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The Keystone Center

MEMORANDUM

To: Participants of the Keystone Exploratory Session on HIV-Related Health Care Financing and Service Provision Systems

From: Abby Dilley

Subject: Materials for the August 7th Meeting

Date: July 30, 1997

Enclosed you will find preparatory materials for the August 7th meeting, including a tentative agenda, participant list, and background paper describing the major publicly funded programs that provide care and related services to people with HIV.

As mentioned previously, the purpose of the meeting is to discuss the changing context within which the public HIV-related health care financing and service provision system is functioning; whether these changes are compelling enough to merit an extensive discussion regarding if and how these systems might be modified to effectively meet the needs of those with HIV; and, if a collaborative, consensus-building dialogue is the appropriate mechanism for exploration and development of recommendations concerning these issues. The agenda is structured to discuss these issues in the morning and the early part of the afternoon. If the group commits to proceeding with a policy dialogue, then several additional questions concerning the structure of this effort need to be addressed. These structural issues will be the focus of the remainder of the afternoon.

An updated participant list also is included. Enthusiasm and attendance for this session is excellent. Some potential participants (indicated with an asterisk) are unable to attend, but indicated a strong interest in being involved in a dialogue project should we move forward.

The background paper, written by Jeff Levi, offers information on the major publicly funded programs that provide care and related services to people with HIV. The information focuses on who is eligible, how many people are being served, what services are being provided, and what they are costing. We will not be devoting a great deal of attention to this paper during the course of the meeting. Primarily it is meant to provide background to the discussion concerning context

for a potential policy dialogue. If the group decides to proceed with a dialogue, the paper will be considered as a potential resource for more detailed discussions, depending upon how the group decides to use this information.

As a reminder, the meeting is taking place at the Omni Shoreham Hotel located at 2500 Calvert Street, NW and is a short walk from the Woodley Park/Zoo metro stop on the red line. The hotel's telephone number is 202-234-0700.

If you have any questions, please call me at 202-783-0248. We very much look forward to a productive session next Thursday.

**Keystone Exploratory Session on Public HIV-Related
Health Care Financing and Service Provision Systems**

*The Omni Shoreham Hotel
Washington, DC
August 7, 1997*

Draft Agenda

- 8:00 a.m. Coffee and Informal Discussion
- 8:15 a.m. Welcome, Introductions, Meeting Background, Meeting Objectives, Ground Rules, and Agenda Review
- 9:30 a.m. Context for a Potential Policy Dialogue Questions
- 10:30 a.m. Break
- 10:45 a.m. Policy Dialogue Questions:
- 1) Does the context create a compelling case for reviewing and discussing the current public financing and service provision systems to consider what, if any, modifications are appropriate?
 - 2) If yes, then what are the key issues and questions that would shape this review and discussion?
- 12:00 p.m. Lunch
- 1:00 p.m. Continuation of Policy Questions Discussion:
- 3) What does a policy dialogue look like?
 - 4) Would a collaborative, consensus-building policy dialogue be a constructive vehicle for conducting this discussion and developing policy recommendations?
- 2:00 p.m. If a consensus-building policy dialogue is determined to be appropriate and desirable, then several issues need to be addressed:
- 1) Dialogue goals and outcomes
 - 2) Key questions or issues to frame the dialogue
 - 3) Participants
 - 4) Ground rules
 - 5) Background materials
 - 6) Funding
 - 7) Time frame and meeting schedule
- 3:15 p.m. Next Steps
- 4:00 p.m. Adjourn

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DRAFT Background Paper DRAFT

for

Keystone Exploratory Session

on Public HIV-Related Health Care

Financing and Service Provision Systems

August 1997

The purpose of this paper is to provide background information on the major publicly funded programs that provide care and related services to people living with HIV. It is meant to provide a snapshot of these programs as they are currently constructed: who is eligible, how many people are being served, what services are being provided, and what they are costing. However, neither these programs nor the epidemic they are responding to are static. Indeed, with newly articulated standard of care guidelines, evolving demographics of who is affected by this epidemic, and decreased mortality rates, publicly funded HIV-related programs face new challenges. It will be for the Keystone Exploratory Session on Public HIV-Related Health Care Financing and Services Provision Systems to determine what, if any, policy questions need to be addressed as a result.

This draft paper was supported by a grant from The George Gund Foundation.

I. Background

Table 1: Estimated Public Spending on HIV-related Care: FY 1997

Source	Program/Agency	FY 1997
Federal Resources ¹	Medicaid ²	\$1,800,000,000
	Medicare ³	\$1,300,000,000
	Ryan White CARE Act	\$996,252,000
	SAMHSA Block Grant	\$52,928,711
	Veterans Administration	\$350,000,000
	HOPWA	\$196,000,000
<i>Total Federal Resources</i>		\$4,695,180,711
State Resources	Medicaid match	\$1,500,000,000
	CARE Act Title II Match	\$166,638,155
	Discretionary ADAP contributions	\$109,055,397
	Estimate of additional State-only money ⁴	?????
<i>Total State Resources</i>		\$1,775,693,552
Total Federal/State Resources⁵		\$6,470,874,263

¹The federal resources category does not include spending on health care for federal employees through the Office of Personnel Management and the FEHBP program, nor does it include DoD spending for active duty military personnel with HIV. In addition, this does not include SSI and SSDI payments, since these are income supports, not the provision of direct primary care or supportive services.

²Medicaid spending is an actuarial estimate.

³Medicare spending is an actuarial estimate.

⁴Efforts are under way to arrive at an estimate of state-only spending beyond ADAP.

⁵This does not include local government spending.

Revised Table 1: Estimated Public Spending on HIV-related Care: FY 1997

Source	Program/Agency	FY 1997
Federal Resources ¹	Medicaid ²	\$1,800,000,000
	Medicare ³	\$1,300,000,000
	Ryan White CARE Act	\$996,252,000
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	Veterans Administration	\$350,000,000
	HOPWA	\$196,000,000
<i>Total Federal Resources</i>		<i>\$4,695,180,711</i>
State Resources	Medicaid match	\$1,500,000,000
	Discretionary ADAP contributions	\$109,055,397
	Estimate of additional State-only money ⁴	\$281,548,452
<i>Total State Resources</i>		<i>\$1,890,603,849</i>
Total Federal/State Resources⁵		\$6,585,784,560

¹The federal resources category does not include spending on health care for federal employees through the Office of Personnel Management and the FEHBP program, nor does it include DoD spending for active duty military personnel with HIV. In addition, this does not include SSI and SSDI payments, since these are income supports, not the provision of direct primary care or supportive services.

²Medicaid spending is an actuarial estimate.

³Medicare spending is an actuarial estimate.

⁴Estimate derived from information submitted by the states to HRSA for FY 1996. It is assumed that this number will be at least at this level in 1997.

⁵This does not include local government spending.

Each year, the public sector devotes about \$6.5 billion to the provision of HIV-related primary care and related services, paying for everything from prescription drugs and doctor's visits to case management and housing. The bulk of these expenditures are through the poverty-based Medicaid system as well as Medicare coverage for the long-term disabled. The Ryan White CARE Act, perhaps the most visible of the AIDS-related programs, pays for less than one-sixth of this amount.

