining "would require a massive program of continuing medical education and retraining for a displaced work force of physicians, most of whom would probably be very unhappy students."¹³ Although most specialists may not like a practice dedicated to primary care, many already provide such care for some of their patients. Physicians enjoy long-term relationships with patients, and specialty practices cannot always be sustained by specialty practice alone. Primary care at specialist prices solves the problem, at least for the physician. For the patient who receives primary care through the prism of a specialty, however, care may be skewed. Physicians more often do what they do best,^{17,24} making it more likely, for instance, that a cardiologist will hospitalize a patient and order more tests than a general internist will for similar condi-

tions; such differences in practice patterns are not related to different needs of patients.²⁵ Specialists also provide more expensive care than that given by primary care physicians to similar patients with similar problems.^{26,27}

For these reasons, primary care physicians are more cost effective in providing primary care than specialist physicians. Teams of primary care physicians and nurse practitioners are even more cost effective and comprehensive. Most studies show that nurse practitioners can manage 80 percent (among adult patients) to 90 percent (among children) of care provided by primary care physicians. Research studies show that the overlap of 80 to 90 percent represents the number of office visits that nurse practitioners can handle completely on their own, without the need for consultation or referral.²⁸

Giving nursing care only under the supervision of a physician would raise a serious barrier for patients who require care from both types of professionals. Particularly under managed-care plans, which will grow considerably with health care reform, the incentives are to do less because of prospective payment and concern about overspending. Without shared authority in team care, the first loss to patients will be in the services most associated with nursing: prevention, adaptation, education, counseling, access to community resources, and health promotion. Yet these services increase the effectiveness of recovery and reduce the number of repeat episodes of illness.⁹ Therefore, the long-term cost benefits of nursing-specific interventions in a managed-care environment are substantial. It has also been argued that employing nurse practitioners fully could save 20 percent of the cost of primary care^{3,28} and that the country may be spending up to \$8.75 billion that could be saved by employing both nurse practitioners and clinical nurse specialists fully.²⁹

The best model — one that reduces costs while enhancing quality and comprehensiveness — is collaborative practice. In this structure, nurse practitioners bear the principal responsibility for the diagnosis and management of uncomplicated illness and provide the education, counseling, and management of disease prevention and health promotion, using primary care physicians as consultants and referral sources. Nurse practitioners have a good record of knowing when to call for help and when to refer a patient to a physician.^{4,9} The physician will always be the primary professional providing diagnosis and treatment in complex cases and managing critical and unstable medical conditions. The areas of equal competence, however, should become the purview of nurse practitioners, as the more cost-effective providers, with the critical contributions of physicians reserved for patients needing a higher level of care.

Advanced-practice nursing may be good for the health care economy and good for patients, but is it good for physicians? America has too many specialist physicians, most of whom do not want to redirect their careers to primary care,¹⁶ and the nation should not

spend scarce dollars on the unnecessary cost of a large work force of primary care physicians. Clearly, organized medicine must practice birth control. Accepting this necessity will allow physicians to recognize advanced-practice nursing as their best ally if medicine is to be sustained at its most attractive levels for future generations of doctors.

When primary care physicians embrace this concept and form collaborative practices with nurse practitioners, there are several positive consequences. The patients in those practices receive more comprehensive and satisfying care than they would be given in practices composed of physicians only or nurses only. If patients are more satisfied, they are less likely to be litigious; indeed, if their care includes nursing services (counseling, teaching, and an explanation of therapy and the need for compliance), true negligence and harm are likely to occur less often. Physicians who have been sued more often change their practices and spend more time talking with patients, not ordering more tests.³⁰ One other advantage is not to be taken lightly in this competitive climate: the practice that offers the most comprehensive services will be the most competitive.

If physicians acknowledge the substantial overlap in primary care between physicians and nurse practitioners, a powerful argument can be made for continuing to train the majority of medical graduates in the specialties. By combining the number of primary care nurse graduates with the number of primary care physician graduates, the nation's goal for access to primary care can be met more quickly and at lower cost. It will take nearly 30 years to reach a 1:1 ratio between primary care providers and specialists if only physicians are counted, even if physicians are from now on willing to enter primary care in these proportions.²⁷ If instead the primary care number included physicians and nurse practitioners, this ratio could be reached by the end of the decade. In addition, a larger proportion of all medical residencies could be devoted to specialties, thereby protecting the research and special care resources of our nation's premier medical centers.

Another advantage of a physician-nurse practice is that it costs the patient less than a physician-only practice — not because nurses cost less for the same service, but because for similar patients nurses select interventions that are less costly than, but as effective as, the interventions selected by physicians.^{5,10} This cost saving takes into account the expense incurred for nurse practitioners who consult physicians or refer patients to them.²⁹ If physicians devote themselves to providing the services and judgments that represent their highest level of knowledge, their salaries and high esteem can be sustained. If, however, they are unwilling to advance the scope of their own practice to do more than provide basic services, they cannot expect their prestige, leadership, and rewards to grow.

