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the

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The President's Health Security Act and the HIV Epidemic



For people with HIV or other serious medical conditions, the security of comprehensive health coverage is essential. Today, an estimated 30 percent of people living with HIV are uninsured. Another 40 percent depend on the Medicaid program for coverage. Many of the 30 percent with private health coverage live in day-to-day fear that their insurance will disappear and their coverage is often inadequate to meet the very real needs of their health status.

For all Americans, but especially for those with a life-threatening condition like HIV/AIDS, the President's Health Security Act will provide the peace of mind and financial protection of private coverage that can never be taken away.

The Health Security Act guarantees every American private coverage for a comprehensive package of benefits. For those with HIV, that will mean coverage of the cost of doctor visits, hospitalization, laboratory tests, and prescription drugs. Coverage of mental health services and substance abuse prevention treatment also are included as is hospice care.

The private insurance market will be reformed in a comprehensive manner to eliminate the inequities of the current system. Health plans will no longer be able to deny or curtail coverage to people with pre-existing medical conditions, including HIV. Plans could not "red-line" communities by refusing to sell or market their coverage in areas perceived to be at high risk for expensive care. Plans will be prohibited from placing annual, lifetime, or disease-specific limits on coverage, and there will be an annual limit on patients' out-of-pocket costs to prevent a medical catastrophe like HIV from becoming a financial catastrophe for individuals or families.

For those who move in and out of the work force, the Health Security Act provides portability of benefits that could be taken from job to job, from employment to unemployment or to self-employment. Individuals, not their employers or the government, will have the power to choose a plan that best suits their needs and to keep that plan if it meets those needs. Consumer input will allow plans to identify problems with the delivery of services.

A new federal/state program will provide assistance to the severely handicapped to obtain home and community-based long term care.

Finally, the Health Security Act protects the vital network of HIV/AIDS service organizations that have so ably served people with HIV. All private health plans will be required to have arrangements with such organizations as "essential community providers." This will prevent any disruption of patient-provider relationships, including Ryan White recipients and community health centers.

Kristine M. Gebbie



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**PHOTOCOPY
PRESERVATION**

HEALTH CARE REFORM: PRINCIPLES & IMPERATIVES

Every American has a tremendous investment in the plan that Congress and the President finally present to us. People in every community can tell stories about how the current health system has failed them and what they want to see reformed. However, given the broad spectrum of health care needs encompassed by this one illness, HIV disease seems to offer a useful lens through which any reform measure may be judged. From **prevention education** to protect people from illness in the first place, to **early drug treatments** and **health management** to keep those who are infected healthy for as long as possible, to **acute care** to battle life-threatening opportunistic infections, to cost-effective **home and long-term care** programs, to **hospice care** for those who are in the end stages of the disease, a health care plan that is responsive to the needs of people with HIV and AIDS will be responsive to the needs of all Americans.

Consider the following:

- ▶ 30 percent of people with AIDS in this country have no health insurance at all. Uninsured people generally do not seek health care until they are experiencing a crisis, foregoing the preventive services and early treatments that can reduce costly emergency care and mean longer, healthier lives.
- ▶ 40 percent of people with AIDS are on Medicaid. Medicaid coverage varies from state to state and often does not include such necessities as diagnostic tests, preventive care, prescription drugs and long-term care.
- ▶ The 30 percent of people with AIDS who do have private insurance, like millions of others who are living with chronic illnesses, have been subjected to dangerous and arbitrary restrictions on care: sudden cancellations of policies, pre-existing condition clauses, caps on coverage, and so on.

A plan that solves these kinds of problems, exemplified by the experiences of people with HIV/AIDS, a plan that provides comprehensive benefits and truly universal coverage, will improve health care for everyone.

(over)

The following five principles are bottom-line imperatives that many advocates agree must be addressed in order for any plan to adequately serve people with HIV/AIDS (see attached chart).

- 1.) **Universality**
Affordable coverage must be guaranteed equally for all Americans by a specific date. Plans that merely guarantee coverage to those who can afford to buy it or that phase in coverage over time represent neither universality nor reform.
- 2.) **Comprehensive benefits**
The benefit package must ensure a full range of medically necessary health services, including prescription drugs, preventive care, substance abuse and mental health services, and comprehensive long-term care. These benefits must be available to all consumers regardless of income or health status. We cannot accept a two-tier health care system that provides a lower quality of care for the poor and the sick. Proposals that would tax workers' health care benefits or limit the deductibility of health care expenditures by employers are unacceptable.
- 3.) **No financial barriers to care**
Employer-based financing must treat all employers equitably and finally level the playing field between those who provide benefits and those who get a free ride. Competition cannot control health care costs; without really, enforceable cost controls, such as premium limits and fee schedules, our crisis of rising costs will continue. Health care costs must be based fairly on geographic averages (community rating) and consumers should not be penalized because of their age or health status. Risk adjustment mechanisms should be established as an incentive to provide service to high-risk consumers.
- 4.) **Consumer protections**
Consumers, not employers, must be able to choose their own doctors and plans in order to ensure ongoing relationships with providers who have the most relevant experience and expertise in responding to particular health care needs.
- 5.) **Maintenance of public health programs**
Existing public health prevention programs, particularly the Ryan White CARE Act, must be maintained as prudent, cost-effective strategies to keep people healthy in the first place.
- 6.) **State single-payer option**
The above principles outline minimum requirements for a national health care reform bill. If individual states choose to go further and establish their own single-payer plans, they should be allowed to do so.

If you have questions or would like to discuss these principles further, please call Liz Smith at the Northwest AIDS Foundation, (206)860-6293.

Presented by:

*Liz Smith, Northwest AIDS Foundation
Sue Tupper, Northwest AIDS Foundation
Lesli Boyd Morse, Olympia AIDS Task Force
Richard Hicks, Olympia AIDS Task Force
Ed Noonan, M.D.*

PRINCIPLE	COVERAGE	WELLSTONE- MCDERMOTT	CLINTON	STARK	DINGLE ¹	CHAFEE- THOMAS	COOPER- BREAUX	MICHEL- LOTT
Universality	All legal U.S. residents covered by a specific date.	YES	YES	YES	YES	NO ²	NO	NO
	Pre-existing conditions restrictions eliminated to ensure access to health care regardless of health status.	YES	YES	YES	YES	NO	NO	NO
Comprehensive benefits	Minimum guaranteed benefits package legislated.	YES	YES	YES	YES	NO ³	NO ³	NO
	Prescription drug coverage, including off-label coverage and experimental treatments.	YES ⁴	YES	YES ⁵	YES	NO ³	NO ³	NO
	Comprehensive substance abuse and mental health services.	YES	NO ⁶	YES	NO	NO ³	NO	NO
	Comprehensive long-term care services.	YES	YES ⁷	NO	YES	NO	NO	NO
	Medicaid recipients get same benefits as all other consumers.	YES	YES	YES	YES	NO	NO ⁸	NO
No financial barriers to care	Premiums based on ability to pay.	YES ⁹	YES ¹⁰	YES	YES	YES ¹⁰	YES ¹⁰	NO
	Out-of-pocket payments limited.	YES	YES	NO	YES	NO	NO	NO
	Mandated employer contribution.	YES ⁹	YES	YES	YES ¹¹	NO	NO	NO
	Financed through combination of individual and employer payments and taxes.	YES	YES	YES	YES	NO	NO	NO
	Government subsidizes small businesses providing insurance.	YES	YES	YES	YES	NO	NO	NO
	Price regulation and other cost controls.	YES	YES	YES	YES	NO	NO	NO
	Community rating -- everyone pays the same premium for the same plan.	YES ⁹	YES	YES ¹²	YES	YES	NO	NO
	Regional alliances mandated.	NO ⁹	YES	NO	NO	NO	NO	NO
Consumer protections	Risk-adjustment incentives to make it easier for insurers to cover high-risk consumers.	NO ⁹	YES	NO	YES	NO	NO	NO
	Strict confidentiality and anti-discrimination protections.	YES	YES	YES	YES	NO	NO	NO
	Consumer choice of plans and providers.	YES	YES ¹³	YES	YES	YES ¹³	YES ¹³	YES ¹³
Safety net	Existing public health services and prevention programs (e.g., Ryan White CARE Act) retained.	YES	YES	YES ¹⁴	YES	YES ¹⁴	NO ¹⁴	YES ¹⁴

(see reverse for notes)

- ¹ Dingle's proposal is based largely on Clinton's bill with a couple notable exceptions in the areas of out-of-pocket caps and regional alliances. The precise stipulations of Dingle's plan are unclear, however, as it is still being negotiated.
- ² All individuals must buy insurance by the year 2005. However, the poor are exempt from this requirement if funds are not available for subsidies.
- ³ Plan lists benefits that *may* be covered; it is left to a national board to determine what actual benefits would be required.
- ⁴ Off-label use and experimental treatments not explicitly covered.
- ⁵ Off-label drugs are covered; silent on experimental treatments.
- ⁶ Mental health services are covered; substance abuse treatment is not included.
- ⁷ Limited long-term care services are included, but they are not accessible to people unless they are completely debilitated, excluding many people with AIDS.
- ⁸ Medicaid is eliminated under the Cooper plan; the poor will receive subsidies for insurance premiums but there will be no guaranteed benefits package or an assurance that current benefits would be retained.
- ⁹ Does not apply to single payer plan since no premiums are collected; the entire program is funded through taxes.
- ¹⁰ Subsidies are provided for low-income individuals; the Clifton plan assures those subsidies in the legislation; the Chafee and Cooper plans make subsidies dependent on savings in overall health care spending.
- ¹¹ Business with 10 or fewer employees are exempt from this mandate.
- ¹² Community rating is within the private plans; community rating is not between the private plan and Medicare.
- ¹³ Cost of coverage may be higher if you choose a provider outside your plan.
- ¹⁴ Stark, Chafee and Michel plans do not address these programs; the Cooper plan maintains Title IIIB of the Ryan White CARE Act programs.

AIDS Action Council Draft List of Amendments

Poverty/affordability/disability issues

1. Those who are on Medicaid and disabled should have premiums and coinsurance covered for fee-for-service.

Rationale: People with HIV disease must be able to pull together a team of care providers that is not restricted to a single network, since often the range of expertise needed is not available within a closed group, especially in smaller communities. The Administration recognized this when it included this option in the original draft of the plan.

2. Subsidy for poor disabled should cover fee-for-service premium and out-of-pocket expenses.

Rationale: The same as above. Unless the coinsurance and out-of-pocket expenses are subsidized, developing an appropriate team of providers may not be possible if limited to one list of providers.