This \$6.5 billion investment is a substantial commitment of public resources. With the exception of the CARE Act and HOPWA, however, these programs are not specifically designed for HIV-positive individuals. They are entitlement programs: people with other diseases meeting similar eligibility requirements (based on status, income, and/or level of disability) also have access to Medicaid, Medicare, Veterans Administration (VA) benefits, etc. The CARE Act and HOPWA are designed to fill gaps in the entitlement programs and make their use more efficient by covering supportive and wraparound services not normally covered by them or by supplementing entitlement services that may be capped.

Despite this major public commitment of resources, many people with HIV are going without care. The precise number is not known, but there is more than anecdotal information to support this. The measures taken in some states to restrict access to the AIDS Drug Assistance Programs (run by the states with funding received, at least in part, under Title II of the CARE Act) are one indication of a shortfall in availability of care.⁶ Another indicator is the number of people who are diagnosed with HIV relatively late in their disease progression⁷.

What is the universe of people who need care? The Centers for Disease Control and Prevention (CDC) estimates that between 650,000 and 900,000 Americans have

⁶See "State AIDS Drug Assistance Programs: A National Status Report on Access," prepared by the National Alliance of State and Territorial AIDS Directors and the AIDS Treatment Data Network. It reports that 35 states took "at least one emergency measure in the last year in response to the crisis in ADAP funding..." and that despite these measures, 11 states were predicting a "shortfall in FY 1997." Recent congressional action to dramatically increase funding for ADAP may address this aspect of the problem.

⁷According to CDC surveillance data, 38 percent of those who were diagnosed with AIDS in 1996 met the case definition because they were already meeting clinical criteria associated with AIDS, not because they had a low CD4 count. Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Report*, 1996; 8 (no.2): 17.

HIV.⁸ Of those, about 500,000 people know their HIV status. Ideally, all Americans with HIV, according to the current standard of care, should be in a system of care. Even if decisions are made to delay therapy, they should have access to primary care and related services that assures they are closely monitored (and have primary prevention messages reinforced).

How many people with HIV are now being served? In the aggregate this is not known. The Health Care Financing Administration (HCFA) estimates that approximately 108,000 people with AIDS (as opposed to all HIV-positive recipients) are being served by Medicaid, and about 40,000 by Medicare. The Health Resources Services Administration (HRSA) estimates that the Ryan White CARE Act serves more than 300,000 people. But these are not unduplicated figures; one individual may actually be served by all three programs, thus making it even harder to estimate how many people are actually being served.

It should be remembered, as will be discussed in more detail later, that the principal sources of HIV-related care -- Medicaid and Medicare -- in most cases require that a person with HIV *already be disabled* before accessing those programs, even at a time when new treatments offer the hope of delaying or preventing disability.⁹ In the early years of the epidemic, when medical interventions were few and treatment essentially began around the time of disability, these restrictions on eligibility were less of a problem. But as earlier and earlier intervention has become the standard of care, Medicaid and Medicare are less often the source of initial care for people living with HIV and without insurance. This has increased the burden on smaller programs, such as the Ryan White CARE Act, where disability has not been a pre-condition for access. This has been most visible in the AIDS Drug Assistance Programs (ADAPs) mentioned earlier, but it has had an impact throughout the four service-delivery titles of the CARE Act.

Clearly, not all people with HIV are or should be dependent on the public sector for health care financing. The private insurance market continues to play an important role in assuring access to primary care for people with HIV. Again, there is relatively little information about the income level, insurance coverage, etc. of people with HIV. However, even those who are employed and have private health insurance may find

⁸JAMA 1996; 276; 120-31.

⁹There are significant exceptions. Poor women with HIV may already be on Medicaid if they are AFDC-eligible (now TANF -- Temporary Assistance to Needy Families); some elderly Americans with HIV may have been eligible for Medicare prior to being disabled.

themselves unable to meet the costs of their HIV-related care without some public assistance. For those with early HIV choosing to take advantage of the new standard of care, pharmaceutical costs alone could exceed \$12,000 to \$15,000 a year. Many with private insurance do not necessarily have comprehensive plans that include prescription drugs; or the drug benefit may be capped well below the \$15,000 level. Even for individuals with a substantial income, these are high costs to incur.

But it should also be remembered that the demographics of HIV suggest that the epidemic is increasingly affecting a population more likely to be uninsured, living in poverty, substance abusers, and racial and ethnic minorities. Available survey data suggest a high proportion of people with HIV and AIDS are dependent on the public sector.¹⁰ This combination of factors -- the demographics of HIV *and* the weakness in private insurance coverage for those in the private market -- place a large burden on the public sector.

II. New challenges

There are three factors that have recently applied additional pressure on the existing HIV care financing and delivery system: the new standard of care for HIV treatment; the changing demographics of the epidemic; and the decline in mortality among people already diagnosed with AIDS.

- *New standard of care.* In June 1997, the Department of Health and Human Services issued draft treatment guidelines for HIV.¹¹ The guidelines addressed the new

¹⁰According to the AHCPR-funded AIDS Cost and Services Utilization Survey, 21.4 percent of those who were HIV infected and symptomatic were uninsured; 49.5 percent were dependent on public insurance. For those with full-blown AIDS, the percentage with no insurance was 11.9 percent; public insurance was at 62.3 percent. These data are more than six years old and more recent data are expected shortly from a new AHCPR study. More current data from the CDC's Supplemental HIV/AIDS Surveillance Study confirms that 15 percent of people with AIDS have no insurance. An HIV Therapy Audit, performed by the consulting firm Scott-Levin, reported that in the first quarter of 1997, 316,890 HIV-positive patients were seeking treatment; 40 percent of these individuals were on Medicaid, the most common form of payment.

¹¹*Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents*, developed by the Panel on Clinical Practices for Treatment of HIV Infection convened by the Department of Health and Human Services and the Henry J. Kaiser Family Foundation.

promise offered by combination antiretroviral therapy that includes protease inhibitors. The draft guidelines suggest that very early treatment with combination therapy -- much earlier in disease progression than has been recommended in the past -- should be offered as the standard of care. While each patient's optimal treatment regimen must be determined on an individual basis, the guidelines generally suggest intervention prior to symptoms and before substantial deterioration has occurred to the immune system. While it is unknown how many people will opt for earlier treatment, all people with HIV should be in a system of care that monitors their condition. There is general consensus that these guidelines will increase the proportion of people with HIV who will seek active treatment. And once initiated, combination antiretroviral treatment must be sustained for an indefinite period of time to assure optimal clinical outcomes and avoid development of drug resistant strains of HIV. This adds to the cost and burden on the existing HIV-related health care system, much of which has been constructed to provide much later intervention.

- *Changing demographics.* HIV is increasingly a disease related to substance abuse. It has been estimated that half of all new HIV infections are related to injection drug use.¹² This has increased dramatically since the beginning of the epidemic. In addition to being a population more dependent on the public sector for health care, substance abusers have broader health care and services needs -- most importantly for substance abuse treatment. This adds to the cost and complexity of the care and services needed by increasing numbers of people with HIV. Similarly, regardless of risk factor, the proportion of people with AIDS in the U.S. who are minorities and/or women continues to rise. These are populations historically underserved by the health care system and who require culturally appropriate and sensitive care.