Columbia University
School of Nursing
New York, NY 10032

MARY O. MUNDINGER, DR.P.H.

SPECIAL ARTICLE

SCREENING FOR COLORECTAL CANCER BY NURSE ENDOSCOPISTS

WILLIAM FORREST MAULE, M.D.

Abstract Background. Case-control studies have demonstrated that screening by sigmoidoscopy is effective in reducing mortality from colorectal cancer. If nurses performed screening examinations, more patients could be screened and, at current income levels, at a lower cost.

Methods. Two registered nurses and two licensed practical nurses learned to perform examinations with the flexible fiberoptic sigmoidoscope in order to screen patients for colorectal tumors. They performed 1881 independent examinations of outpatients more than 45 years of age. During the same period, 730 examinations were performed by two gastroenterologists in similar patients.

Results. The mean depth of insertion of the sigmoidoscope was slightly but significantly greater in the patients examined by the physicians than in those examined by the nurses (48 vs. 46 cm in men, $P = 0.003$; 41 vs. 38 cm in

women, $P = 0.002$). Adenomas were found in 14 percent of the men and 8 percent of the women examined ($P = 0.001$). Nine cancers were found in men and four in women. There were no significant differences between the nurses and the physicians in the proportion of examinations that were positive for adenomas or cancer. No complications occurred during the initial examinations or during 894 follow-up sigmoidoscopic procedures. Among the patients whose initial examination results were normal, more of those examined by nurses returned for follow-up sigmoidoscopy after 12 months or more (45 percent, vs. 30 percent of those examined by physicians; $P = 0.001$).

Conclusions. Nurses can carry out screening by flexible sigmoidoscopy as accurately and safely as experienced gastroenterologists. (N Engl J Med 1994;330:183-7.)

METHODS

Training Program for Nurses

Two registered nurses and two licensed practical nurses volunteered to learn to perform flexible sigmoidoscopy. First, each nurse read a standard textbook on the rationale for screening and the technique of sigmoidoscopy⁹ and reviewed a collection of 35-mm slides showing endoscopic anatomy. The nurse gained proficiency with the controls of a 60-cm fiberoptic flexible sigmoidoscope (Olympus CF-P10S, Olympus, Lake Success, N.Y.) during supervised practice with a plastic model of the rectum and sigmoid colon (Olympus). She then used a fiberoptic teaching attachment or a video monitor to observe the technique of a gastroenterologist who served as preceptor. Next, the nurse withdrew the instrument after it had been inserted by the preceptor. Finally, the nurse performed a complete examination. During withdrawals and complete examinations, the preceptor supervised each procedure, using the teaching attachment or video system. The completion of each stage of the training depended on the preceptor's judgment of the nurse's performance. Approximately 35 observation trials, 30 withdrawal trials, and 35 supervised complete examinations during a period of three to five weeks were required before independent examinations were attempted. All the nurses successfully completed training, and the results of all their independent examinations are included here.

Sigmoidoscopy was scheduled to be performed by a nurse only when the preceptor or another gastroenterologist was immediately available in an adjacent examination room. All suspicious lesions were observed by one of the gastroenterologists. Specimens from all raised lesions greater than 0.2 cm in diameter were obtained with standard biopsy forceps. The biopsy technique was taught when the nurses discovered lesions during independent examinations. The withdrawal portion of each independent examination performed by a nurse was recorded on videotape. For the first two years of the program, these videotapes were reviewed on a timely basis by the gastroenterologists.

Fiberoptic Flexible Sigmoidoscopy

Sodium phosphate enemas (C.B. Fleet, Lynchburg, Va.) were recommended two hours and one hour before the procedure. Written informed consent was obtained from each patient immediately before the examination. No anesthesia was used. The depth of insertion from the anal verge was estimated to the nearest 5 cm by

COLORECTAL carcinoma is the second leading cause of death from cancer in the United States,¹ and almost 50 percent of patients with colorectal cancer die of the disease. Since the prognosis is related to the depth of invasion of the cancer, and since surgery cures 90 percent of cancers limited to the mucosa and submucosa, early diagnosis could improve survival.² Furthermore, since colorectal cancer usually arises in adenomas,³ removing adenomas should prevent most cases of cancer.

The American Cancer Society,⁴ the National Cancer Institute,⁵ and the American College of Physicians⁶ recommend that asymptomatic adults older than 50 years of age undergo screening by sigmoidoscopy to detect adenomas and early cancer. Conversely, the U.S. Preventive Services Task Force⁷ and the Canadian Task Force on the Periodic Health Examination⁸ do not support such screening because there have been no data from controlled studies that demonstrate a survival advantage in the screened group.

Impediments to widespread screening include inadequate numbers of trained practitioners and the expense of the examination. A considerable increase in the availability of screening and a reduction in cost could be achieved if nurses performed screening sigmoidoscopy instead of physicians, and if the difference in cost between nurses and physicians were maintained. My colleagues and I undertook this study to determine whether screening by flexible sigmoidoscopy could be performed safely and accurately by nurses.