3. Cash assistance recipients pay 20% of standard co-payments; however, providers absorb the difference creating a financial disincentive to serve these patients. Require the alliance to reimburse the plans/providers for these co-payment differentials. (This creates complexity re billing and does not solve the problem of allowing the provider to know who is subsidized; are there better ideas?)

Rationale: One of the strengths of the Clinton plan is that it tries to eliminate the distinctions between those on Medicaid and those who are not. While the same fee schedules will now apply, providers may use the lower co-payment schedule as an excuse to provide less quantity or lower quality care to those who are on Medicaid.

4. Currently, premium and cost sharing assistance is on a sliding scale for those between 100 and 150% of the federal poverty line; fully subsidize people to 150% of poverty; implement sliding scale for people from 150 to 200%.

Rationale: 150% of poverty is still a very low income level; a sliding scale above 150% would eliminate disincentives for those who are high users of health care from earning just above the 150% level.

5. Make explicit that premium expenditures are capped at 3.9% of income for *any plan selected* for people earning \$40,000 or less. (not just up to the average cost plan)

Rationale: This would assure that those who opt for fee-for-service plans because the closed networks cannot provide the same quality care would not be penalized.

6. Medicare disabled can opt into regional alliance.

Rationale: Medicare has disadvantages for high users of the system, especially the fact that there are no limits on out-of-pocket expenses.

7. Out-of-pocket payments should be pro-rated on a monthly basis.

Rationale: While a \$1,500 maximum in out-of-pocket expenses might seem manageable over the course of a year, many people with HIV disease may actually reach that maximum in a few months because they can be such high users of the system. Therefore, a pro rated maximum out-of-pocket cap would help mitigate that burden without costing the system more.

8. Include the mental health and substance abuse expenditures in out-of-pocket cap.

Rationale: Without this inclusion, accessing mental health and substance abuse care, which may be critical for people with HIV, may be financially impossible since they will also be incurring significant out-of-pocket costs for primary health care at the same time.

9. Include the following expenditures in the out-of-pocket: long term care; covered services beyond the amount, duration, and scope in the benefits package.

Rationale: This would mitigate any burden imposed by the failure to cover certain important benefits within the plan.

10. Modify "primary care provider" definition to include specialty expertise for certain chronic diseases.

Rationale: Very often, persons with disabilities will see specialists for all their primary care. Requiring these individuals to have to use a generalist as a gatekeeper at all times is wasteful, since a referral is more than likely to be made anyway.

11. Because the risk adjustment methodology may prove difficult to develop, it is important to make the interim reinsurance methodology as effective as possible in creating incentives for plans to accept expensive enrollees. It is currently conceptualized as reinsurance for expensive diseases. This could be augmented by including basic SES and demographic factors: below 200% poverty; SSI; residing in designated medically underserved areas; over 65; other.

Rationale: This would address, after the fact, all the elements intended to be in the risk adjustment mechanism, which would adjust prior to use of services. This will reduce even further any incentive for providers to risk select among clients.

17. In Title I cities, Ryan White Planning Councils guaranteed representation on alliance board.

Rationale: The Clinton plan is relatively weak in trying to integrate existing public health/care delivery structures into the decision making and planning associated with the regional alliances. This would be one way of assuring, in high incidence communities, that the needs of people with HIV are addressed and integration with existing programs might occur.

18. Essential community providers given minimum percentage representation on provider advisory councils in each regional alliance.

Rationale: This is another way of assuring input from advocates for the underserved and to make sure that essential community providers are treated as partners in the regional alliance.

19. Definition of family should be more broadly defined to include "families of choice" or some such definition for collateral services under substance abuse benefit; that broader definition could then be standardized later to extend the definition of family throughout the legislation.

Rationale: This is not just a backdoor approach to domestic partner coverage. Particularly in substance abuse care, the support needed by those close to someone in treatment can be critical to the success of that treatment, and this is very often not one's biological family.

20. Definition of eligible family must include any family as defined by the states.

Rationale: It must be made clear that the federal government is not overriding any decisions by the states to recognize domestic partners, if they so choose.

21. Add sexual orientation to protected classes in discrimination sections.

Rationale: This is to prevent the use of sexual orientation as a surrogate for HIV risk.

22. National health board must assure access to services for out-of-school and runaway youth prior to implementation date.

Rationale: This is an important group at risk to HIV; the plan does require that the board develop a system, but there is currently no timeline.

Consumer Rights/Protections

12. Require any plan certified by any alliance to accept enrollees from anywhere in the alliance area. This does not mean that all plans must be infinitely large. There is already language allowing plans to declare themselves "full".

Rationale: If it is legal to restrict plan enrollment to certain geographic areas, there could well be a legal form of redlining -- plans could choose to operate only in wealthy areas or avoid gay neighborhoods without violating the law. This could have the effect of weakening those plans serving those poorer or sicker neighborhoods. This could result in financially weaker plans and/or a new version of Medicaid mills.

13. This "full" declaration should be better specified to preclude its use to risk select. For example, perhaps plans could file and be certified only up to an annual maximum number of enrollees. They could not declare themselves "full" until this number was reached; when reached, they could accept no more enrollees. The secretary or board develop criteria for determining reasonable capacity limits.

Rationale: This is designed to avoid use of a "full" declaration to avoid high-cost patients. A well-run plan should be able to estimate in advance its capacity.

14. A plan must automatically be investigated for decertification if disenrollment patterns are not reflective of the demographic distribution of those enrolled in the plan.

Rationale: This is borrowed from the Cooper bill. This would highlight any discriminatory practices or poor quality in delivery of care.

15. Define "major life events" (permitting mid-year plan change) to include diagnosis with a terminal or life threatening disease or condition.

Rationale: People moving or recently divorced, etc. have the right to switch plans. As long as everyone cannot be in a fee-for-service plan, an adjustment for a new diagnosis that requires a different kind of care than the plan is expert in should be permitted.

16. Health plan boards and regional alliance boards must include high utilizers. Health plan boards must have one-third consumer representation.

Rationale: This is to assure both consumer representation generally, and that those who are sick will have a voice in the kind of choices plans and alliances make -- rather than making financial and care decisions based only on the needs of the healthy.

28. Community based substance abuse providers should be added legislatively to the list of automatic essential community providers.

Rationale: This would help compensate for the relatively poor coverage of substance abuse in the basic benefit. In all likelihood most of these programs will become eligible under the criteria to be established by the Secretary; immediate inclusion is more efficient and will communicate to regional plans the need to commit to full access to substance abuse treatment. Moreover, the health care system has little experience in treating substance abusers. Community providers offer the plans critical expertise in outreach and treatment to ensure the plans' ability to offer the basic benefits package.

Prevention benefit

29. Add HIV testing (age 13 and above) as prevention benefit with no copayment and not part of deductible.

Rationale: This is an important part of basic preventive services. Existence of this benefit should not result in reduced funding for anonymous test sites since many at-risk individuals will still be seeking testing from alternative sites -- and no point of access to HIV testing should be cut off.

30. Increase frequency of PAP smear covered as preventive benefit for those with HIV infection.

Rationale: Underlying HIV infection requires more frequent PAP smears; the primary care physician should be permitted to order more frequent testing as part of the preventive benefit (preventing cervical cancer is still the goal) for HIV-infected women.

Drugs

31. Cost of experimental treatments not part of a clinical trial must be covered by a plan if charges incurred through a treatment IND.

Rationale: The Clinton plan makes coverage of experimental treatments optional for plans. Generally, companies do not charge for the drugs available through a treatment IND. If they do, it must be the cost of production only; this should be covered to make access to experimental treatments equitable.

23. Cap marketing budgets of health plans (and regulate marketing)

Rationale: Marketing of plans should be based on quality measures, not "feel good" messages that are currently dominating advertising.

24. Require consumer information to be available in languages other than English in areas where a significant amount of the population does not speak English.

Rationale: If consumers are to make a rational choice in health care, they should have accessible information.

25. Prohibit provider reimbursement schemes that allow providers in managed care settings to benefit financially from decisions regarding care.

Rationale: This relates both to rewarding providers for limiting visits or referrals and to profiting from referrals. Decisions regarding care should be based on patient need, not financial incentives.

Essential Community Providers

26. Essential community providers be considered "in network" by all plans (adjust requirement for contractual or Medicare reimbursement arrangement to contractual).

Rationale: For essential community providers to be true partners, they must be in network; without this designation, patients will be discouraged from seeking what may be more appropriate care because of added costs. Essential community providers may be forced to absorb some of the out-of-pocket costs of their patients if they are being seen out of network, without any reimbursement scheme to help them.

27. Academic medical centers should be considered "in network" by all plans.

Rationale: To be assured that those with the most knowledge about HIV will be available to provide care, arrangements must be possible with any academic health center (including those out of state). If the relevant academic health center is out of network, accessing the care will be prohibitively expensive. Not all academic health centers have expertise in all diseases; by limiting access to health centers some diseases will have less access to state of the art treatment.

32. Cost of associated care for experimental treatment not part of a clinical trial must be covered by a plan if for a treatment available under an FDA approved expanded access protocol for life-threatening diseases.

Rationale: If the FDA determines that a drug is promising enough to be part of an expanded access protocol, then plans should be required to cover the associated care costs (usually additional tests; the drug is usually made available at no cost). These protocols are most often only for those who have failed or are intolerant of any approved treatment. All patients should have equal access to this kind of therapy.

33. Require drug price transparency -- that all companies publish their price lists -- to allow large buying groups to comparison shop, as is required in Medicare.

Rationale: We would prefer some kind of price controls. In their absence, forcing companies to disclose their prices will create a level playing field for all plans and might even embarrass a company or two.

34. Formularies for drugs covered shall be determined at the federal level.

Rationale: The plan currently permits plans to develop formularies. Unless these are determined at the federal level, there will be discrepancies in coverage from plan to plan, region to region, and state to state. All patients, regardless of plan or place of residence should have access to the same drugs.

Long-term care benefit

35. Long-term care benefit exempt from three ADLs limitation in last 24 months of life.

Rationale: This would permit access to the long-term care benefit for people with end-stage AIDS but not be an open-ended cost. Access to this care for people with AIDS actually reduces hospitalization time and other care associated costs.

36. Adopt a standard of palliative care that would allow ongoing non-curative treatments into the hospice benefit that is part of the comprehensive benefits package.

Rationale: Access to the hospice benefit should permit treatment or prophylaxis of opportunistic infections. For example, an end-stage patient in hospice care should be permitted to receive treatment for CMV retinitis to prevent blindness, even though this will not prolong life expectancy.

37. Alter the formula for distributing the long term care funds between states to include a factor for actual case counts for specific diseases (like HIV/AIDS and Tay-Sachs) whose incidence varies by demographic factors other than the ones in the proposed formula.