- *Declines in mortality.* Mortality rates among people already diagnosed with AIDS have declined. The most recent reports indicate a decline of 19 percent in the first nine months of 1996 as compared with the first nine months of 1995. These reports reflect, in part, the success of new treatments and the programs designed to provide access to them. But these declines in mortality also place pressure on the care delivery system; there results a natural increase in the total number of people living with an HIV diagnosis.

The new standard of care, the changing demographics, and the decline in mortality require a discussion of whether and how publicly funded HIV care programs need to adapt to a new environment. The goal would be to assure the best utilization

¹²"IV Drug-Related HIV Spread Contained by Outreach, Needle Exchange," Reuters, May 28, 1997.

and stewardship of the \$6.5 billion in public funding so that all HIV-infected individuals can access appropriate care. While increased resources may be required to meet this goal, in times of severe fiscal constraints, it is also essential to make sure that the funds already in place have the maximum impact possible.

III. Key Programs

As a starting point for such a discussion, this paper will look at the key programs as they are currently constructed. To a large degree, this paper is a qualitative description of the current federally funded care and services programs. Unfortunately, there are relatively limited data associated with these programs -- from knowing with precision how many people are being served nationally by each program, to details about what proportion of spending is going toward different types of services or the stages of disease progression at which clients are entering the various care programs. Nonetheless, a clear sense of the mission and scope of each program can be given.

A. Medicaid

Medicaid is the largest single provider of HIV-related care. The Health Care Financing Administration (HCFA), which manages the Medicaid program in partnership with the states, estimates that over half of adults living with AIDS (about 108,000) and over 90 percent of children living with AIDS are covered by Medicaid. Still more people with HIV (but without an AIDS-defining condition) are enrolled in Medicaid. However, they represent a smaller portion of the overall HIV-positive population due to eligibility restrictions.¹³

Medicaid is a joint federal-state program, with basic eligibility and benefit standards set by the federal government, cost sharing between the federal government and the states, and significant discretion given to the states as to how they manage their programs. States have the option to move beyond the minimum benefits or eligibility standards, and can still receive a federal match for those optional costs.¹⁴ Current estimates are that overall AIDS-related costs for the Medicaid program are \$3.3 billion,

¹³HCFA's estimates of the number of people served by the Medicaid program are based on actuarial estimates, not an analysis of claims data.

¹⁴The federal portion of state Medicaid costs is determined by a formula that compares the state's average per capita income level with the national income average. The federal match cannot be lower than 50 percent or greater than 83 percent.

with \$1.8 billion accruing to the federal government and \$1.5 billion to the states.¹⁵

To be eligible for Medicaid, an individual must fit into certain legally specified categories *and* meet certain income and asset requirements. There are four categorical bases for eligibility:

(1) Those individuals who are indigent and aged, blind, or disabled who are recipients of Supplemental Security Income (SSI) from the Social Security Administration (SSA). This is probably the principal mechanism for accessing Medicaid for people living with HIV/AIDS. For people with HIV, this means those who are poor (in most states, less than \$484 a month in "countable" income)¹⁶ and meet the SSA's definition of disability for people with AIDS.¹⁷

(2) Low-income parents and children who, prior to welfare reform, would have been eligible for Aid to Families with Dependent Children (AFDC). Recent welfare reform legislation eliminated the AFDC program; however the eligibility criteria for the old AFDC program are still used to determine Medicaid eligibility. Thus, a family will receive Medicaid benefits even if it does not meet the income eligibility standards for the new Temporary Assistance to Needy Families (TANF), as long as it would have been eligible under old AFDC standards. This is the mechanism through which many HIV-positive, poor women and their children gain access to Medicaid.

(3) All pregnant women, infants and children up to age 6 with family incomes below 133 percent of the federal poverty level,¹⁸ even if this exceeds current or prior income standards in the AFDC/TANF category described above. More than half the states actually provide benefits at 185 percent (or higher) of the poverty level. This is a mechanism for accessing HIV-related care for pregnant women who wish to use antiretroviral therapy to reduce the likelihood of transmission of HIV from mother to child.

¹⁵This is an actuarial estimate of costs incurred by people with AIDS; the costs of those with HIV only are not known.

¹⁶Not all earnings are included in determining income levels for SSI eligibility.

¹⁷A simple diagnosis of AIDS is not sufficient to meet the Social Security Administration's definition of AIDS disability. A person with symptomatic HIV infection must show that this severely limits his/her ability to engage in substantial work activity.

¹⁸The federal poverty level for an individual is \$7,890.

(4) There is also an optional "medically needy" category, for those persons who do not meet the financial standards for the cash assistance programs, but meet the other categorical standards and have high medical costs. To be eligible under the "medically needy" category, individuals with HIV would have to meet the SSA's definition of disability for AIDS *and* meet their state's medically needy income and assets level. This category permits individuals to "spend down" to Medicaid eligibility. Individuals whose income might exceed requirements either for SSI or for the medically needy category could deduct medical expenses from their monthly income calculations. If out-of-pocket expenses brought these individuals below the medically needy income level, they would become eligible for Medicaid benefits. For people with HIV, with very high pharmaceutical and other primary care costs, this can be an important factor in determining eligibility. However, 16 states do not have medically needy programs.¹⁹ Among states with such programs, maximum allowable monthly income limits range from \$104 in Texas to \$2,000 in Hawaii.²⁰ But it must be emphasized that even within the medically needy category, individuals who spend down to meet income requirements must *also* be disabled.

States are required by federal Medicaid statutes to offer certain standard benefits. These are: inpatient hospital services; outpatient hospital services; prenatal care; physician services; nursing facility services for persons aged 21 or older; home health care for persons eligible for skilled-nursing services; family planning services and supplies; rural health clinic services; laboratory and x-ray services; pediatric and family nurse practitioner services; nurse-midwife services; certain federally-qualified ambulatory and health-center services; and early and periodic screening, diagnostic, and treatment (EPSDT) services for children under age 21.

States may also receive federal assistance for funding if they elect to provide other approved optional services. These include: clinic services; nursing facility services for the aged and disabled; intermediate care facilities for the mentally retarded;

¹⁹The states without medically needy programs are: Alabama, Alaska, Arizona, Colorado, Delaware, Idaho, Indiana, Louisiana, Mississippi, Missouri, Nevada, New Mexico, Ohio, South Carolina, South Dakota, and Wyoming.

²⁰Medically needy income levels for other high-incidence states are: New York, \$575/month; California, \$600/month; Florida, \$180/month; New Jersey, \$367/month. Thus, for example, an individual disabled with AIDS in California, could earn \$1,850 a month but still be eligible for Medicaid if he/she also had \$1,250 a month in medical expenses -- not an unusual amount for a person with HIV/ AIDS.

optometrist services and eyeglasses; prescription drugs; prosthetic devices; dental services; and TB-related ambulatory services and drugs. States may also provide home and community-based care to certain persons with chronic impairments, including AIDS. It should also be noted that states are not required to offer the same package of benefits to those eligible under the medically needy category as under the other eligibility categories.