From the Section of Gastroenterology, Department of Medicine, Ochsner Clinic of Baton Rouge, 16777 Medical Center Dr., Baton Rouge, LA 70816, where reprint requests should be addressed to Dr. Maule.

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comparison with a scale marked on the shaft of the instrument. Insertion to 60 cm was always attempted, but the procedure was stopped if stool compromised the examination or if the patient reported discomfort. The results of each procedure were entered into a computerized data base (The Endoscopy Database, MUMPS Medical Information Management Systems, Oak Park, Ill.) by the primary endoscopist immediately after the examination, and a computer-generated report was placed in the permanent medical record of each patient.

Patients

Screening by flexible sigmoidoscopy was encouraged for outpatients older than 45 years of age and was routinely performed by gastroenterologists at the Ochsner Clinic of Baton Rouge before the Nurse Clinic was established. Patients who had never undergone sigmoidoscopy at the clinic were eligible for referral to the Nurse Clinic. No attempt was made to determine whether the patients had previously undergone sigmoidoscopy elsewhere. We requested that each patient have six stool samples tested for occult blood before sigmoidoscopy, but many patients were referred without documentation of testing. We also suggested that patients with a history of colorectal cancer or adenomas and patients with symptoms related to the colon be referred to the Gastroenterology Clinic, but many patients with symptoms or bleeding were examined in the Nurse Clinic. Patients in whom cancer or adenomas were detected during sigmoidoscopy were offered outpatient colonoscopy. No attempt was made to remove tumors during sigmoidoscopy.

Assessment of Patients' Perceptions

Immediately after the first procedure, some patients were asked to complete forced-choice visual-analogue scales¹⁰ to measure their perceptions of the severity of cramps, burning, pressure, bloating, and embarrassment during sigmoidoscopy and their perceptions of the explanation of the procedure and the results before and after sigmoidoscopy. The patients were also asked to estimate when they would be willing to undergo reexamination. Six possible responses were allowed for each item in the scale. The first 128 patients examined in the Nurse Clinic and 64 consecutive patients examined in the Gastroenterology Clinic during the same six-week period served as the first sample. A second sample of 118 consecutive patients from the Nurse Clinic and 28 consecutive patients from the Gastroenterology Clinic was tested three months later.

Statistical Analysis

The relations between categorical variables were assessed with the Mann-Whitney U test, the chi-square test, or Kruskal-Wallis analysis of variance of the ranks. The relations between continuous variables were assessed with Student's t-test. Analyses were performed on GBSTAT statistical-analysis software (Dynamic Microsystems, Silver Spring, Md.). All reported P values are two-tailed.

RESULTS

A total of 1475 women (mean [$\pm$ SD] age, 60 ± 10 years) and 1136 men (61 ± 10 years) underwent their first sigmoidoscopy at the clinic as a part of this study. The ages of the 1881 patients examined by the nurses were similar to those of the 730 patients examined by the physicians. Fifty-six percent of the patients examined by the nurses and 57 percent of those examined by the physicians were women. The only complication was in a 51-year-old man who had abdominal pain 24 hours after being examined by a nurse endoscopist. He was admitted to the hospital, where his symptoms resolved without fever or leukocytosis. The results of serial abdominal radiographic examinations were normal.

The mean depth of insertion recorded by the two

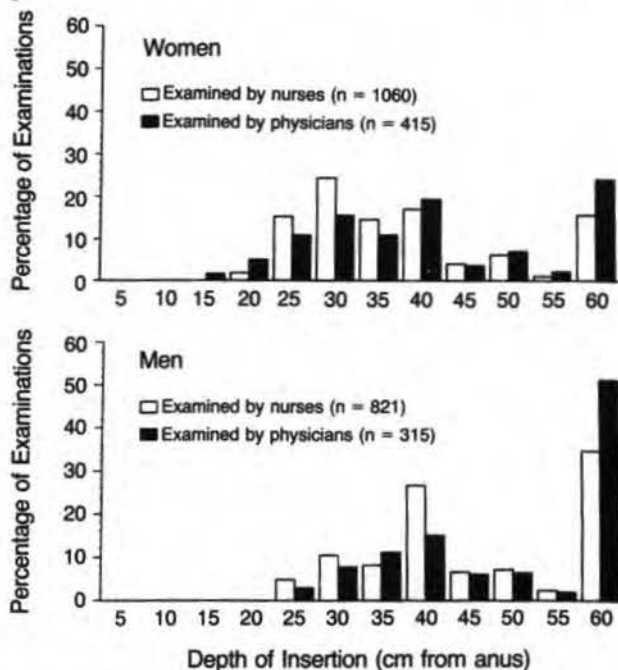


Figure 1. Depth of Insertion during the First Flexible Sigmoidoscopy in 2611 Women and Men Examined by the Nurses or by the Physicians.

physicians was greater than the mean depth recorded by the four nurses in examinations of both women (41 vs. 38 cm, $P = 0.002$) and men (48 vs. 46 cm, $P = 0.003$). The endoscope was inserted to 60 cm twice as frequently in men as in women (Fig. 1). In men, the first peak of the distribution was at 40 cm, the depth just proximal to the junction of the sigmoid colon and the descending colon. Successful passage of this area usually insured insertion to 60 cm, but when the angle between the sigmoid colon and the descending colon was acute, further insertion caused discomfort and the examination was frequently stopped. In women, the peak at 40 cm was blunted by difficulty passing the junction of the rectum and the sigmoid colon at 20 cm. The differences in depth of insertion between men and women were present in patients of all ages. More examinations in women than men were stopped because of discomfort (Table 1), but there were no significant differences in the proportion stopped because of the presence of stool.