Rationale: This will result in a more realistic distribution of funds based on actual usage.

Public health programs

38. Retain separate funding streams for Ryan White CARE Act, community and migrant health centers, STDs, TB, family planning, substance abuse block grant, etc.

Rationale: These programs will continue to be essential services; because of the special outreach these programs do to bring people into care and because the trust relationships they have developed with their clients.

39. Create a clear earmark for HIV services (care, prevention) so not folded into a general public health block grant.

Rationale: We are concerned that health departments, left to their own priority setting, will channel resources into more "popular" programs and not make choices based on public health needs (especially in lower incidence states with poorly organized HIV constituencies).

WA ALLIANCE FOR NATIONAL HEALTH CARE REFORM
COMMON STATEMENT
February 14, 1994

As the health care debate is heating up in Congress, a unique "alliance" of consumers, labor, health care providers, children's advocates, persons with disabilities, older Americans, civic groups and religious organizations which represents over a million people in the State of Washington, is joining forces to kick off a broad based grassroots campaign supporting comprehensive health care reform. The common thread that brings these groups together is to ensure that Congress includes comprehensive and affordable coverage, universal access, long term care coverage for persons of all ages, and systems-wide cost containment in health care reform.

Members of the Alliance pledged to mobilize their members and their resources to push for comprehensive health care reform in the coming year. Leaders of the WA effort agreed to concentrate their activities on lobbying Members of the Washington Congressional Delegation, and educating and informing their memberships about the need for health care reform. Sharing information and resources, presenting unified messages and coordinating their advocacy activities will effectively express public support for comprehensive health care reform.

The Alliance recognizes Washington State's support of this effort with the passage of the Washington Health Services Act of 1993. This law proposes the kinds of changes needed to ensure access, coverage and affordability for every Washington resident by 1999. That effort should set an example for a national health care reform plan.

Today, too many Americans feel unsure about their health care coverage. Over the next two years, 1 out of 4 Americans will be without health coverage at some point. About 40% of American families have had their health benefits seriously cut back. Others are denied coverage because a child has asthma or a parent has diabetes or because of other pre-existing health problems. One in five workers feel locked in their jobs because they fear losing their health coverage, were they to move. About 85% of Americans who have lost health insurance are workers and their families.

It is estimated that 300,000 Washingtonians will need long term care services by the year 2010, while 11 million Americans will require such services nationally. Long term care needs to be available to children, as well as adults, for the duration of chronic conditions which include physical and/or mental disabilities. (It should be noted that 36 percent of the population needing care over the long term are under the age of 65.) It addresses the individual needs of persons of all ages who are limited in their functional capacities and require skilled care and/or assistance with performing activities of daily living (such as eating, toileting, bathing, dressing and moving about) for a relatively long or indefinite period of time. Long term care includes the delivery of a wide range of health and social services. Each individual's requirement for long term support may be

accommodated in his/her home by the family or other individuals, in the community, or in a formal setting.

Home and community-based alternatives to hospital and nursing home care have not been adequately addressed in the present separation of acute care funding from long term care funding. Many, incorrectly, believe that their health insurance policy or Medicare will cover the cost of long term care. Medicare and private insurance pay less than 5% of the nation's long term care bill. Medicaid provides some relief for low income persons who need nursing home care. Its requirements force people to spend their savings and assets until they reach the poverty level to qualify. Many families want to provide long term care services, but need assistance to prevent deterioration of their own health and bankruptcy of their financial and emotional resources.

The Alliance is also dedicated to the timely enactment of national legislation that will:

- * improve health care quality
- * protect consumers
- * encourage innovative alternatives for delivering service
- * provide equitable financing
- * foster health promotion and wellness
- * increase coordination of patient services across the full health care continuum including preventive, acute and chronic care.

A list of the participating organizations is attached.

This Alliance is not committed to any particular legislative proposal. All participating organizations are united in their conviction that Congress must enact comprehensive health care reform without delay. The Alliance seeks a bi-partisan solution to the health care reform crisis.

In joining this campaign, each organization retains its autonomy regarding specific legislative proposals or modifications that it may support. The Alliance will operate as a support structure to member organizations to better enable them to work on behalf of all Americans for comprehensive health care reform.



KEY ELEMENTS OF REFORM	WASHINGTON'S HEALTH SERVICES ACT OF 1993	PRESIDENT CLINTON'S PLAN
Universal Access	Yes, individual mandate by 1999.	Strives for universal access by 1998 (unclear if mandated).
<i>Expansion of state programs</i>	The Basic Health Plan (BHP), a successful pilot program for families below 200% of federal poverty, is the primary state program for the low-income uninsured.	State-tailored programs (like the Basic Health Plan) are not excluded, as long as they provide and may receive federal matching funds.
<i>Provider shortages</i>	Requires University of Washington to train more primary care physicians. Funds training of providers in underserved areas.	Provides incentives for more primary care doctors. Set guidelines for total number of specialty and residency positions. "Loan forgiveness" program for primary care doctors is established.
Guaranteed Minimum Level of Coverage	Yes, called the Uniform Benefits Package (UBP).	Yes
<i>Standard benefits</i>	UBP standard, supplemental plans variable.	Minimum guaranteed benefits standard, supplemental plans variable. (Considering several versions.)
<i>Scope of benefits</i>	Comprehensive, includes: - visits to the doctor and other providers - hospital care and surgery - prescription drugs - maternity, reproductive and wellness services - home health and hospice care - case managed chemical dependency treatment - case managed mental health services - preventive dental care for children only - long-term care in 1999 - case managed short-term skilled nursing facility (SNF)	Comprehensive, includes: - visits to the doctor and other providers (full coverage for primary and preventive care) - hospital care and surgery - prescription drugs - maternity, reproductive and wellness services - home health and hospice care - substance abuse services - mental health services - dental care (children only) - long-term care by 2000 - occupational and speech therapy - eye care
<i>Focus on prevention</i>	Yes	Yes
<i>Long-term care</i>	Study integration and conduct two pilot social health maintenance organization projects. Begin full integration by 7/99.	Home and community-based services phased in by the year 2000.

KEY ELEMENTS OF REFORM	WASHINGTON'S HEALTH SERVICES ACT OF 1993	PRESIDENT CLINTON'S PLAN
<i>Medicare</i>	If Medicare waivers are not secured, the state shall make Medicare Supplement Plans available to all eligible state residents by 1/95.	Added prescription drugs to Medicare benefits.
<i>Supplemental benefits</i>	Allowed at rates pre-approved by the Insurance Commissioner	Standardized policies developed and may be offered by plans.
<i>Plan design</i>	Managed care and preferred provider organizations (PPOs) allowed. No fee-for-services plans are allowed after July 1995.	Managed care, preferred provider organizations and fee-for-service plans are allowed.
Government Price Regulation	Moderate	Minimal
<i>State commission</i>	Yes, called the Health Services Commission (HSC).	National Health Board enforces budget.
<i>Maximum premium</i>	Yes, the HSC determines a maximum premium for the Uniform Benefits Package in 1995.	None
<i>Inflation limits</i>	Yes, beginning July 1, 1996, the growth in maximum premium will be reduced by 2% a year until it is comparable to the growth in personal income (this is a reduction from 14% to 4% by 2001).	Yes, beginning October 1, 1996, inflation rates will be decreased over time until they are comparable to the increase in the CPI, plus a percentage that has yet to be set.
Finance		
<i>Employers</i>	Employer-based system. Employers must pay at least 50%, but up to 100% of the premium for their employees and dependents of the lowest-priced plan in a region.	Employer-based system. Employers must pay 80% of the premium of the average-priced plan in an area. Supplemental health benefits will be taxable.
<i>Government</i>	Taxes on alcohol, cigarettes, providers and non-profit hospitals are raised to fund public programs for the low-income uninsured.	Savings from Medicare and Medicaid, taxes on benefits above minimum level and taxes on alcohol and cigarettes will fund the federal government's share of Medicaid for the low-income uninsured.
<i>Individuals</i>	Employed individuals will pay 0-50% of the premium for themselves and dependents. There will be moderate point-of-service cost-sharing. Unemployed and near-poor will pay the portion of the premium not covered by the state. There will be minimal point-of-service cost-sharing. Unemployed and below poverty will not have to pay toward their premiums. There will be minimal point-of-service cost-sharing.	Employed individuals will pay no more than 20% of the premium. There will be moderate point-of-service cost-sharing. Premiums will be subsidized for those earning less than 150% of federal poverty. There will be discounts for small, low-wage businesses.

KEY ELEMENTS OF REFORM	WASHINGTON'S HEALTH SERVICES ACT OF 1993	PRESIDENT CLINTON'S PLAN
Insurance Reforms		
<i>Certified health plans (CHPs)</i>	After 7/95, only plans certified by the state may offer the UBP. They must offer no less than the UBP at no more than the maximum premium.	Federal standards will be developed that plans must meet. States must certify health plans.
<i>Community rating</i>	One statewide community rate with adjustments allowed for geographic regions and family size. Single community rated premium (composite family) across state programs will result in increased Medicaid reimbursement rates when merged into single risk pool.	One regional community rate with adjustments allowed for age. There will be exceptions to community rate for Medicaid risk pool. Health alliances pay plans a risk adjusted rate to cover high-risk populations.
<i>Pre-existing condition exclusions</i>	After 1/94, once a person has met a pre-existing condition waiting period for one policy, he/she does not need to meet another waiting period on a new policy.	No new regulation. All individuals guaranteed universal coverage. Plans may not exclude or charge more to individuals on the basis of age, employment or health status.
<i>Guaranteed issue and renewability</i>	After 7/95, plans must offer to continue enrollment for residents in their plan area.	Plans must offer to continue enrollment.
<i>Open enrollment</i>	Plans must have an annual open enrollment.	Plans must have an annual open enrollment.
Purchasing Reforms		
<i>Consolidated state purchasing agent</i>	One state agency, separate from the Commission, purchases benefits for all state programs.	Federal health care purchasing will be streamlined and coordinated across programs.
<i>Health insurance purchasing alliances</i>	A voluntary option for employers. There will be four non-competing regional Health Insurance Purchasing Cooperatives (HIPC's), which must allow any group or individual to participate and offer every plan in the region.	Individuals and firms with fewer than 5,000 employees must purchase through alliance. \$29 billion to set up alliances.
<i>Managed competition</i>	Yes, benefits are standardized and employers' contributions are tied to a percentage of the lowest-priced plan in a region.	Yes, benefits are standardized and employers' contributions are tied to a percentage of the average-priced plan in an area.
Employer Participation		
<i>Premium contribution</i>	Employers must pay at least 50% of lowest-priced plan for employees.	Employers must pay 80% of the premium for an averaged-priced plan.
<i>Dependents</i>	Employers must cover and pay at least one half of premium.	Employers must pay 80% of the premium for dependents.