One of the important elements of Medicaid is the variation in benefits and eligibility requirements. Thus, a person living with HIV/AIDS residing in one state may be eligible for a full range of comprehensive health care services but would be totally ineligible with the exact same set of circumstances if she resided in a different state -- or otherwise might face serious limitations on accessing those services. This variability in Medicaid coverage and enrollment policies has the potential for affecting health outcomes for a person with HIV. This variability also affects related programs, from the level of uncompensated care faced by public hospitals due to poor Medicaid coverage to the degree to which discretionary programs such as the Ryan White CARE Act must fill in gaps in Medicaid coverage. Thus, in some states CARE Act programs cover services and populations that might be covered by Medicaid in another state. This is especially telling in the variation in coverage and eligibility requirements within the ADAP programs across the states.²¹

Medicaid costs incurred by the states for HIV-related care vary greatly. This is affected by the level of covered benefits; the demographics of the epidemic in a state (those with higher numbers of substance abusers might have higher costs if substance abuse and mental health benefits are accessed); geographic differences in utilization and treatment patterns; and variations in reimbursement rates. Even in two states with relatively generous Medicaid programs, the costs vary greatly. While New York estimated that in FY 1993 average per patient costs were \$26,836, California estimated that costs for FY 1994 were about \$18,900. This is a 42 percent difference.²²

²¹Indeed, an analysis of jurisdictions identified by the National Alliance of State and Territorial AIDS Directors as having had to take emergency measures due to ADAP shortfalls shows that many of these states have no medically needy program or very restrictive income eligibility requirements.

²²New York State, "Medicaid Expenditures for Persons with AIDS, New York State, Federal Fiscal Year 1993"; and California Department of Health Services, "Demographics and Expenditures for Persons with AIDS 1980-94," *Medi-Cal Studies in AIDS*, No. 5, 1996. (It should be noted that there are relatively few states that have analyzed their HIV-related costs in detail. This makes it hard to estimate the overall cost of HIV to the Medicaid program; it also makes it difficult to assess differences in coverage and costs

An increasing number of states are moving their Medicaid clients into managed care systems as a cost-saving measure. Those savings can be used to expand the number of people served or to expand the scope of benefits provided. The proportion of Medicaid clients in managed care has risen from 9.5 percent in 1991 to 29.4 percent in 1995 and 40.1 percent in 1996. To a large extent, states have exempted persons with disabilities, including people with HIV, from mandatory enrollment in managed care. Those with HIV, eligible for Medicaid for reasons other than their HIV status, may be placed in managed care. But it is not known, overall, how many people with HIV or AIDS are in managed care plans. This exemption of the disabled is changing. For example, HHS just approved a waiver for New York State that will permit the state to move its Medicaid clients with HIV and AIDS into special needs plans under managed care. What impact this will have on the quality of care for people with HIV is not known -- nor is it known what impact it will have on discretionary programs such as the CARE Act, whose supportive services often intersect with Medicaid-supported primary care.

B. Medicare

The federally funded and managed Medicare program is best known for its provision of health care for the elderly. Medicare also provides coverage for the long-term disabled including an estimated 40,000 people with AIDS, at an estimated cost of \$1.3 billion in FY 1997.²³ Eligibility for Medicare for the disabled is tied to Social Security Disability Income (SSDI) eligibility.²⁴ Those beneficiaries who have been on SSDI for 24 months or longer are automatically eligible for Medicare benefits. Including an initial five-month waiting period, it takes at least 29 months for a disabled individual to become eligible for Medicare. Thus, only those with late-stage AIDS are eligible for Medicare. The waiting period for the disabled was designed to be sure that the disability covered was indeed long-lasting, if not permanent, before Medicare was accessed. An exception was made for those with end-stage renal disease.

and what impact this has on outcomes.)

²³This is also an actuarial estimate of clients served and costs. While most people with AIDS on Medicare are eligible because of their disability, some percentage of these clients will be eligible because they are over 65. (There have been over 7,600 cases of AIDS diagnosed in people over 65.)

²⁴An individual must meet the SSA's definition for AIDS-related disability *and* must have contributed to Social Security for a specified period of time.

Medicare benefits are covered by two parts of the program: hospital insurance (known as Part A) and supplementary medical insurance (known as Part B). The hospital insurance program reimburses participating institutions for inpatient hospital, skilled nursing facility, home health, and hospice services costs. There are some limitations in duration of these benefits that result in co-payment requirements. The Supplementary Medical Insurance benefits covered under Part B are optional; the individual eligible for Part A must pay a monthly premium for Part B benefits. In practice, most Medicare beneficiaries opt for Part B coverage. Part B covers physician services (both inpatient and outpatient), as well as non-physician services such as clinical laboratory tests, durable medical equipment, influenza vaccinations, drugs that cannot be self-administered, most supplies, diagnostic tests, some other therapy services, ambulance services, certain other health services, and blood not supplied under Part A. Certain services are *not* covered by Part B, including prescription drugs (except certain self-administered anti-cancer drugs), long-term nursing care or custodial care, and certain other health care needs such as dentures and dental care, eyeglasses, hearing aids, etc. The lack of prescription drug benefits is a major omission in Medicare coverage, one that is particularly important for people with HIV. Indeed, without another source of payment for prescription drugs, Medicare hospitalization costs can be dramatically higher for a person living with HIV, since basic antiretroviral treatment and opportunistic infection prophylaxis may not be accessible.

There are two options available to a Medicare beneficiary to expand benefits under Medicare Part B. The first is to participate in a managed care plan. Those who opt for managed care often receive a broader package of benefits as an inducement, usually including prescription drug coverage. However, these plans often have caps on the prescription drug benefits that may diminish their value to people with high drug-related expenditures. The second option is for the individual on Medicare to purchase a MediGap insurance policy -- a series of legally defined plans that offer different levels of coverage for the gaps in Medicare coverage, including varying (and not complete) prescription drug benefits. However, unless forbidden by state law, these plans have pre-existing condition exclusions for the non-elderly. For the almost five million disabled Medicare beneficiaries under 65, including those with HIV/AIDS, there is no access to MediGap policies unless state law requires it.²⁵

A significant, though unknown, number of people with AIDS are dually eligible

²⁵Senators Chafee and Rockefeller have introduced legislation to require a one-time open enrollment period for the current Medicare disabled so they can also access MediGap policies.

for Medicare and Medicaid. This can occur for several reasons: lacking health insurance during the waiting period for Medicare eligibility, an individual may have spent down to Medicaid eligibility; lacking sufficient resources to cover prescription drug benefits, the individual may have had to turn to Medicaid to close the gap in Medicare coverage; or, lacking resources for the Medicare Part B and/or MediGap premiums, the individual may be relying on Medicaid to cover those costs. In fact all three of these factors may come into play for any one individual. Thus, it is not known how many of the estimated 40,000 Medicare beneficiaries are also counted among the estimated 108,000 Medicaid beneficiaries.

C. Ryan White CARE Act

The Ryan White CARE (Comprehensive AIDS Resources) Emergency Act was first passed in 1990 and was reauthorized in 1996. It was designed to address the disproportionate impact of HIV on the public health infrastructure. Government and community representatives found that many people living with HIV/ AIDS were depending on public hospitals, emergency rooms, or simply going without care. The CARE Act was created as a mechanism to expand access to outpatient primary care and to provide supportive services that reduce dependence on more costly inpatient and emergency room services. The CARE Act is unique in that there is no other disease-specific discretionary program offering such a wide range of services. It is now funded at almost \$1 billion.