Every lesion seen underwent biopsy, but only one tumor per examination was recorded for the purpose of calculating prevalence. Adenomas were found more frequently in men (14 percent) than in women (8 percent, $P = 0.001$), but no significant differences between the nurse endoscopists and the physician endoscopists were noted. Altogether, 214 tubular adenomas (83 percent of all adenomas), 29 villous adenomas (11 percent), and 16 adenomas containing carcinoma in situ (6 percent) underwent biopsy. Fifty-eight of the tubular adenomas (27 percent) were 1 cm or more in the largest diameter. Six patients with very small

Table 1. Results of the First Flexible Sigmoidoscopy in 2611 Patients.

RESULTS	WOMEN (N = 1475)	MEN (N = 1136)	P VALUE*
	no. (%)		
Complete to 60 cm	251 (17)	442 (39)	<0.001
Terminated because of stool	344 (23)	279 (25)	0.46
Terminated because of discomfort	807 (55)	366 (32)	<0.001
Terminated because of stool and discomfort	54 (4)	22 (2)	0.009
Reason for termination not recorded	19 (1)	27 (2)	0.14

*By the chi-square test.

adenomas (≤ 0.4 cm) declined colonoscopy. Nine carcinomas were found in men and four in women ($P = 0.20$). One cancer was found during colonoscopy after a 0.6-cm tubular adenoma had been sampled during sigmoidoscopy.

Among the study patients, 1249 women (85 percent) and 901 men (79 percent) with normal examinations underwent their first sigmoidoscopy at least 12 months before the end of the study; 519 of these women (42 percent) and 375 of these men (42 percent) returned for a follow-up examination after 13 to 53 months. More patients initially examined by nurses (45 percent) than patients examined by physicians (30 percent, $P = 0.001$) returned for follow-up. The mean depth of insertion during follow-up sigmoidoscopy was 41 cm for women and 49 cm for men. There were no significant differences in depth of insertion between physicians and nurses.

Videotape review revealed that a single, small tubular adenoma (< 1 cm) was missed during the first examination. However, 16 women (3 percent) and 29 men (8 percent) had tumors at follow-up sigmoidoscopy that were not detected during the first sigmoidoscopic examination (Table 2). Forty-three were tubular adenomas (all but three of which were less than 1 cm in diameter), one 0.8-cm adenoma had villous architecture, and one 0.8-cm lesion contained carcinoma. The carcinoma, a Dukes' stage A lesion (T1N0M0), was located just inside the anal verge and was found 16 months after normal results on an examination performed by a nurse.

Assessment of Patients' Perceptions

The discomfort scores were low, and most patients rated the explanations given before and after the examination as excellent. The majority of patients reported that they would be willing to undergo a repeat sigmoidoscopic examination within 6 to 12 months, if indicated. In the first sample, patients examined by a physician had more cramping than those examined by a nurse ($P = 0.001$) and had a greater mean depth of insertion (45 cm vs. 39 cm, $P = 0.001$). However, there was no correlation between cramping and depth of insertion. Patients whose exami-

nations were stopped because of discomfort had higher cramping scores than those in whom insertion to 60 cm was achieved ($P = 0.003$). There were no other significant differences between physicians and nurses in any item on the rating scale. Among the patients in the second sample, the depth of insertion in the two groups was equivalent, and there were no differences between nurses and physicians in any item on the scale.

DISCUSSION

No randomized clinical trial has demonstrated that screening by sigmoidoscopy improves survival in patients with colorectal cancer, but two recent reports reinforce the case for screening. In a study of 261 patients who died of cancer located within 20 cm of the anus and 868 control patients, the odds ratio of having undergone screening by sigmoidoscopy was 0.3 in the patients who died of cancer, as compared with the control patients (95 percent confidence interval, 0.2 to 0.5).¹¹ In a smaller study,¹² the odds ratio of having undergone screening by sigmoidoscopy was 0.2 among 66 patients who died of distal colorectal cancer, as compared with 196 control patients. If the U.S. Preventive Services Task Force⁷ were to reevaluate the quality of the data supporting screening by sigmoidoscopy today, we believe that periodic screening of patients at average risk for colorectal cancer would probably be recommended.