KEY ELEMENTS OF REFORM	WASHINGTON'S HEALTH SERVICES ACT OF 1993	PRESIDENT CLINTON'S PLAN
<i>Part-time employees</i>	Employers must pay a pro-rated amount of part-time (<30 hours/week) employees' premiums.	Employers must pay a pro-rated amount of part-time (<30 hours/week) employees' premiums.
<i>Seasonal workers</i>	Coverage not required for seasonal workers or dependents with coverage pending further study.	Seasonal workers receive coverage through regional alliances and contribute to the cost their premiums.
<i>Phase-in</i>	By firm size, small employers last (1995-1999).	No phase-in. All states required to establish health alliances by 1997. State have the option to enter the system earlier.
<i>Plan offerings</i>	Employers must offer at least three plans, including the lowest-priced plan in the region. Alternatively, employers may purchase state coverage or join a purchasing cooperative/ alliance.	Employers must offer at least three plans, including a fee-for-service option. If the firm has less than 5,000 employees, it must purchase through a purchasing alliance.
<i>Small business assistance</i>	\$150 million in small (<25) business assistance will be available. Small business advisory group and economic impact statement required. There may be future legislation establishing a tax credit for small employers by 1/97.	Small businesses and firms with low average wages would receive subsidies. Small, low-wage firms would pay no more than 3.5%-7.9% of payroll toward the cost of premiums for their workers.
Malpractice/Liability Reforms		
<i>Mandatory mediation</i>	Yes	Alternative dispute resolution established.
<i>Quality assurance</i>	Yes	Yes
<i>Collateral source offset</i>	Yes	Yes
<i>Contingency fees</i>	No	Cap of 33.3%
Other		
<i>Employee tax credit</i>		The guaranteed minimum package will continue to be tax exempt. Benefits above the minimum will be tax exempt for 10 years if currently offered by an employer.

WASHINGTON ALLIANCE FOR
NATIONAL HEALTH CARE REFORM
February 14, 1994

American Association of Retired
Persons
Alzheimers Association of
Puget Sound
Children's Alliance
Coalition of Retired Higher
Education Employees
Community Psychiatric Clinic
Home Care Association of WA
League of Women Voters of WA
National Asian Pacific Center
on Aging
Nikkei Concerns
Northwest AIDS Foundation
Paralyzed Veterans of America
Retired Teachers Association of WA
Senior Services of Washington
Service Employees International
Union, WA State Council
Washington Citizen Action
Washington Association of Adult
Day Centers
Washington Association of Area
Agencies on Aging
Washington Coalition of Citizens
with disabilities
WA Community Mental Health Council
Washington Education Association
Washington State Catholic Conference
Washington State Council of Senior
Citizens
Washington State Labor Council
Washington State LTC Ombudsman
Washington State Nurses Assoc.
Washington State Nursing Home
Resident Councils
Washington State Senior Citizens
Lobby
Western Washington, National Multiple
Sclerosis Society

FOCUS

A Guide to **AIDS** Research and Counseling

Volume 9 Number 4 March 1994

Health Care Reform and AIDS

Warren W. Buckingham III

The ability of people with HIV infection to acquire health insurance varies tremendously from state to state, from jurisdiction to jurisdiction within states, and from job to job within the workplace. In far too many situations, insurance is either completely unavailable or prohibitively expensive. When it is available, it often includes draconian limitations on pre-existing conditions and important benefits like prescription drugs, mental health care, home care or hospice.

President Clinton's Health Security Act makes significant progress in dealing with most of these problems. Most importantly, it would eliminate all pre-existing condition exclusions: no one could be denied insurance, or charged a higher premium, because they had any illness prior to coverage. It would also eliminate lifetime maximums, which in recent years have affected hemophiliacs with HIV disease who must spend up to \$15,000 every two months for blood products, and would cover prescription drugs and mental health services.

The plan is not perfect. Some critics say it does not go far enough in reforming the current confusion of public and private programs with different eligibility criterion, widely varying benefit packages, and exclusionary rate structures. Others say it goes too far—raising the battle cry of "socialized medicine." Between the two extremes are a large number of people who believe the Health Security Act is a thoughtful, comprehensive, and equitable effort to extend health care coverage to all Americans.

For the vast majority of people with HIV disease who have private insurance, the comprehensive benefits package in the Health Security Act would be comparable

to—or richer than—the benefits they have now. For those receiving coverage under Medicaid or other public programs, the package would be a significant improvement. And for those with no coverage at all, the plan eliminates a major source of stress and anxiety in their lives, ensures adequate treatment, and protects against financial ruin.

The Rationale and Motivation for Reform

While some public figures assert that there is no crisis in health care, the White House Health Care Task Force did not hear from an "ordinary" American who did not have a health care horror story about him or herself, or his or her family or close friends. In conversations with people with HIV disease and AIDS, the stories have been even more pronounced. It is the statistics behind health care reform, however, that recount the most compelling story of all.

First, for people without private health insurance across the country, there are terrible discrepancies in terms of access to care and services available, and 100,000 Americans move into the ranks of the uninsured each month. These inequities are exacerbated for people with HIV disease. According to the National Commission on AIDS, in 1991, 40 percent of people with AIDS were covered by Medicaid and 29 percent had incomes too high to qualify for Medicaid, but nonetheless could not get or afford private insurance.

State Medicaid programs themselves are notoriously inaccessible. Patients must "spend down" and divest themselves of resources in order to become eligible for benefits. Forms are often so confusing to fill out that many public hospitals have hired full-time staff to decipher them. Patients can wait months for initial appointments at clinics that accept Medicaid, and because of lower reimbursement rates and delayed payments, many health

Editorial: Health Care Mythology

Robert Marks, Editor

It's hard to imagine that there is anything left to say about health care reform, anything that has not already been reported in the media blitz surrounding President Clinton's Health Security Act. But the media has not covered clearly the implications of reform for HIV-related care. Nor, in its focus on the economics of managed care, has it dealt with philosophical issues related to managing health.

This issue of *FOCUS* brings together two health care policy wonks who have looked at this issue from their different perspectives: one from the inside—sitting on the president's health care reform advisory task force—and the other from the outside—watching the proposals unfold from the leading AIDS policy advocacy organization in the country. These two views come to similar conclusions: health care reform at its best will improve HIV-related care; at its worst, it could sacrifice crucial services funded under existing HIV-related legislation. Of particular concern, most propos-

als limit mental health care and substance abuse treatment—but perhaps not any more than they are under typical health insurance plans.

It is this limitation that raises questions that have not been sufficiently addressed in the health care reform debate. There has been little public discussion about the American conception of health and the role of health care. In a fascinating article, which we abstract in this issue's Recent Report section, William Gaylin, a Columbia University psychiatrist, raises these issues. Among his conclusions, he states that we have become victims of health care that is too effective—that medical knowledge and technology keep us alive after we would have "normally" died, that is, with our ill health intact and requiring expensive maintenance.

In a society where fitness and good health are idolized, is it ironic that health care is only grudgingly acknowledged as a governmental responsibility? Is it ironic that many of the health

services that should make us feel "well" are not adequately covered by health insurance? Or, is Gaylin correct that we are overreaching in our desires to feel well longer and to expect government to pay for what has become an unreasonable desire?

Where does mental health fit in all of this? We in the United States have never acknowledged mental health as a legitimate concern, except when its deterioration threatens the social order. Can society ignore less dramatic manifestations of mental illness, including substance abuse, depression, and anxiety? On the other hand, can society bear the cost of long-term therapy—or, for that matter, the Prozac revolution—for someone who is for the most part functional? To what extent are many of the psychosocial needs of people with HIV-related concerns luxuries that must be sacrificed to the era of managed care?

Ultimately, health care reform is the pin that punctures the balloon of our national mythology of perpetual health and unlimited health care. But since these ideals have been unattainable for most people, health care reform seems to promise at least a more honest and equitable approach.

care providers will not accept Medicaid patients.

Second, these problems are not exclusive to the poor. More than half of the uninsured in 1990 were full-time workers and their families, and more than one million of those who lost health insurance in 1992 were earning between \$25,000 and \$49,000 per year. One out of every three Americans earning between \$30,000 and \$50,000 annually report that members of their household have stayed in jobs they wanted to leave because they were afraid of losing health care coverage. There appears to be a tragic corollary to this statistic: many people with HIV disease actually fear losing their jobs and insurance more than they fear losing their lives, in large part because they do not want to become a financial burden to family, friends, or society.

Finally, in just 25 years time the percent of the U.S. Gross National Product (GNP)

consumed by health care expenditures more than doubled, from 6 percent to 12 percent, and the actual numbers soared from \$42 billion to \$666 billion. Health care expenditures increased at more than twice the rate of GNP growth. This accumulation of staggering economic and personal costs has brought about a rare moment in the life of this nation: a moral imperative—the need to care for one another—has also become a political and economic imperative.

Benefits of the Health Security Act

There are many elements of the Health Security Act that have positive implications for people with HIV disease. The following points highlight those changes that will have the most immediate or substantive benefits in four areas: extent of coverage, types of services, and systemic efficiency, and mental health and substance abuse coverage.

The plan would offer limited mental health care, but even this would represent an improvement for people with Medicaid or no insurance.

Extent of Coverage. First, the plan would end "medical underwriting," eliminating "pre-existing condition" exclusions and waiting periods for anyone, regardless of health status. Second, insurers would no longer assess premiums based on individual demographics or health characteristics. Instead, factors that currently increase costs to individuals—such as age and pre-existing conditions—would be spread across whole communities. Finally, the plan would eliminate lifetime maximums. No one would need worry that an expensive medicine or course of treatment would raise costs to an arbitrary "ceiling" and lead to an end to their coverage for all other services.

Types of Services. The plan would include home- and community-based alternatives to hospitalization as an integral part of the health care reform package. It would recognize and cover preventive intervention, programs and services that seek to keep people well and prevent the onset of serious HIV-related diseases.

Perhaps most importantly for people with HIV disease, it would make prescription drugs affordable.

For too many people and families struggling with HIV disease, drugs are the largest cost of daily living, forcing people to choose between buying food and paying for medication. In addition, for people with AIDS on Medicaid, prescription drug benefits vary widely from state to state. In some states, AIDS drug assistance programs (ADAP) cover zidovudine (ZDV; AZT) and its analogs and nothing else; in others, like New York, ADAP covers all drugs and some nutritional supplements.