Table 2: Recent Funding History for the Ryan White CARE Act
(in millions of dollars)

Title	FY 1996	FY 1997
I (Cities)	\$391.700	\$449.943
II (States)	260.847	416.954
<i>Regular Grant</i>	208.847	249.954
<i>ADAP Set-Aside</i>	52.000	167.000
III (Clinics)	56.918	69.568
IV (Pediatrics)	29.000	36.000
Dental Program	6.937	7.500
AIDS ETCs	12.000	16.287
Total	\$757.402	\$996.252

There are now seven programs funded under the CARE Act, including the four "original" titles focusing on primary care and supporting services. All the CARE Act programs are administered by the newly established AIDS bureau at HRSA.

Title I provides direct grants to 49 high-incidence eligible metropolitan areas (EMAs) for the provision of outpatient and ambulatory health and support services for individuals and families with HIV disease. Grants may also be used for inpatient case management services that expedite discharge or prevent unnecessary hospitalizations. Half the Title I funds are allocated to the EMAs based on a formula; the remaining funds are awarded through a grant application review process, where the EMA is required to submit a proposed spending plan based on a comprehensive assessment of need performed by the locally appointed HIV Planning Council.

While some direction is given by HRSA regarding how these resources should be spent, maximum flexibility is given to localities to respond to the variation in the nature of the epidemic in a community and the availability of other resources (e.g., the relative benefit and coverage level of a Medicaid program). The planning council, chosen by the local elected official (usually the mayor), must be representative of the constituencies affected by the epidemic (including representation by people living with HIV). The council has authority to oversee not just the development of the local plan, but also the

implementation of that plan when funds are received.

Most of the services provided under Title I are through contracts between the local governments and community based service providers. Eligibility for Title I services varies from jurisdiction to jurisdiction. All require an HIV diagnosis for the provision of direct services; generally, disability is *not* a requirement for accessing these services.

Among the services provided under Title I are: primary medical care, case management, support for state ADAP programs, health insurance continuation, substance abuse treatment, mental health services, home health care, dental care, hospice care, rehabilitation care, and support services (e.g., buddy companion services, client advocacy, day or respite care, housing, food services, and transportation). Again, the allocation of resources to these services varies by jurisdiction: some may need to provide higher levels of support for one kind of service as compared to other jurisdictions, depending on the underlying need for and availability of this service. Nationally, in FY 1996, 48 percent of Title I dollars went to health care services; 7.5 percent to pay for medications; 12 percent for case management; 24 percent for support services; and 9 percent for administration and planning council support.

Title II provides formula grants to the states to support activities in one or more of the following areas: creation of HIV care consortia to provide a comprehensive continuum of care to people with HIV disease, home- and community-based care services, assistance to continue health insurance coverage, and payment for treatments and pharmaceuticals. Within Title II, there is now a set-aside for the AIDS Drug Assistance Program. States can support ADAP through both the set-aside funds and any portion of the base Title II grant they choose to apportion to this program.

Most of Title II funds have gone to either consortia or ADAP. Until the reauthorization of the CARE Act in 1996, states with more than one percent of the nation's AIDS cases were required to spend at least 50 percent of their grants on consortia. This provision was lifted to give more flexibility to state decision making. In addition, the reauthorized program now requires the development of a state-wide coordinated statement of need, to assure better coordination and integration of Title I and Title II services within the state (as well as other non-CARE Act HIV-related services). In FY 1996, 24 percent of Title II funds went to non-ADAP health care services; 46 percent went to ADAP; 11 percent to case management; 12 percent to support services; and 7 percent to administration, planning, and evaluation.

Precisely how many people with HIV are served by Titles I and II is not known on a national basis. Current data collection does not require unduplicated counts of

clients served. HRSA estimates that in excess of 300,000 people are being served by these two programs.²⁶ Nor is the overlap of CARE Act clients with Medicaid beneficiaries known. More precise figures are known for the ADAP program, with an estimated 80,000 people served during the FY 1996 grant period, with approximately 40,000 people on the program at any one time.

Title III provides grants to community-based clinics for the provision of outpatient HIV early intervention services. The programs provide a continuum of HIV-related services including risk reduction counseling and education, HIV antibody testing, medical evaluation, and clinical care. There are 151 grantees involving a cross-section of community-based organizations. Forty percent of grantees are federally funded community/migrant health centers; 20 percent are hospital- or university-based medical centers; 19 percent are city and county health departments; and 18 percent are non-federally funded community-based health centers.

In 1995, almost 85,000 patients received comprehensive primary care and preventive services under Title III. Of these patients, 74 percent were male, 26 percent were female; two-thirds were 20-39 years old; almost two-thirds of those in care were from racial or ethnic minority groups; more than 25 percent were substance abusers; and about 44 percent already had severe immune impairment and advanced disease at entry into the program. Clients in Title III programs without third party coverage are charged fees based on income.

Title IV of the CARE Act, administered as the HIV Program for Children, Youth, Women and Families emerged out of the Pediatric AIDS Health Care Demonstration Program. Its purpose is to improve and expand the infrastructure of comprehensive care services in order to increase the access of HIV/AIDS affected women, infants, children, and youth to a comprehensive, community-based system of care. It is also designed to develop innovative models that link clients to clinical research trials. Five types of projects are funded: Pediatric/Family AIDS projects providing or coordinating comprehensive family-centered health, social, and support services; Comprehensive Care Consortia, which are required to provide matching private sector funding; planning and development grants to support needs assessment and initial planning activities to develop a comprehensive core system; cooperative agreements with national resource centers; and hemophilia/AIDS special initiatives.

²⁶The duplicated number of clients served in Title I in 1995 is 626,620; in Title II, it is 333,950. The duplicated numbers, however, could reflect the fact that one client is counted several times, because she or he is served by different providers for primary care, ADAP, case management, buddy assistance, etc.

In FY 1996, 60 projects were funded in 26 states, DC, and Puerto Rico. In 1995, 32,530 HIV-positive clients were served by the programs, with over 12,000 individuals enrolled in clinical trials or other research protocols.

The remaining programs under the CARE Act reimburse dental schools for the provision of dental care for people living with HIV, provide professional provider education through the AIDS Education and Training Centers, and support Special Projects of National Significance, which are direct grants to study innovative approaches to providing care for people with HIV.

D. Housing Opportunities for People with AIDS Program (HOPWA)

The HOPWA program, administered by the Department of Housing and Urban Development, provides housing assistance and supportive services for low-income persons with HIV/AIDS and their families. Grants are provided by formula to states and metropolitan areas with the largest number of cases of AIDS, and through a national competitive grants program to states, localities, and non-profit organizations. In FY 1997, a total of \$153.9 million is being allocated by formula to 53 eligible metropolitan statistical areas (EMSAs) and to 27 states for areas outside the EMSAs. In 1996, \$17.1 million was awarded through the competitive grants program. HOPWA funds may be used for a variety housing services, social services, program planning, and development services. HOPWA funds may also be used for support services such as health care and mental health services, chemical dependency treatment, nutritional services, case management, assistance with daily living, housing information, and other services. Thus, while technically not a direct care program, the relationship between housing needs and the ability to access appropriate (and the least costly) forms of health care makes this a program central to care, as with many of the support services provided under the CARE Act.²⁷

A General Accounting Office study of the HOPWA program showed that 71.1 percent of HOPWA funds expended between 1992 and 1996 went to housing assistance, and 16.1 percent went to supportive services.²⁸ The GAO also found that those served

²⁷Indeed, some HOPWA money is used for direct primary care. Several jurisdictions are using HOPWA funds to support their ADAP programs.