Two reports have evaluated the ability of nurses to perform screening by flexible sigmoidoscopy. In one report, a registered nurse practitioner who was trained to use a 60-cm instrument performed 825 examinations with no complications.¹³ The mean depth of insertion was 50 cm. In another study, Schroy et al.¹⁴ trained a nurse practitioner to use a prototype 40-cm video sigmoidoscope; he then examined

Table 2. Tumors Detected at Follow-up Flexible Sigmoidoscopy after 13 to 53 Months in 894 Patients Who Had No Tumor at the First Examination.*

CHARACTERISTICS OF TUMOR	MEN	WOMEN	DIAMETER		TIME BETWEEN
	(N = 375)	(N = 519)	OF TUMOR		
			RANGE	MEDIAN	
	<i>no.</i>			<i>cm</i>	<i>mo</i>
Tumor located proximal to the maximal depth of the first examination	4	4	0.3-1.0	0.6	13-30
Tumor detected at the first examination but no biopsy (<0.2 cm)	1	3	0.3-0.3	0.3	13-18
Tumor detected at the first examination but interpreted on biopsy as non-neoplastic tissue	6	2	0.3-1.5	0.4	13-22
Tumor within the distance recorded at the first examination but not detected	18	7	0.3-0.8	0.5	13-53

*All tumors were tubular adenomas except one villous adenoma (in a man) and one colorectal cancer (in a woman) that were not detected at the first examination.

100 patients with no complications. The mean depth of insertion was 38 cm.

In our study nurse endoscopists safely inserted flexible sigmoidoscopes to depths similar to those reported by colorectal surgeons,^{15,16} gastroenterologists,¹⁷ and primary care physicians in practice¹⁸ and in training.^{19,20} We found significant differences in the mean depth of insertion between men and women patients that were greater than the differences between physician and nurse endoscopists. Meaningful differences in the depth of insertion between men and women during screening by flexible sigmoidoscopy have not been reported previously, but in one report the depth of insertion during symptom-limited rigid sigmoidoscopy was greater in men than in women.²¹ The differences in the prevalence of adenomas between men and women were not explained by differences in depth of insertion, because 90 percent of the lesions were located within 40 cm of the anus. Others have also reported that distal adenomas and cancer occur more frequently among men.^{22,23}

The sensitivity of screening by sigmoidoscopy has not been rigorously evaluated. When successive colonoscopic procedures were performed,²⁴ 12 percent of adenomas less than 1.0 cm in diameter and situated in the sigmoid or descending colon were missed by the first examiner. When patients with adenomas underwent colonoscopy within three months after diagnostic sigmoidoscopy, 5 percent of adenomas greater than 0.5 cm in diameter that were found in the rectum and sigmoid colon had been missed during sigmoidoscopy.²⁵ Among 894 of our patients who returned 13 to 53 months after a normal sigmoidoscopy, fewer than 5 percent had tumors in the distal colon. My colleagues and I do not know how many of the lesions we found at the second examination were present during the first. However, only four large tubular adenomas, one villous adenoma, and one invasive cancer were noted during the second examination; the remainder were small tubular adenomas (≤ 1 cm). The risk of cancer in small tubular adenomas is low,²⁶ and the risk of proximal cancer in patients with small tubular adenomas is no higher than that in the general population.^{23,27}

The patients in our study accepted sigmoidoscopy performed by nurses without complaint. However, the nurse endoscopists had considerably more supervised practice than is usually recommended for nonendoscopist physicians who are learning sigmoidoscopy.²⁸⁻³⁰ We were surprised by the number of examinations terminated early because of the patient's discomfort, given the low pain scores recorded by patients immediately after the procedure. Apparently, in our relatively asymptomatic patients, even low levels of discomfort were not acceptable. It is not clear why sigmoidoscopy was terminated early because of pain in more women patients, but anatomical differences, trauma occasioned by past pregnancy, or adhesions from pelvic surgery²¹ probably contributed to procedure-related discomfort among the women.

Except for the cost of training, few new expenses accrue to a program in which nurses perform screening by sigmoidoscopy. Most of its expenses, including those for salary and fringe benefits, are considerably lower than those incurred when physicians perform screening examinations. Since there is no evidence that physicians are more effective as endoscopists than nurses, and since screening by nurses could result in substantial savings, consideration should be given to the widespread training of nurses in sigmoidoscopy for screening purposes.

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Pindos Mountains, Greece

EVERT LAMFERS, M.D.

THE WHITE HOUSE
WASHINGTON

Testimony of

Kristine Gebbie, R.N., M.N.

National AIDS Policy Coordinator

Executive Office of the President

Before the

House Committee on Energy and Commerce

Subcommittee on Health and the Environment

January 24, 1994

Mr. Chairman and members of the Committee, thank you very much for this opportunity to share with you what the President's plan will do to help vulnerable populations -- those with HIV/AIDS, people with disabilities, Native Americans, migrant workers and others.

Their special circumstances, illnesses, and disabilities amplify their needs and illustrate poignantly the failures of the current system to provide the security of coverage when help is needed the most.