Systemic Efficiency. The proposal would level the tremendous regional disparities in public programs, that is, Medicaid and state-only plans, minimizing the need for people with HIV disease to migrate to other places for adequate health care coverage. Over time, as HIV-related expertise grows more routinely available, people with HIV disease living in urban areas could move back to their families of origin without worrying about variations in treatment capability and covered benefits, which would be uniform throughout the country. It would also streamline the process by standardizing forms and reducing the micromanagement of care delivery by health care "gatekeepers," people who may never have been near

the front lines of health care delivery.

Mental Health and Substance Abuse Coverage. The plan would offer limited mental health and substance abuse benefits, and mental health benefits would achieve full parity with physical health benefits after 2001. The plan would cover services by mental health providers including psychiatrists, psychologists, and licensed social workers. The initial plan would closely resemble most private plans today, for example, 30 mental health visits per year with either a \$10 or 20 percent copayment (psychotherapy would initially have a \$25 per visit or 50 percent copayment), and 30 days per year of inpatient treatment. The copayments associated with these services, however, would not count in the annual out-of-pocket maximums of \$1,500 for individuals or \$3,000 for families. Since most state Medicaid programs do not cover mental health services, for the 70 percent of people with AIDS who have no insurance or who rely on Medicaid, even this initial benefit would represent a significant improvement.

Conclusion

The primary alternatives to the Health Security Act include the Cooper-Grandy, McDermott-Wellstone, and Chafee-Dole plans. Cooper-Grandy is currently receiving a great deal of media attention, but while the proposal would offer universal access to coverage, it would not guarantee the financial means to pay for it. McDermott-Wellstone is a single-payer plan with numerous proponents, but, because the federal government would become the insurer and the entire private insurance industry would be eliminated, the plan is not thought to be viable. The Chafee-Dole plan would substitute an individual mandate for the employer mandate, that is, all individuals would have to purchase insurance, but employers would not be required to provide it.

For the first time in decades—and probably in the current session of Congress—it is very likely that a hybrid of these plans will result in meaningful reform of the financing and delivery of health care in this nation. The Health Security Act includes many proposals that offer improvements in coverage and financial relief for people with HIV disease and all other long-term chronic, disabling—and expensive—diseases.

In his State of the Union address, the President emphasized the fundamentals of reform: every American must be covered and the coverage must always be there. For the HIV-affected community, no two benefits could be more important.

Authors

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The AIDS Agenda and Reform

Jeffrey Levi

People with chronic diseases like HIV infection demand the most from our health care system and, in its present form, often get the least. Currently, 40 percent of people with AIDS are on Medicaid and another 29 percent are uninsured, and those with private health insurance often have limited benefits or high out-of-pocket costs. This inability to access care diminishes the length and quality of life for people with HIV disease. While it is clear that some kind of health care reform will be approved in 1994, how well the final reform plan addresses these realities will be the true measure of its value.

The Health Security Act

President Clinton's Health Security Act proposes to guarantee health insurance coverage with a standard set of comprehensive benefits for all legal residents of the United States. The act would provide insurance through regional alliances that would oversee the purchase and administration of health insurance plans for all residents of a geographic area. It would require all employers to offer their employees health insurance, paying, on average, 80 percent of the premium for full-time employees. The self-employed and unemployed would also be required to purchase health insurance through the regional alliances, with their premiums subsidized or covered by Medicaid if they are poor.

All plans offered under a regional alliance would have to provide the same package of basic benefits, which are fairly comprehensive in covering primary care needs. While everyone would be required to pay something for their care—in the form of fixed copayments or a percentage

of fees—different plans could offer different options for accessing care, for example, closed network managed care versus fee-for-service options, although these options would be more expensive. The act would limit premium increases for all types of plan to the rate of health care inflation, and hold individual out-of-pocket costs to about \$1,500 a year.

Strengths and Weaknesses of the Act

One way of measuring the strengths and weaknesses of the Clinton proposal is to examine it in terms of some basic principles that should inform any reformed health care system: universality, comprehensiveness, choice, affordability, and government responsibility. Unless these principles are addressed, people with HIV disease will not benefit from health care reform.

Universal Coverage. The Clinton proposal would assure all U.S. citizens and legal residents coverage by January 1, 1998. It would not cover undocumented immigrants and incarcerated inmates, leaving these two populations with high rates of HIV disease to receive care only through the existing public health safety net. For those who are covered, there would be important protections: all plans would have the same minimum benefits package, would eliminate pre-existing condition clauses, would determine premiums by community rating, and would be free from ceilings on coverage for any specific disease. Community rating, whereby everyone pays the same premium regardless of health status, is particularly crucial for making insurance accessible for people with chronic diseases.

Comprehensiveness. The Clinton proposal would cover all medically necessary services, including the full range of benefits normally associated with a good private health insurance plan, that is, most inpatient and outpatient services. In addition,

Clearinghouse: Health Care Reform

References

Birenbaum A. *Putting Health Care on the National Agenda*. New York: Greenwood Press, 1993.

Brennan TA. An ethical perspective on health care insurance reform. *American Journal of Law & Medicine*. 1993; 19(1): 37-75.

Cantor JC. Health care unreform: The

New Jersey Approach. *The Journal of the American Medical Association*. 1993; 270(24): 2968-2971.

Deber RB. Canadian Medicare: Can it work in the United States? Will it survive in Canada? *American Journal of Law & Medicine*. 1993; 19(1):75-95.

Goodman J, Musgrave GL. *Patient Power: Solving America's Health Care*

Crisis. Washington, DC: Cato Institute, 1993.

Gostin LO. Foreword: Health care reform in the United States—The presidential task force. *American Journal of Law & Medicine*. 1993; 19(1): 1-21.

Graig LA. *Health of Nations: An International Perspective on US Health Care Reform*. Washington, DC: Congressional Quarterly Books, 1993.

Jost TS, Tanenbaum SJ. Selling cost containment. *American Journal of Law & Medicine*. 1993; 19(1): 95-121.

tion, the plan emphasizes coverage of clinical preventive services, including screening for cervical and breast cancer, HIV antibody testing, and immunizations. The plan also covers, among other things, limited substance abuse and mental health treatment, hospice care, and 60 days of home health care as an alternative to hospitalization. Additions or changes to this minimum package could be made

by Congress or by the National Health Board, created to oversee the entire new system.

Unfortunately, the combined substance abuse and mental health benefit has severe limitations on usage. For example, each time a person accesses mental health services, his or her substance abuse benefit would diminish accordingly, and vice versa. Not until 2001 would substance abuse and mental health services achieve the same level of coverage as other health benefits. Within limits, the Clinton proposal would cover inpatient and residential mental illness and substance abuse treatment; intensive nonresidential mental illness and substance abuse treatment; outpatient mental illness and substance abuse treatment, including case management, screening, and assessment; crisis services; and collateral supportive services.

The combined benefit would be limited to a total of 30 days per year of residential or inpatient treatment, with the possibility of a 30-day extension, and 60 days

of outpatient treatment. Each day of residential or inpatient treatment could be swapped for two days of intensive nonresidential treatment or three days (visits) of outpatient counseling. The mental health benefit would also require significant copayments.

These severe limitations impose obstacles for people with HIV disease or at risk for HIV infection, who are likely to need to address underlying substance abuse issues as well as mental health issues associated with having HIV disease. This proposal would make it almost impossible to get effective substance abuse treatment and adequate mental health services. Even if substance abuse treatment were the only part of the benefit accessed, care would be insufficient.

Access to experimental treatments and off-label uses of approved treatments is critical to the care of people with HIV disease. The Clinton proposal would, in general, assure access to off-label indications (licensed drugs prescribed for new uses), but individual plans would have the discretion to impose some restrictions. The act would also assure coverage of participants in clinical trials; the extent of coverage of experimental treatments outside trials, however, would be left up to individual health plans. The act does not cover alternative therapies such as acupuncture, chiropractic care, or homeopathy.

Freedom of Choice. The Clinton proposal assures that everyone would have more than one plan to choose from, not often the case for those getting insurance through their employers. However, the proposal would depend upon the managed care approach to hold down costs, and fee-for-service or flexible network plans would incur higher copayments and premiums. Those on Medicaid would not be subsidized for these more expensive plans. Choice is therefore dependent on ability to pay.

The combined substance abuse and mental health benefit has severe limitations: each time a person accessed mental health services, his or her substance abuse benefit would diminish accordingly.

Mariner WK. Problems with employer-provided health insurance: The Employee Retirement Income Security Act and health care reform. *New England Journal of Medicine*. 1992; 327(23): 1682-1685.

Moon M, Holahan J. Can states take the lead in health care reform? *Journal of the American Medical Association*. 1992; 268(12): 1588-1594.

Parmet WE. Regulation and federalism: Legal impediments to state health care reform. *American Journal of Law &*

Medicine. 1993; 19(1): 121-145.

Patrick DL, Erickson P. *Health Status and Health Policy: Allocating Resources to Health Care*. New York: Oxford University Press, 1993.

Reinhardt UE. Reforming the health care system: The universal dilemma. *American Journal of Law & Medicine*. 1993; 19(1): 21-37.

Rothfeder J. *Privacy for Sale: How Computerization Has Made Everyone's Private Life an Open Secret*. New York, NY: Paramount Publishing, 1992.

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See also references cited in articles in this issue.

*For a family of four, 150 percent of poverty is \$21,500; for an individual, it is \$10,800.

This is particularly troublesome for people with HIV disease. The kind of expertise HIV-related care requires may not be available in every plan, especially for those in smaller communities. The higher cost sharing associated with fee-for-service plans, however, may make it prohibitive for people with HIV disease and impossible for people on Medicaid.

Two elements of the Clinton proposal would mitigate this situation to some extent. The proposal would require all plans to have arrangements with academic health centers to provide expert care for diseases like HIV infection, and treatment at these centers would not cost more. Similarly, each plan would have arrangements with so-called "essential" community providers, those existing health clinics—including Ryan White CARE Act providers—that specialize in caring for underserved populations.

Affordability. The Clinton proposal assumes some predictability in costs: premiums could rise only with the rate of health care inflation, out-of-pocket expenses beyond premiums would be capped at \$1,500, no individual would have to pay more than 3.9 percent of his or her income in premiums, subsidies would be provided for those with incomes below 150 percent of poverty but not on Medicaid, and Medicaid would cover the premiums of people on Medicaid cash assistance.* These are important improvements, but people with chronic diseases may still face special challenges, for example, coming up with \$1,500 in one lump sum and early in a year. In addition, more flexible subsidies—beyond 150 percent of poverty—would help people who would not meet the proposal's criteria for "poverty."