²⁸United States General Accounting Office, "Housing: HUD's Programs for Persons with AIDS," March 1997, GAO/RCED-97-62. These estimates are based on actual funds expended. The GAO found that only 27 percent of HOPWA's funds had been spent by October 1996.

by the program are the very poor, with 29.4 percent of participants having monthly incomes of \$250 or less; 40.9 percent having monthly incomes between \$251 and \$500; and 26.1 percent having monthly incomes between \$501 and \$1,000.

E. Veterans Affairs

The Department of Veterans Affairs, through its medical care program for veterans, is the largest single provider of health care for people living with HIV. An estimated \$350 million in primary care expenditures will be incurred through the VA's medical care budget in FY 1997 to provide inpatient, outpatient, and clinic based services to veterans at local and regional medical centers and facilities. Through December 1996, the VA served a cumulative total of 26,415 HIV-positive veterans. In the first quarter of FY 1997, there were 9,552 patients being treated. Recipients of VA benefits may be accessing Medicare, Medicaid, CARE Act, and HOPWA programs as well.

IV. Additional considerations

This is not a complete review of publicly funded programs available for the health care related needs of people living with HIV. There are other federal programs that serve people living with HIV -- from the Substance Abuse and Mental Health Services Administration's substance abuse block grant set-aside for HIV counseling, testing, and early intervention, to the thousands of people with HIV who receive care at HRSA's community and migrant health centers (in addition to those funded under Title III of the CARE Act). There are also millions of dollars spent at the local level with state, county or municipal funds to support care services.

Together, these programs provide for a wide array of services and reflect a considerable public investment in treatment for people living with HIV. With a new standard of care, with a changing population needing HIV-related care, and with the extended longevity of many people living with HIV, how these programs adapt to this new reality, how they maximize the use of their resources, and how they can be woven together to provide integrated and comprehensive care will be the continuing challenge of the next few years for care and service providers. The Keystone Exploratory Session on Public HIV-Related Health Care Financing and Service Provision Systems will meet on August 7, 1997 to determine what, if any, policy questions posed by these new challenges need to be addressed.

ONAP Letter Tracking

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Subject

Meeting Agenda

☐ Response Needed?

Response Type

Response Date

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Responder Name

Action Promised

Action Complet

Action Date

Notes



The Keystone Center

MEMORANDUM

To: Participants of the Keystone Exploratory Session on Public HIV-Related
Financing and Service Provision Systems

From: Abby P. Dilley and Debbie Eakin

Subject: Draft Meeting Summary

Date: August 28, 1997

Attached is a draft of the meeting summary from the August 7th exploratory session. Please review for accuracy and clarification, and submit any comments to Abby Dilley by close-of-business Monday, September 8, 1997. A revised draft, incorporating corrections, will be distributed to all participants.

As encouraged by the group attending the session on August 7, a working group, comprised of volunteers, met to discuss and develop a possible proposal for moving forward with an initiative on issues associated with HIV-related health care services and financing systems. A draft of their conclusions is being reviewed by the working group and will be distributed to all participants of the August 7 meeting in the very near future. Depending upon reaction to the proposal, next steps will be determined.

If you have any questions about the summary or the work group's activities, please call at 202-783-0248.

Thank you again for your time and interest. Have an enjoyable Labor Day weekend!

Keystone Exploratory Session on Public HIV-Related Health Care Financing and Service Provision Systems

August 7, 1997

Draft Meeting Summary

Overview

Approximately forty-five decision makers from a broad spectrum of interest groups, public agencies, and private organizations convened for a day-long meeting in Washington, D.C. to discuss issues associated with public HIV-related financing and service provision systems. A portion of the agenda focused on the changing context of these issues. In addition, the group discussed whether a specific effort to address some of the challenges associated with the changing context is appropriate and, if so, what vehicle or appropriate approach might be most constructive. At the conclusion of the meeting there was general agreement by the group on two issues:

1. The changing context within which service provision and financing systems are operating create a compelling case for initiating an effort, in addition to those already underway, to address some of the challenges posed by these changes.
2. A subset of the larger group will convene to develop a proposal for moving forward with a collaborative effort. This proposal will be distributed for consideration by the plenary group and appropriate next steps determined.

Below is a draft summary of the highlights of the deliberations and does not represent consensus.

Meeting Deliberations

The meeting began with brief introductions by all participants (see participant list), discussion of meeting background and objectives, determination of ground rules for the meeting, and a review of the agenda.

Meeting Background

The concept for a dialogue effort on HIV-related health care financing and service provision systems emerged from a report by the Presidential Advisory Council for HIV/AIDS which, in its December 1996 report, recommended an effort to, "Assess the implications for the service delivery system of [the] changing standard of care (as well as the systemic evolution toward managed care)--as it affects Medicaid, Medicare, and Ryan White CARE Act programs." The Advisory Council further recommended that, "...a mechanism [be created] for the public sector, private sector, and the community to engage in a formal, facilitated dialogue process on how to set priorities for HIV care and services that assures the best use of resources and recognizes a context of shifting demands for services." In addition, the recently released "Guidelines for the

Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents” suggesting that people with HIV should be in care as early as possible heightened interest in reviewing the service delivery system.

The Keystone Center, a non-profit organization, has conducted policy dialogues on HIV-related issues for approximately ten years. The suggestion by the Presidential Advisory Council on HIV/AIDS for a formal, facilitated dialogue prompted Keystone Center staff to explore the degree of interest and support for a Keystone policy dialogue on HIV-related health care financing and service provision systems. Assisting Keystone with this assessment is Jeff Levi, currently an independent consultant, and formerly with the White House Office of National AIDS Policy and AIDS Action Council. He also is a veteran of several Keystone policy dialogues on HIV-related issues.

Assessment of the potential for a policy dialogue began with several conversations, by telephone and in person, with multiple stakeholders involved and interested in HIV-related health care service delivery and finance systems. During the course of these conversations, a draft proposal for a policy dialogue was developed and circulated for comment and discussion. These interviews demonstrated a strong interest in pursuing an effort to address the critical issues raised by the changing context in which these systems are operating. In order to carry the discussion further in terms of determining an appropriate mechanism for addressing these issues, an exploratory session involving a broad cross-section of decision makers was organized by The Keystone Center and at the request of Keystone, funding was provided by the Health Resources and Services Administration..

Meeting Objectives

The objectives of the exploratory session were the following:

1. Encourage a substantive discussion of the current context within which HIV-related financing and service provision systems are functioning.
2. Determine if the context creates a driving force or imperative for a focused effort on these issues.
3. Discuss possible mechanisms to address these issues, including a policy dialogue process.
4. Depending upon what mechanism appears most appropriate, discuss next steps for moving an effort forward.

Agenda Review

The agenda was organized around the above listed objectives. The morning was dedicated to a substantive discussion of the issues concerning HIV-related financing and service provision systems, and the afternoon discussions focused on process considerations.

Ground Rules

To help create a more open atmosphere for discussion of these complex issues, two ground rules were proposed for the day's deliberations:

1. All comments are off-the-record and not for attribution.
2. People are attending as individuals, not as formal representatives of their respective organization, agency, or company.