I'd like to share with you the stories of some real people, to illustrate how devastating a chronic illness -- in this case HIV/AIDS -- can be. As you'll see, because these people could be any one of us here in this room today, there are no guarantees in the system for any of us.

Christina, a 25 year old woman, was covered under her father's insurance policy while she was a college student. During this time, she tested positive for HIV, the virus that causes AIDS. When her father disclosed this to his self-insured company, they pursued several strategies to get Christina off company policy. Finally, the company solved its problem by firing Christina's father.

Charles has coverage but he doesn't feel very good about what he has to do to keep it. Charles is a 37 year old male who was diagnosed with AIDS in 1985. At the time he was working and had no insurance because he couldn't afford the high premiums. He knew he would need some help with his medical expenses, so he turned to Social Security for help. Charles quit his job in order to apply for disability and Medicaid. Charles would like to work, but in order to have his \$4,000 a month medical bills covered, he had to stay unemployed and disabled. Charles feels that he is "caught in a trap" and fears the day when "the day the house of cards will collapse."

Fortunately, the President's plan provides universal coverage for every American, and that includes all the Charles's and Christina's out there, regardless of their needs or risks.

Congress -- particularly members of this Committee -- has demonstrated great concern about the ability of underserved populations to obtain access to health care services. The President recognizes, as you do, that a Health Security Card alone cannot guarantee that all Americans will receive necessary health care services. To achieve this goal, the Health Security Act includes additional measure that will provide special protections and secure access and quality for our vulnerable populations. Let me share them with you.

Security of Comprehensive Coverage

All Americans will have the security of comprehensive health coverage -- with no exceptions. People with disabilities or chronic illnesses will no longer be subject to the precipitous loss of coverage they face today. No one can lose their coverage. Under the Health Security Act, hospital services are covered; doctor visits are covered; prescription drugs are covered. In addition, certain extended care, hospice services, and outpatient rehabilitation services are covered. These services, and others offered under the benefit package become a crucial link for the very survival of people with certain disabilities or illnesses.

Mental illness and substance abuse treatment services are guaranteed elements of the comprehensive benefits package. By 2001, this coverage is without day or visit limitations -- on the same terms as other services.

those being funded by Ryan White, Community and Migrant Health Centers, programs for the Homeless, family planning, and maternal and child health, are guaranteed payments for covered services from all health plans. This program assures that vulnerable populations have continued access to practitioners with experience in meeting their needs, regardless of which health plan they choose to enroll in.

Protections Against Discrimination

The Health Security Act assures that no individual is discriminated against in obtaining comprehensive coverage. Health plans will no longer have lifetime limits on coverage. Health plans will offer an open enrollment, accepting everyone applying for coverage at that time without charging a higher premium to those with a pre-existing condition. States and alliances further assure that no one faces barriers to care based on race, ethnicity, sexual orientation, age or gender.

To protect health plans that attract disproportionate number of vulnerable individuals, the Health Security Act assures proper payment through an alliance-based risk-adjustment and reinsurance systems.

To ensure confidentiality of patients, national privacy protection standards are established. These standards forbid the linkage of individual-specific information with aggregate data on patterns of care. Privacy protection as applied to health care information will be a continuing focus of the National Health Board.

From the onset, mental illness and substance abuse treatment benefits covered by the Health Security Plan (within certain guidelines and criteria) include: screening and assessment; inpatient and residential treatment; crisis services; intensive non-residential treatment; outpatient treatment; collateral services; and case management. Benefits are provided in variety of settings, including offices and clinics, residential treatment and intensive non-residential programs.

Continuity of Care

The Health Security Act assures that all Americans will have a choice in selecting their providers and health plans. Each individual will be able to enroll in a traditional fee-for-service plan, join a network of doctors and hospitals, or join an HMO. In addition, all health plans must offer a point-of-service option -- individuals will not be restricted to the plan providers.

To further guarantee continuity of care, all individuals will have access to medical specialists for unique services they need. All health plans must sufficient arrangements with providers to assure the provision of all items and services covered by the comprehensive benefit package. In addition, plans must contract with academic health centers for services that are rare and performed in enough frequency at these sites to ensure quality. Further, states may require plans to contract with centers of excellence they identify to further guarantee appropriate access to care.

The essential community provider provision guarantee services of federally-funded clinics and other providers delivering care in difficult-to-serve areas. Qualifying providers, e.g.

Special Services

The Health Security Act leaves in place certain programs to address additional needs of these vulnerable populations.

Ryan White and other safety net providers. Current safety-net programs like Ryan White will continue to receive funding for services beyond the guaranteed package. Transportation, outreach, case management, translation, and personal support services remain critical for vulnerable populations and will be sustained under the Health Security Act.