Government Responsibility. The Clinton Administration is committed to having the government exercise greater authority over health care, from limiting costs, to regulating how insurance is underwritten, to assuring that underserved communities have sufficient providers. Importantly, the Clinton proposal also recognizes that this more centralized system—complete with health security cards—would require vigilant attention to confidentiality and discrimination. Unfortunately, much of the confidentiality protections for the proposal are to be written in the future, and, of those that have been defined, some would not go far enough. For example, the proposal would ban discrimination in providing services based on health status, but would lack protection against sexual orien-

tation discrimination and would include no recognition of alternative family arrangements. Finally, the Clinton proposal retains the existing public health infrastructure (including the Ryan White CARE Act program), while expanding, within the plan and through new initiatives, a commitment to prevention.

Conclusion

This summary of a complex plan—some would argue too complex for its own political good—shows that the Clinton Administration has moved forward in critical directions for people with HIV disease. The proposal would achieve relatively universal coverage, clear predictability of cost for the individual, reasonably comprehensive coverage, and assistance to the poor in accessing these services.

While it is hard to predict the ultimate outcome of the proposal, three things are clear. Congress will pass some legislation this year and call it health care reform. The final product will look significantly different from the original Clinton plan. There is strong pressure to leave the system alone, undertaking only minor reforms that rely on the marketplace to assure access.

It is impossible to know what approach will finally prevail, but it is clear that people with HIV disease will be the losers if the resulting legislation does not incorporate fundamental change. AIDS advocates need to join with the Clinton administration to assure that the final plan offers: universality of coverage through the employer mandate, a comprehensive benefits package guaranteed by law, community rating that spreads the risk of illness among all Americans and makes insurance affordable for people with HIV disease, and the previously instituted HIV-related safety net created by programs such as the Ryan White CARE Act.

Authors

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Comments and Submissions

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UCSF AIDS Health Project, Box 0884
San Francisco, CA 94143-0884

Recent Reports

Privacy and Health Care Reform

Gostin LO, Turek-Brezina J, Powers M. Privacy and security of personal information in a new health care system. *The Journal of the American Medical Association*. 1994; 271(1): 2487-2493. (American Society of Law, Medicine and Ethics, U.S. Department of Health and Human Services, Georgetown University, Johns Hopkins University.)

Policy makers are trying to balance appropriate privacy and autonomy with the requirements of an efficient health care system and an adequate and reliable informational basis for health care planning, according to a commentary on confidentiality and health care reform.

Currently, privacy and confidentiality protections are a product of federal and state constitutional law and statutes, and

state common law—"a morass of erratic law." Due to the absence of uniform privacy and confidentiality protection, continued reliance on current legal safeguards is incompatible with the policy objective of an integrated national health care system. State-by-state regulations, for example, ignore the fact that the flow of medical information is rarely restricted to the state in which it is generated. Further, state protections become futile at a time when the physical location of health informa-

tion is no longer relevant, when databases with huge amounts of health information provide immediate access by a variety of eligible users in remote locations.

In response, the federal government should first establish national privacy safeguards based on a code of fair information practices, including: the individual right to know about and approve uses of data; the prohibition of secret data systems; and the individual right to review and correct data.

Second, the government must establish a universal identifier that will provide more privacy protection than a social security number, the most common identifier.* Third, the government should develop standards to ensure the security of automated information systems.

The health care reform debate has misdiagnosed the economic ills plaguing the system and has failed to address central philosophical issues.

*Universal identifiers are unique numbers, or number and letter combinations, used to track individuals as they use a system's resources.

Fourth, the government should empower a data protection and security panel. Its responsibilities would include: setting and monitoring privacy and security standards; establishing mechanisms through which individuals could question the propriety of the collection and use of information; and supporting the development of a fair and comprehensible disclosure consent process.

Finally, the government must develop a comprehensive education program to teach health care professionals about their rights and responsibilities regarding privacy and security of information.

Access, Egress, and Allocation

Gaylin W. Faulty diagnosis. *Harper's Magazine*. 1993; 287(1721): 57-64. (Columbia University, The Hastings Center.)

The health care reform debate has misdiagnosed the economic ills plaguing the system and has failed to address central philosophical issues, according to an essay on rationing health care. "Efficiency experts" have taken control of the debate, erroneously assuming that eliminating waste will obviate the need for rationing. Further, by ignoring societal attitudes toward life and death, the goals of medicine, the meaning of "health," suffering versus survival, and who shall live and who shall die, planners have lost the opportunity to reach democratic consensus about rationing.

Health care costs are driven by four factors: the increase in health problems due to good medicine that enables people in poor health to live longer; the expanding concept of health; the seduction by technology of both doctor and patient; and the "American character," which seeks to solve things completely and immediately. Given these factors, there are three ways to contain health care spending: limit access (who gets care), egress (for how long) and allocation (what can be provided).

Access to scarce and expensive resources must be organized on some equitable basis—even if equitable does not mean full coverage for everybody and everything. Various factors might be considered to determine who should receive what, most prominently, age: all things being equal, most would agree a 16-year-old boy has a greater claim on an organ than a 72-year-old man.

Even more complex than deciding who deserves access, is when, and if, access should end. For example, how long should one patient have an artificial heart while others are waiting? New medical technology has become so ingrained that once life-saving technology is introduced, we tend

FOCUS

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FOCUS March 1994

to consider it a right, not a privilege. Perhaps we need to think more seriously to begin with about what sorts of technologies we want to develop. But how can we limit scientific inquiry? We can't—but we can debate what we as a society are willing to fund, just as we now debate whether we really need a supercollider.

The central issue of allocation is coming to terms with the fact that no matter how efficient or economical we make health care, we will never be able to do everything for everyone. Choices among competing health needs, sometimes tragic, are moral and ethical, not medical. They are best made through the democratic process by all of us—as was accomplished in Oregon—rather than through the current health care reform process, which is being conducted behind closed doors.

Privatized Mental Health Care

Wisor RL. Community care, competition and coercion: A legal perspective on privatized mental health care. *American Journal of Law and Medicine*. 1993; 19 (1-2): 145-175.

Massachusetts state officials are privatizing mental health care in response to pressures to provide better care at lower cost. According to an overview of this experiment, which includes a detailed history of mental health care in the United States, the plan aims toward achieving the ideal of efficient and effective community care by closing outmoded state hospitals and transferring patients into privately owned and operated community-based alternatives.

The foundation for this change was laid by the 1986 *Brewster* decree. The decree ordered the creation of three components: new residences and acute care beds in private general hospitals to provide former state hospital patients care in their own communities; treatment, training, and support programs to ensure clients transferred into the community continued to function successfully; and management services to develop, coordinate, administer, monitor, and evaluate the network of community programs.

By harnessing marketplace competition to encourage cost savings and quality, privatization uses resources in new ways to achieve higher quality and greater efficiency. It frees the government from providing care and enables it to concentrate on quality control. Its foundation—that patients are happier and more effectively treated in community versus institutional settings—is borne out by the Massachusetts experiment.

The Massachusetts plan improves the quality of short-term institutional care by creating more psychiatric beds in private general hospitals. This eliminates an historical inequity that relegated uninsured patients to remote state institutions while treating insured patients in community hospitals.

The peril of privatization is that "revolving door" patients—mentally ill patients who, functional at release, stop taking their medications and must be readmitted to hospitals again and again—may fall through the cracks of community care. Even more troublesome, is that under a privatized system, the quantity of acute short-term care beds is strictly limited, and providers may find themselves under pressure to release people not "dangerous enough" to meet commitment standards, but still in need of short-term care.

While these dilemmas are significant, privatization's promise can be achieved if the plan has sufficient staff support, programs, and services. To avoid a breakdown of the system, virtually all savings generated from transferring mental health care into private hands must be rededicated to the programs that keep patients functioning in the community.

Next Month

The National Association of Social Workers made news last summer when they became the first of the counseling professional organizations to put into its code of conduct ethical guidelines for attending the assisted suicides of clients. In the April issue of FOCUS, **Jerome A. Motto, MD**, an internationally recognized expert on suicide and Professor Emeritus of Psychiatry at the University of California San Francisco, discusses rational suicide in the context of clinical practice. He briefly recounts the recent history of rational suicide and explores the clinical approach to clients who wish to pursue this option.

Last spring, *Compassion in Dying* was founded in Seattle to facilitate physician-assisted suicide. Also in the April issue, **Susan J. Dunshee**, President of the Board of *Compassion and Executive Director of the Seattle AIDS Support Group*, writes about the organization's experience counseling terminally-ill people and their loved ones about suicide.



March 11, 1994

Kristine Gebbie
AIDS Policy Coordinator
Executive Office of the President
750 - 17th Street NW, Suite 1060
Washington, DC 20503

Dear Ms. Gebbie:

We understand from Representative Unsoeld's office that you will be attending the meeting she is hosting for us tomorrow to discuss health care reform for people with disabilities. To confirm the information you may have received from her, that meeting will take place at 3:00 on Tuesday, April 12 in Room 1604 of the Longworth Building.

The AIDS/health care advocates in our contingent will include myself and Sue Tupper from the Northwest AIDS Foundation, Lesli Boyd-Morse and Richard Hicks from the Olympia AIDS Task Force, Dr. Ed Noonan, a Seattle physician specializing in AIDS treatment, and a representative from the AIDS Action Council. We will be joined by the delegates from Washington state and their aides. We know that your schedule prevents you from arriving till around 3:30, but since we don't expect you to give a presentation, that should still allow opportunity for you to speak with members of our group, if you wish.

For your reference, I am enclosing a fact sheet which stresses the health care reform principles we feel are imperative for the wellbeing of people impacted by HIV and AIDS. If you have any questions, please call my program assistant, Tracy Huddleson, at (206) 860-6304. We appreciate your interest and concern in this vital matter, and look forward to discussing it with you soon.

Sincerely,

A handwritten signature in cursive script that reads "Liz Smith".

Liz Smith
Director, Public Policy and Communications
Northwest AIDS Foundation



BROWARD HOUSE

*Atttime - I
think I wrote
to him, but I'm
not sure ---*



FEB 25 1994

Steve

February 22, 1994

Ms. Kristine Gebbie
National AIDS Policy Coordinator
Executive Office of the President
750 17th Street N.W., Suite 1060
Washington, D.C. 20503

Dear Ms. Gebbie:

I write to tell you how excited we are that you will be in Broward County on April 9. We appreciate all that you have done for people living with AIDS, and the strides you have made in heightening public awareness concerning this critical health issue.