The group agreed to use these ground rules for the day.

Opening Comments

Bill Corr, Chief of Staff, Office of the Secretary at the Department of Health and Human Services began the substantive portion of the discussion with a few opening comments. He stressed the importance of service provision and financing issues and the need for various discussions among different interest groups. He mentioned that the Department of Health and Human Services is beginning a series of discussions with interested parties. Mr. Corr posed a key question to be resolved by these cumulative discussions, "Are we responding to today's and tomorrow's needs?"

Nick Bollman, Chair of the Services Committee for the Presidential Advisory Council on HIV/AIDS and Senior Program Director at The James Irvine Foundation also provided opening comments, particularly with regard to the Council's decision to recommend a focused discussion on the service delivery system. He said that with the advent of new guidelines for care, there is an opportunity to move away from the assumption that the care system responds to versus treats disability and move toward a system that can encourage staying healthier longer. In order to realize this opportunity, many questions need to be answered concerning the current structure of care and services and whether we are best meeting the needs of people with HIV. Mr. Bollman indicated that a critical part of this discussion and any changes to the structure encouraged by this paradigm shift must also include continued support of the important components of the current system so that the transition is not harmful to people with HIV.

Changing Context and Compelling Issues

The floor was then open to comments and perspectives concerning the context within which the current service provision system is functioning. Issues that were raised include the following:

- Even though AIDS mortality rates are generally declining, many of those now living with HIV and/or are now becoming infected with HIV are not in systems of care. Some of the key challenges involve reaching out to those populations who do not have care.
- In the past, there has been a constant tension between primary health care services and other services. This tension is demonstrated in the Ryan White CARE Act programs. Advocates end up debating the merits of different services, pitting primary care against other services.

A more constructive approach would be to discuss a holistic set of services that include both primary and other types of care. Part of this discussion may involve looking at the current health care programs, especially Medicaid, and determining how to maximize resources for primary care. This exercise may help prevent the false dichotomy of either primary care or other services.

- We need to look at which populations health care programs have been directed and analyze whether we have created systems to be responsive to their needs. Are their particular populations we currently are not serving and, if so, we need to figure out how to create programs that are more responsive.
- With the advent of combination therapies, an assumption is being made that this approach is the most successful, even though we do not have the data to completely confirm that this is true. This situation makes resource allocation and budget discussions very difficult.
- Prevention and intervention strategies for different populations need to be revisited. We are at a transition point where we can more effectively reduce the opportunity for zero-conversion.
- The continuum of health care services needs to reflect the continuum of needs for people with HIV, from determining HIV status to access to care through final stages of AIDS care.
- Different epidemics are happening in different parts of the country. This phenomenon needs to be kept in mind when various options for modifying the service structure are discussed.
- Different models that have been successful for providing services need to be identified, discussed, and applied more broadly. We need to share knowledge. These model programs need to be assessed not only in terms of where we have spent money, but where and how these programs have been effective.
- We also need to think outside the box. There may be models that are better than what are being used currently.
- In order to create a more cohesive system, we need to break down boxes. Various policies of government should be reviewed in terms of their impact on people with HIV. For example, housing policies have a bias against people with HIV as a result of restrictions on drug users and people with criminal records.
- In responding to this epidemic, we are dealing with a whole variety of inequalities that are highlighted by this disease. These inequities are not only manifested in the treatment of various populations, but also geographically.
- We need to better understand the health care marketplace.
- There is a dynamic tension between financing and service provision systems. Both systems need to be looked at. The new treatment guidelines encourage diagnosis and treatment earlier. As a result, clients are accessed at a time when they need many more and diverse services. These changes need to be assessed as to how they impact on current care systems.
- Five major shifts of the landscape on which structuring systems:
 1. Epidemics are changing.
 2. Treatment strategies are changing.
 3. Health care financing is changing.
 4. Public perception of the government's role is changing.
 5. Increased understanding of social inequities are highlighted by HIV.

- Prevention and services linkages need to be improved. Some believe that flexibility in how dollars are allocated at the community level is necessary to better tailor services. Often when dollars reach the community level, they have been allocated based on goals set several years ago. Even though needs have changed dramatically, there is no flexibility allowed to modify their use accordingly. On the other hand, too much flexibility can be problematic. Some communities just receiving dollars are looking at the old ways of doing things and want the same types of programs even though newer models and services are more appropriate. There have been both positive and negative results with local flexibility. These inconsistencies have been used as an excuse to cut federal funding for local or community programs.
- There are inequities with regard to who receives state-of-the-art treatment. We have a minimal national standard of care and when translated in various parts of the country, it does not result in the most effective care for people with HIV because of these inequities.
- Substance abuse issues need to be at the center of discussion because this is where the future of the epidemic is. We need to better integrate these services.
- Where we really need to think outside the box is on the budget. We may need to put more money in some areas to save money in other areas.
- There is a disconnect between funding streams and planning of services, between the dollars and their application. Part of the mismatch is the attempt to fit services into categorical funding boxes.
- We need to look at the shifts of people from general services to HIV-specific services and why this happens. For example, are these shifts occurring because the appropriate intervention requires a different program, or is it because of the stigma or assumptions attached to certain populations, or are there other reasons?
- An approach for a dialogue might be to create the best system given the needs of people with HIV within the changing context, and then evaluate the current system against the best system.
- We need to address multiple system changes and think of long-term needs and goals. Most decisions are made on a very short-term basis, such as annual budget cycles, and this has exacerbated some of the problems.
- We have a moral imperative to see that this work continues and we address these critical issues.
- Clients do not stay in one place and often are turning to the public sector for assistance. Private insurance, even for those who do have it, is very inadequate, especially with caps on drug benefits.
- Another dynamic that makes these issues more difficult is that the public is tired of this epidemic.
- These issues need to be looked at in a broader context, including how other programs affect some of populations where the epidemics are occurring. For example, welfare reform and eligibility for substance abusers. What are the political dynamics associated with these issues and how have they affected health care? Many of the issues discussed are not new; the disease, however, is unique. We have an opportunity to go beyond HIV/AIDS to address the needs of people who perpetually have not had access to care.

- We need to expand the table to be sure that those with HIV--especially those affected by recent policy changes regarding welfare, immigration, and SSI eligibility for drug users--are also heard. The discussion also should include women and people of color.
- We cannot wait to address urgent issues associated with HIV/AIDS while we try to fix the whole system.
- The epidemic hasn't changed for people with drug and alcohol problems. We must address not only the needs for new populations but also maintain and improve services and resources for people who always have been affected.
- Many of the extraordinary challenges are those we face at the intersection of various issues and dynamics, such as the following:
 6. Prevention and care
 7. Public and private
 8. Public health and the correctional systems
 9. Local and federal systems
 10. Interaction between different public programs (e.g. Medicaid and Ryan White)

While these areas provide some of the most difficult challenges, they also offer hope for solutions, including better integration of services, cost savings, and other benefits.

When the question was posed as to whether all of the above mentioned issues and associated discussions created a compelling case to take a step back and look at these issues more thoroughly, the group agreed that it does.