Medicaid. All Medicaid eligible children will be eligible for a new federal program of wrap-around services that supplements the comprehensive benefits package. States will continue to receive matching payments for wrap around services for adults who receive SSI or AFDC benefits and dual eligible. Long term care Medicaid services (e.g., nursing home, ICF/MR, home health, personal care, etc.) continue to be available for all Medicaid eligible as under current law. In addition, all states will be required to take Medicaid expenditures into account in determining financial eligibility for Medicaid coverage of nursing home care. Also, Medicaid patients in institutions will be able to keep \$50 per month for their personal needs, up from a minimum of \$30 per month.

Transitional Insurance Reform

As you know, the reform will take a few years to fully implement. During the interim it is critical that we protect existing insurance coverage for employers and families. We must

assure that insurers do not drop the most vulnerable in anticipation of a system in which they are forced to compete based on price and quality, rather than their ability to attract the healthy and avoid the sick.

The Health Security Act, therefore, includes a series of transitional insurance reforms that guard against the most egregious abuses by health insurers prior to the creation of a fully reformed market and the formation of health alliances. These reforms include:

- Health insurers are prohibited from terminating or failing to renew coverage for a group or individual, except in cases of non-payment of premiums, fraud, or misrepresentation in an application for coverage or claim for benefits.
- Insurers are required to provide coverage for new employees of an employer that purchases insurance, regardless of health status.
- Premium increases cannot be varied according to the health status of the group or individual.
- Exclusions for pre-existing conditions are limited, and individuals who are continuously insured are not required to meet a new waiting period for pre-existing conditions when switching coverage.
- Self-insured health plans may not arbitrarily reduce benefits for high cost illnesses.
- The National Transitional Health Insurance Risk Pool is established to provide coverage to individuals who are unable to obtain private coverage because of their health status.
- Insurers are required to obtain prior approval for excessive premium increases.

These transitional insurance reform by no means represent comprehensive reform, as ultimately envisioned by the Health Security Act. They will, however, protect against the most extreme abuses we see in the insurance market today, and they will ensure an orderly transition

to a system that guarantees health security for all Americans and effective control of health costs.

Other Special Programs

School-Age Youth. The Health Security Act will address the problems of one of our Nation's most vulnerable groups: adolescents and young adults. The current health care system has failed to provide our youth with the information and services they need to avoid risky behaviors and make healthy decisions. Adolescents are also often reluctant to seek help, ignorant about what help is needed or where to get it, and concerned about confidentiality. These barriers contribute to the substantial problems with substance abuse, unwanted pregnancy, and HIV/AIDS among this age group.

The Health Security Act will reach out to school-age youth and adolescents in two ways. The Comprehensive School Health Education initiative will establish a national framework within which States can create school health education programs that improve the health and well being of students, grades K through 12, by addressing locally relevant priorities and reducing behavior patterns associated with preventable morbidity and mortality. This program will be targeted to areas with high needs, including poverty, births to adolescents, and sexually-transmitted diseases among school-aged youth.

The School-Related Services program will support the provision of health services -- including psychosocial services and counseling in disease prevention, health promotion, and

Conclusion

Mr. Chairman, Members of the Committee: 37 million Americans, including many people who have special needs, go without health coverage. Far too many people most in need of services, such as those with HIV infection, are uninsured, or lose their insurance just when they need it most. We can either address the problem head on -- organize health care delivery and financing, so that system works for all Americans -- or deny the problem and let the system grow more and more unfair, expensive, and out of control. We must join forces and solve this problem. We must work together to create a rational system where those who need health care the most have security of care.

important source of primary health care for many migrant workers throughout the nation. These Migrant Health Centers are also protected as Essential Community Providers for at least the first five years of health care reform. The PHS Initiatives also contain a new grant program to assist providers in offering support services that will make their services more accessible, including transportation, outreach, and translation services. These services will be very important in helping providers offer more culturally appropriate services for migrant workers.

Indian health. American Indians/Alaska Natives receive special treatment under the Health Security Act in recognition of the historic obligations of the government-to-government relations that exist between the Federal government and Indian tribes.

Under the Act, Indians will receive an improved benefit package and new choices of providers. Indians may choose to enroll either with an Indian health program or with a health plan offered by an alliance. The health programs of the Indian Health Service will be maintained and expanded so that they will be able to offer the full range of the comprehensive benefit package services by 1999. All Indians, whether they enroll with an Indian health plan or an alliance health plan will remain eligible for supplemental services, such as environmental health, outreach, transportation, etc. The PHS Initiatives will reaffirm the emphasis on these important services.

individualized risk behavior -- in school-based or school-linked sites. Grants will be made to states for the development and implementation of state-wide projects targeted at high-risk youth ages 10-19. In states that do not take this initiative, grants will be available to local community partnerships including public schools, experienced providers, and community organization

Severely Disabled Persons. The plan also includes a major expansion of home and community based services for individuals with severe disabilities. This new long term care program will offer significantly increased federal funding to help states to offer a wide array of personal assistance and related supports to people at home, in the community. Eligibility for this program is not limited by age, type of disability, or income. When this program is fully phased in, approximately \$38.5 billion new federal dollars will be available to help people who have significant needs for assistance with activities of daily living to live more independent lives.