While you are in South Florida, we invite you to visit Broward House, an AIDS service organization which has been in existence since 1989, providing assisted living to individuals in the community with AIDS/HIV disease. Broward House is the only Adult Congregate Living Facility licensed by the State of Florida exclusively for men and women with HIV disease in Broward County. In addition to assisted living, Broward House provides case management, education and outreach to homeless individuals. The facility is looked upon as a model for other such housing facilities in the nation, and we frequently are called upon to share our experiences and procedures with other agencies.

Again, we extend a warm welcome to you and hope that your schedule may permit a visit to Broward House. Please feel free to contact me at (305) 522-4749 for further information.

*117m 3rd
(Federal Hwy 117m 3rd
Cor. Hwy)*

Sincerely,

Thomas J. Shidaker
Administrator

TJS:ml

P.O. Box 350367
Fort Lauderdale, Florida 33335
305-522-4749

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Memorandum

Memo to: Andrew Barrer, Office of AIDS Policy Coordinator

From: Nina Oligino, Hill & Knowlton

Subject: Broward County Visit

Date: March 22, 1994

Copies: Jeff Trammell

Monday April 11, 1994

8:00am-9:00am

Breakfast

LOCATION:

Riverside Hotel, 620 East Las Olas Boulevard

ATTENDEES:

Wayne Sheppard, Director, HIV/AIDS Support Services
Betsy, Koski, Special Project Coordinator, HIV/AIDS Support Services
James W. Jordan, Jr., Vice President, North Broward Hospital District &
Chair, HIV Health Services Planning Council
Carolyn N. Graham, Director, Broward County Human Services Department
Allan H. Terl, Esquire, Private Attorney, PWA Governors Red Ribbon Panel
on AIDS, author of AIDS AND THE LAW, member of
HIV planning council
Eugenie Suter, Director Office of Intergovernmental Affairs
Dennis Myers, Special Projects Coordinator, Office of Intergovernmental Affairs
Jeff Trammel, Senior Vice President, Hill and Knowlton
Nina Oligino, Senior Account Executive, Hill and Knowlton

ALSO INVITED:

Commissioner Gerald Thompson (District No. 1)
Commissioner Sylvia Poitier (District No. 2)
Commissioner John P. Hart (District No.3)
Commissioner Scott Cowan (District No. 4)
Commissioner Lori Nance Parrish (District No. 5)
Commissioner Suzanne Gunzburger (District No.6)
Commissioner John E. Rodstrom, Jr. (District No. 7)

Senator Bob Graham (D)
Senator Connie Mack (R)
Representative Peter Deutsch (D-20th)*
Representative Harry Johnston (D-19th)
Representative E. Clay Shaw (R-22nd)
Representative Alcee Hastings (D-23rd)

Jim Naugle, Mayor of Ft. Lauderdale
Carlton Moore, Vice Mayor

*Representative Peter Deutsch's wife is very involved in fundraising for AIDS treatment and we may extend the invitation to her as well as the other Congressional spouses

9:15am-9:45am

LOCATION:

ATTENDEES:

Tour of Pediatric AIDS facility
Children's Diagnostic and Treatment Center at 417 S. Andrews Avenue
same as above plus see attached list of possible additional attendees (those marked are certain to be in attendance)

9:45am-10:15am

LOCATION:

ATTENDEES:

Press briefing
on site at the facility (room TBD)
Sun Sentinel
Miami Herald
Miami Sun Tattler
Broward Bureaus of the South Florida TV stations (4)

MEMO

TO: Mr. Wayne Sheppard, Director
Broward County HIV/AIDS Services

FROM: Stormy Schevis, Manager
Comprehensive Pediatric AIDS Project

DATE: March 9, 1994

RE: Kristine Gobbie's visit to CDTC - April 11, 1994

Thank you for your assistance in facilitating Ms. Gobbie's visit to Children's Diagnostic & Treatment Center on Monday, April 11, 1994. Listed below are the Comprehensive Pediatric AIDS Project staff who may be present that morning.

Please let me know if you need any further information.

STAFF:

✓ Susan M. Widmayer, Ph.D.	CDTC Director
✓ Richard M. Beach, M.D., Ph.D.	CPAP Medical Director
✓ Joni Leterman, M.D.	CMS Medical Director
	CPAP Consulting Physician
✓ Beverley Curtis, M.D.	CDTC/DEI Medical Director
✓ Stormy Schevis	CPAP Project Manager
Tracee Bellio, M.S.	CPAP Coordinator
Vickie Tutunick, M.S.W.	CPAP Social Service Coordinator
Anne Kogan, R.N.	CPAP Clinic Coordinator
David Lord, M.Div.	CPAP Social Worker
Marie Brown	CPAP Social Worker
Cay Perr	CPAP Social Worker
Arlene Gurwich, M.S.	CPAP Social Worker
Camille Brouillard, M.S.W.	CPAP Social Worker
Kim Purinton	CPAP Social Worker
Pam Munger, R.N., B.S.N.	CPAP Nurse Case Manager
Tara Strawbridge, R.N., B.S.N.	CPAP Nurse Case Manager
Kristin Halldors, R.N.	CPAP Nurse Case Manager
Betty Bryant, L.P.N.	CPAP LPN Case Manager
Linda Merritt, R.N., B.S.N.	CPAP Nurse Case Manager
	ARIEL Study Coordinator
Naomi Rosario	CPAP Secretary
Jane Tamburo	CPAP Secretary
Jamie Blood	Family Resource Assistant
Sharon Neal	Family Resource Assistant
✓ Evelyn Kendricks	Family Resource Assistant

1. DESCRIPTION OF THE EPIDEMIC IN THE EMA

Broward County has the second largest number of reported AIDS cases in the State of Florida. As of September 30, 1993, there were 5,107 cumulative adult cases which equate to an adult incidence rate of 369.2 per 100,000 population, up from 368.2 September 30, 1992. The total cumulative cases has increased fifty-one percent in the past two years, twenty-seven percent in the past year, and represents sixteen percent of all reported cases statewide.

In addition to the adult cases, there are 107 pediatric cases, up from 85 last year. However, this number does not accurately reflect the pediatric HIV epidemic, since there are presently 460 children receiving care through the Comprehensive Pediatric AIDS Project at Children's Diagnostic and Treatment Center. During FY 92-93, 562 children utilized these services compared to 321 in FY 91-92. Twenty to twenty-five new patients are referred monthly.

With respect to the pediatric cases, 82% are African-American, 14% Anglo/White, and 4% Hispanic. Ninety-eight percent of the pediatric cases has a mother with AIDS/HIV or had AIDS/HIV and two percent transfusions. Eighty-six percent of the pediatric cases are under five years of age, with fourteen percent from age five to twelve.

Of the adult cases 4,214 are male and 893 are female or 17.5% (up from 16.2% in 1992 and 14% in 1991). This compares to 11% of

cases nationally. African-Americans represent 15.5% of the population in Broward County but account for 37% of the AIDS cases, which has increased from 30% in 1990 and 34% in 1992. The percentage nationally is 30%. Anglo/Whites account for 57% as compared to 60% in 1992 and 61% in 1991. Percentage of cases among Hispanic-Americans has remained constant since 1991 at approximately six percent, substantially lower than 17% nationally.

The patient risk behavior categories reflect 52% as homosexual or bisexual as compared to 55% in 1992, 19% are IV drug users (the same as last year, but down from 22% in 1990), 6% homosexual and IV drug users which has remained fairly constant, 19% heterosexual, compared to 18% in 1992 and 17% in 1991.

A February 1993 study by the Broward Coalition for the Homeless estimates a homeless population of 6,076. Of this number, ninety-seven were determined to be HIV infected by agencies who surveyed HIV status. This figure is considered to be much lower than actual numbers infected, since two of the largest agencies providing services to this population did not inquire as to HIV status. A new outreach program which provides education and referral for HIV testing is finding increasing numbers of homeless persons who are HIV infected, and we anticipate a substantial increase in this population. One segment of this population increasing in numbers, includes runaway adolescents who

are high risk because of their substance abuse and/or prostitution.

The largest number of reported AIDS cases is in the 30-39 age group with forty-four percent, twenty-three percent in the 40-49 age group and twelve percent over 49.

In 1992, Broward County reported 147 new cases of tuberculosis for an incidence rate of 11.3% per 100,000 total population (up from 9.38 in 1985). The non-white communities are most drastically affected, accounting for 61.2% of new cases in 1992, with an incidence rate of 39.7 per 100,000 for non-whites as compared to 5.3 per 100,000 for whites. Final data is not yet available for 1993, however 110 new cases were reported in Broward County during the first ten months.

There are currently approximately 250 patients with tuberculosis in treatment, with an additional 500 who have tested positive but show no signs of active disease, or have had close contact who are on preventive treatment.

While there is no mandatory HIV testing of TB patients, samples provide an estimate that almost thirty percent of all TB cases in Broward are also HIV-positive and that more than 10% of AIDS patients also have TB. Multi-drug resistant TB has also begun to appear in Broward County. The medication compliance rate in Broward is low, with less than fifty percent of patients completing

therapy. In an effort to improve compliance and more effectively manage patients with TB and HIV disease, a new senior physician and public health nurse was funded in our 1993 Ryan White plan. This medical team provides comprehensive epidemiologic and medical care at each of four TB clinics and the Northwest Health Center, allowing patients to have both problems addressed at a single site for the first time.

According to the 1990 census, approximately 10.2% of the total population is below the federal poverty level. In 1993, Broward County had an incidence rate of 107 per 100,000 population for Syphilis, Gonorrhea, and Congenital Syphilis, and an incidence of 138 per 100,000 births to mothers 19 and under, with non-whites accounting for 18.4% of these births in Broward County.

As noted above, African-Americans represent a disproportionate percentage of AIDS cases in Broward County. Demographics on hospital admissions for patients with HIV disease and for those in public outpatient primary health care clinics demonstrate the historical problem of getting the African-American community tested for HIV, enrolled in early medical intervention programs, and providing regular outpatient primary care services.

At the two largest tax assisted hospitals in Broward County, with the largest number of HIV admissions, African-Americans represented 55% and 49% of total admissions. This compares to 37%

of total cumulative AIDS cases and 15.5% of total population. African-Americans with HIV disease account for 31% of HIV patients at the Northwest Health Center, which has the largest number of active AIDS cases in the County, and 32% of the HIV caseload at the Broward County Primary Health Care Clinics.

Extra efforts have been made the past two years, especially with added outreach efforts through a cooperative Ryan White Title III grant to provide early intervention within the African-American communities.