Migrant Workers. Migrant Workers are guaranteed a new level of health security under the Act. With their health security card, legal residents employed as migrant workers will be able to easily transfer their coverage from one geographic area to another. In fact, the portability will be assured by regional alliances whose job it is to keep track of employer payments and enrollment for all workers.

The Public Health Service Initiatives in the Act also provide a supportive framework for the benefit package coverage that is assured. The Community and Migrant Health Center Program is maintained, and as you know, Mr. Chairman, Migrant Health Centers are an

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Timely and unique, this all-new conference combines the value of systems thinking and organizational learning with hands-on use of our computer simulation model, *The Mastering the Transition to Capitation* microworld. A powerful learning tool developed exclusively for The Healthcare Forum, the Microworld is based on the model of a hospital as it moves from fee-for-service to a capitated system. In expertly facilitated sessions, your team will utilize the Microworld to safely test business assumptions, learning from the outcomes of each step in the process.

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Please take a moment to review the enclosed brochure and register soon. If you have questions, need additional copies or would like further information, please call The Healthcare Forum at (415) 421- 2411.

Sincerely,

John G. King
President/CEO
Legacy Health System

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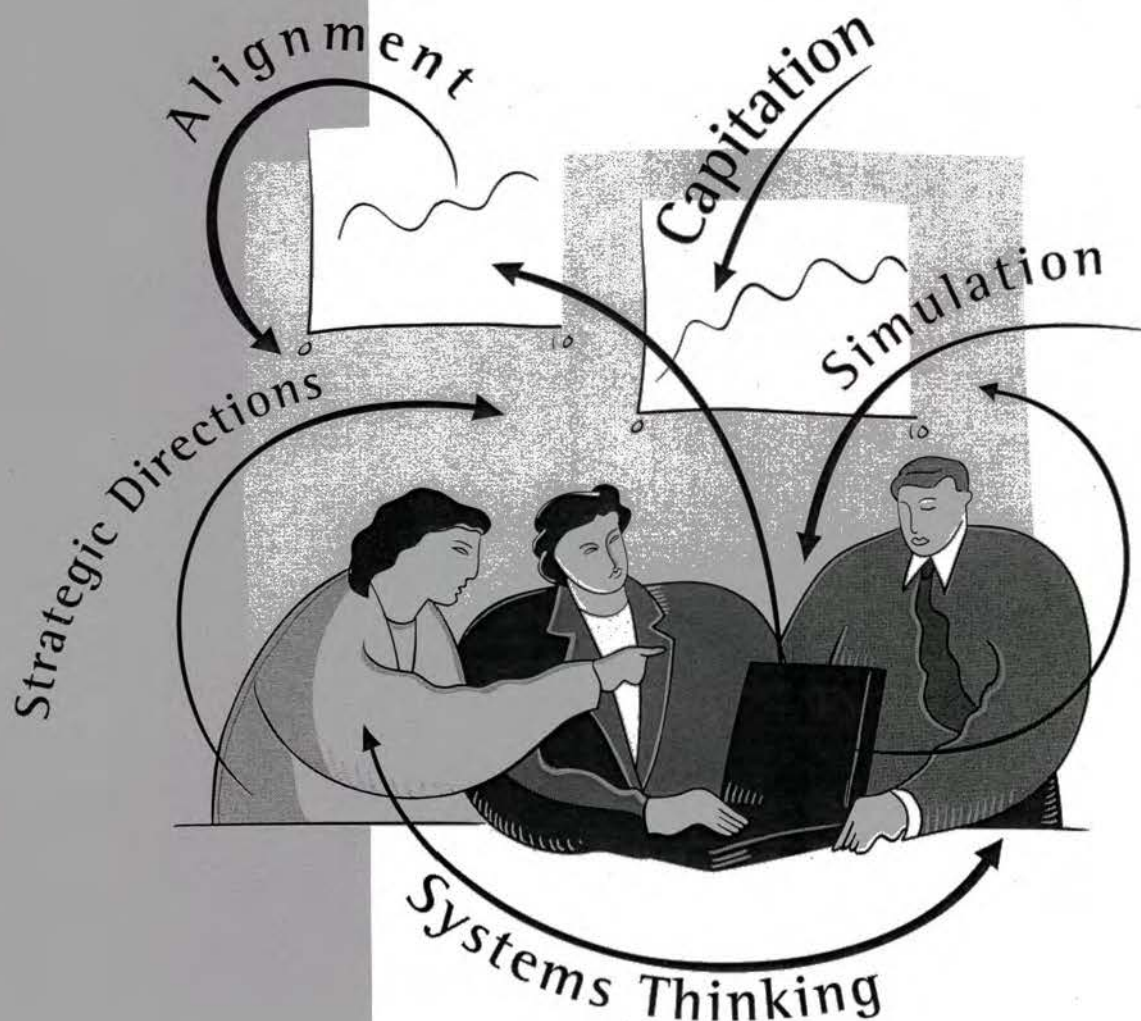
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