One extremely hard to serve population in Broward County is the Haitian-American population. Discrimination, even within the non-white community, undocumented resident status of many, religious and cultural differences, and language barriers have contributed to this population not accessing available services. These factors, especially fear of discrimination, prevents many in this group from even self-identifying as Haitian-American; therefore, statistical information is lacking for this population. There are large concentrations of Haitian-Americans in the northwest section of the City of Fort Lauderdale, as well as in western Pompano Beach, in the northern section of Broward County. Two community health centers (Broward Family Health Center in Fort Lauderdale and Sunshine Health Center in Pompano Beach) have implemented effective outreach programs within these communities thanks to a Ryan White Title III grant, and both receive Title I

funding for primary medical care services. These efforts along with an increase in a culturally sensitive staff have significantly increased the number of Haitian-American receiving services at these centers. This increase in caseloads have significantly impacted these centers with a need for additional medical and case management personnel to meet demand.

As noted above, the percentage of females continues to increase in Broward County, accounting for 17.5% of total cases in 1993 (up from 14% in 1991). Data from the two largest tax assisted hospitals show that females accounted for 26% and 35% of total HIV inpatient admissions. While it is acknowledged that female patients have unique medical problems that may account for greater hospital admissions, part of this may be due to the historical lack of specialty physician services and regular preventative primary care services for women, especially women with children.

Lack of private specialty physicians within the community willing to accept Medicaid patients, lack of adequate transportation services, and lack of child care services, have been major barriers for women in accessing service. Title I funds this past year have expanded transportation services, specialty physician services for women, including gynecological services at the same site where their children are receiving medical care.

One serious problem historically has been the inability of providing medical care for adolescents without parental consent. Local and statewide advocacy efforts have been successful in addressing this obstacle. With the State of Florida now classifying HIV as a sexually transmitted disease, medical treatment may be provided without parental consent. Children's Diagnostic and Treatment Center continues to increase treatment and support services to this underserved population. Further efforts are needed especially within the large group of runaway adolescents.

POSITIVE

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TOM MARTIN

P.O. Box 25580
Tamarac, FL 33351
305-525-9032



POSITIVE
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FEB - 7 1994

February 1, 1994

Q. Lee

W. Steve Lee
Executive Office of the President
National AIDS Policy Office
750 17 Street N.W. suite 1060
Washington DC 20503

Dear Mr. Lee,

I am writing to confirm our phone conversation of 1/28/94. I had called your office to inquire about Kristine Gebbie and her South Florida appearance on April 9, 1994. I have an AIDS talk show that airs each Sunday and I would love to have Ms. Gebbie on my April 10, 1994 show.

You had stated that the trip was not entirely planned out yet but, you might be interested in the show. I hope we will be able to coordinate with each other and have President Clintons AIDS Czar on our show.

Let me tell you a little about myself. I am a PWA and have been for about two and a half years. Rather than becoming depressed about my diagnosis my life has become a wonderful experience that I now thank HIV for creating. I have enclosed some information on the POSITIVE PERSPECTIVE SHOW and I hope that will help you in your decision in joining us on the air.

I started the show (First week of airing is February 6, 1994) mainly due to the lack of knowledge so many people have. I have lost a great many friends and our country has lost a great many people simply because they did not have the proper information about maintaining their own health. Some people are even concerned with disclosure if they walk in to an HIV specialists office or an AIDS service agency. Hopefully people will feel more comfortable tuning in their radios in the privacy of their own homes. Also, if they have questions about HIV they can call in and not disclose who they are. The show airs on Sundays at 7:00pm and runs until 8:30pm. We have guests, call in segments, news, prevention education, ect. Social Security has an employee on the show each week to answer any questions that may come up about SSD or SSI.

2100 NW 21st Ave
Ft. Lauderdale, FL
(305) ~~525~~
733.1400

POSITIVE

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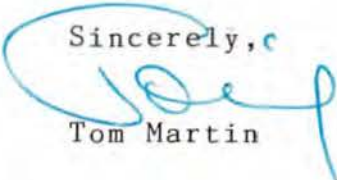
I am excited about Kristine Gebbie coming to South Florida. I think this would be a great opportunity for her to share with our listeners what exactly her job is. She can also explain what she plans on doing in the future as the AIDS Czar. If you like she can also talk about President Clinton and his health care reform.

I am very easy going. I feel some of the topics mentioned above would be great for people to hear - if you have other ideas on what you would like to discuss on the show please feel free to share them. I am open to all ideas.

Once again, The Positive Perspective Show airs on Sundays on WFTL 1400am at 7:00pm. I am hoping we can have Kristine Gebbie on our April 10, 1994 show from 7:00pm to 8:30pm. We can have her speak alone or we can open the phone lines for conversations - whichever you prefer.

I thank you for taking the time to consider this. I look forward to meeting you both on April 9, 1994 at the awards banquet and hope to have you on the show April 10, 1994. If you have any questions please feel free to call me at 305-525-9032.

Sincerely,



Tom Martin

POSITIVE PERSPECTIVE

POSITIVE PERSPECTIVE
P.O. BOX 25580
TAMARAC, FLORIDA 33351
(305) 525-9032

* South Florida has the THIRD highest prevalence rate of AIDS in the United States.

* Estimates are 1 in 60 people in Broward County are HIV positive. There is no way to estimate how many people are affected when one in sixty are infected with HIV.

There seems to be a stigma, even today, attached to HIV. People, both affected and infected, need a safe environment to learn, discuss and share information about HIV. A large number of people will not enter an AIDS service agency or even an HIV physicians office because of the stigma attached.

These individuals, affected and infected by HIV, need to be educated about the virus, their health, and their future.

Unfortunately, because these infected and affected individuals are isolated from information that can help keep them alive, healthy and educated, we are seeing an increase in AIDS related deaths, illnesses and hospital stays that may have been avoided.

The best way to avoid the complications of HIV is through education. One of the best ways to educate these isolated individuals and their families is in the privacy of their own home.

What could be more private than becoming educated in your own home or car by simply tuning in your radio? This way **ALL** residents, infected and/or affected by HIV, will have the means of receiving information and education without the fear of exposing themselves.

POSITIVE PERSPECTIVE will be a weekly talk show on AM Radio (WFTL 1400). We will have frank discussions about HIV and AIDS. We will also discuss the prevention of transmission of HIV and other sexually transmitted diseases. One goal of **POSITIVE PERSPECTIVE** is to help avoid further transmission of the virus as well as educate those already infected.

POSITIVE PERSPECTIVE will cover prevention of transmission, nutrition, exercise, health matters, opportunistic infections, prophylactic medications, medical needs, psychological needs, news, current events and social services available to HIV infected and affected individuals.

POSITIVE PERSPECTIVE will run for thirteen consecutive weeks with an option to continue for one year. Response and calls to the show will also be tracked by **POSITIVE PERSPECTIVE**. The purpose of tracking is to assure that we are reaching the entire spectrum of residents that our area is fortunate enough to have.

POSITIVE PERSPECTIVE plans to air on Sundays 7:00pm - 8:30pm on 1400AM, WFTL.

PROMOTION

Positive Perspective will be promoted through many different avenues. This way we feel we can reach a spectrum of residents in our broadcast range.

WFTL has committed themselves to numerous public service announcements to promote the show.

We will also have press releases sent to ALL local newspapers, television stations and public news sources. We feel that these resources are all willing to have pre-air coverage of the show. This will help inform the community at large.

We plan to distribute thousands of flyers at local bars, schools, beaches, AIDS and social service agencies, hospitals, and physician's offices.

We also feel word of mouth will spread the news of this much needed educational show.

Of course, all of this depends on our sponsor's and advertiser's response. We look forward to hearing from you. As always, we encourage your views and comments.

the host

My name is TOM MARTIN. I am a 26 year old Broward resident. I was diagnosed HIV positive over two years ago.

Since that time I have been a volunteer at Center One (Broward County's AIDS service agency). I provide one on one counseling, for both affected and infected individuals. I facilitate two support groups. I am a hotline volunteer. I am also on the speakers bureau (which gives me many opportunities to do AIDS education with wonderful groups of teens and adults). I do client intake. This is the process through which an HIV positive person registers as a client of the center. One on one counseling occurs often in this situation. I am also on a fundraising committee for Center One.

I feel I am fortunate to work for Broward Community College as an AIDS consultant. B.C.C. has an outstanding HIV/AIDS education program. I am proud to be a part of their educational/outreach sessions.

I have also been fortunate enough to speak for the American Red Cross (Teen AIDS Conference) in West Palm Beach, as well as many other groups. I also speak with teens in psychiatric wards and at local hospitals. I am able to do this through Katy Yankie, Henderson Mental Health's AIDS education coordinator.

Through the unwavering love and support of my family and friends, I am able to cope with my HIV diagnosis extremely well. I have been taught so much by so many and I feel this is what caused such a positive perspective about my life - and acceptance, ultimately, of my death - many, many decades from now!

HIV has taught me many valuable lessons about living. I feel it is a tragedy that so many people do not have the opportunities to learn to love their lives - no matter what their sero-status may be.

I look forward to having a number of educational guests on the POSITIVE PERSPECTIVE show. I know we will be able to make a difference in many peoples' lives. I thank you for caring and I hope you will join us for a POSITIVE PERSPECTIVE.

Sincerely,

TOM MARTIN

CenterOne

3015 N. Ocean Boulevard • Suite 111
Fort Lauderdale, Florida 33308

Telephone: (305) 537-4111
Fax: (305) 537-3344



Since 1984

Ms. Kristine Gebbie, RN
750 17th Street
Suite 1060
Washington, DC 20503

Solve
How do I
these days
fit in?
RECEIVED
FEB 22 1994

Dear Ms. Gebbie,

As a Registered Nurse and CenterOne Board member, I am thrilled that you will be the keynote speaker for our first dinner. I would like to take this opportunity to also plan a reception in your honor for the nurses of South Florida. Your visit would be a fine opportunity for the nurses to meet and honor one of own. Your visit has, in fact, also caught the interest of some of the students at Barry University in Miami Shores.

They have asked me to extend an invitation on their behalf for a visit to the school for later in the day. Perhaps a continental breakfast Sunday morning at Pier 66 for the nurses would be appropriate? I would be more than happy to coordinate the planning and arranging of the event. I can also be the liaison for the students with Professor Michael Melody if that is acceptable to you and your staff.

I will certainly approach the Nursing organizations for assistance in underwriting the breakfast, but may I ask if there are any restrictions in raising funds for this? I would not wish to embarrass you or your office in any way. I can be reached @ 305/920-7715 during the day and in the Trauma ICU at Jackson Memorial 305/585-1168 (7p - 7a) for any questions that you or your staff may have. I am looking forward to the Center One dinner and I'm very excited about the possibility of the breakfast with the nurses. With my best wishes, I am

Respectfully,

Siobhan McLaughlin
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