Important Considerations in Moving Forward with Addressing These Issues

- It is critical that as we make changes in response to the new paradigm, that we do not make the service structure worse. That the rationale for the need to make changes is not misconstrued or used as an excuse to dismantle programs without more effective ones to take their place.
- We need to look at the whole infrastructure and the inherent inequities. We also need to look at different models that offer alternative infrastructures that may provide solutions to the HIV-related health care infrastructure, such as health care for the homeless. Another model suggested was that which Great Britain employs for addressing the needs of drug users.
- We need to take advantage of the opportunity to rethink basic assumptions upon which the HIV-related health care service delivery and finance systems are structured.
- What criteria are being used to make decisions about resource allocation?
- A key question for discussion is the disaggregation of resource sources. Are the difficulties created because of the categoricals themselves or the integration of the different categoricals? In other words, are structural adjustments needed in the finance and service provision systems, or are structural adjustments needed because these two different structures are bumping in to one another?
- Another critical question is how far do we go with structural modifications?
- We need to determine where we are and where we want to be going with the service provision system. Recommendations could be developed accordingly and directed toward a broad audience along with a strategic plan to insure that the effort doesn't result in a

lessening of services in the current political climate. Part of the recommendations could include actions that would help move from the current system toward the more ideal system.

- The private sector donor base for community-based organizations needs to be educated. They are not always willing to change directions to support different services that, while maybe more effective, are different from what they have been supporting traditionally. Also, the intersection between public and private funding needs to be looked at more closely.
- We must start discussions with the assumption that we are creating the best, most effective system of care for people with HIV, not with the assumption that we are downsizing the service provision system.
- Services for people with HIV are not interchangeable with services for people with AIDS. The whole continuum of services is necessary. The challenge is how to create a system that encourages the outcome of more people living with HIV versus more people disabled with AIDS.
- The political context for addressing these issues effectively, without lessening services, is difficult. We think these issues are especially critical, but not all people do, especially government officials at all levels.
- When will we reach a critical level politically to finally address substance abuse issues?
- We are already struggling to address the shift to managed care. There will be resistance to additional change. We need data and a rational policy base to ground any changes recommended so that we are confident that the changes will be for the better.

Ship Analogy

The health care service provision system could be viewed as a big ship. We are on a big, sinking ship and we are assuming that there are only so many lifeboats on the ship. There are confused rules about who gets in the boats and who doesn't. We need to have a more open and thorough discussion about these assumptions and change our thinking to achieve getting all people in the lifeboats. Strategies to accomplish this goal include:

1. Create more slots for people
2. Secure more lifeboats from somewhere on board the ship
3. Have more lifeboats brought on to the ship

We also need to know where the lifeboats are headed so they can move in a common direction toward land (better care).

Process Options for Moving Discussion Forward

1. One option proposed focused at the national policy level and included the following steps:
 - A. Determine principles of an ideal HIV service delivery system.
 - B. Define the needed changes in policy and funding to facilitate reaching the ideal system.
 - C. Acknowledge different needs in different situations and locations and provide flexibility in the system accordingly.

- D. Determine how to create the political will necessary to make these changes happen.
2. Another option stressed dialogues at the local or community levels. Given that portions of diverse populations affected by the epidemic are best understood at their community level, and this is also the level where conduits for access to care exist, the best solutions will be created at this level.
 3. Another option structured discussions somewhere between the national and community levels, or including elements of both. The rationale was that sources of funding for services comes from all levels and all need to be engaged in discussing the challenges and finding solutions. If the discussion is only at the national level, the dialogue may be too esoteric and removed from the real impact points. If the discussion only occurs at the local level, then a portion of the picture is missing to most effectively address the health care service system.

It was observed that the fact that a structure for HIV care exists at all is miraculous and elements of the structure are functioning well and are real accomplishments.

Process Options

The group next discussed possible options for pursuing a focused effort. The Keystone dialogue process approach was first outlined, followed by questions, and then other possible options also were discussed.

Keystone Policy Dialogue Process

The Keystone dialogue process uses a collaborative, consensus-building approach to the development of creative, constructive recommendations to address complex, often controversial issues.

Collaborative

“Collaborative” means that the process and outcome of a dialogue is participant driven. The participants determine all components of the initiative and outcome, from agenda to report development. Dialogue groups are comprised to reflect a balance of interests involved and active in the specific issues that are being addressed while maintaining a size that is functional and productive. All participants have equal voices at the table and in determining any final outcome. Work primarily is drafted by participants. Outside resources may be used, but the final report and any recommendations are drafted by participants as original material and created or drafted collaboratively.

Keystone staff assist with editing, incorporating comments, and finalizing materials, but do not draft the substantive content of reports. Keystone staff are very active in facilitating the deliberations, work development, and drafting, but the participants are the substantive experts.

Because dialogue projects are participant driven, a significant dedication of time and energy by all involved is essential. Consistent participation in meetings, work on assignments between meetings, and commenting on drafts of report by all dialogue group members is essential. Participation in dialogue activities not only is important, but keeping colleagues informed of discussions and ideas, particularly as a report is evolving, is very helpful so that as a document and possible recommendations are developed and released publicly, as much support as possible is generated for the ideas and recommendations. In addition, it is important that each participant keep their respective organization, agency, or company colleagues and key decision makers apprised of discussions and recommendations so that when asked to “sign on” to the final report, there is not an unexpected delay in completion because of unanticipated concern with the document.

Signing on does not mean an official endorsement by any organization, agency, or company of the document or associated recommendations.

Consensus-Based

As mentioned, the Keystone dialogue process focuses on the development of a consensus-based result, often a final report. “Consensus” means that the final report and package of recommendations can be supported by the whole dialogue group. Consensus recommendations are those that, as a whole package, all participants can live with and support. Taken individually, each recommendation may not be ideal, but as a whole set of recommendations, representing different compromises and agreements, the package is acceptable to all participants. Consensus does not only apply to recommendations but to the report. Agreement on characterization of issues and the deliberations often is just as critical as the recommendations. The dialogue group may not reach full agreement on every single issue, but may agree on fair and accurate descriptions of issues and options discussed in cases where consensus is not reached. This process does not use voting and strongly encourages the development of one consensus report rather than majority/minority reports.

Impact

The impact of a dialogue process, just as with the development of a final product, is generated and determined by participants. The power of the report and recommendations lies not only in their hopefully creative and compelling means of addressing issues, but also in the diversity of people involved in crafting and supporting them. Also, any strategy for the presentation or implementation of recommendations is developed by participants and heavily relies on their enthusiastic support. Targeted audiences often include colleagues of participants. Additional decision makers who are identified as those who should receive information about the deliberations are determined from the final outcome, and by the participants.

Ground Rules

Ground rules are used to govern the deliberations of a dialogue process in order to encourage an open and frank discussion of often difficult and contentious issues. Two used for the exploratory session also often are used for dialogues, including the following:

1. People attend as individuals, not as formal representatives of their respective organization, agencies, or companies.
2. All comments are off-the-record and not for attribution.

An additional ground rule often used is the following:

3. Draft documents are the property of the group and not circulated outside the group, particularly portrayed as consensus, until all dialogue members agree to release the document publicly.

Questions and Discussion

Following the description of the Keystone dialogue process, several questions were raised.

- 1. Does the process have to result in recommendations and to whom are they directed?*

The process can result in whatever conclusion the participants think most beneficial. In the past, the result often has been recommendations, even if they are not specific policy recommendations, but suggestions for additional discussions or other actions. However, the outcomes and goals of the dialogue can take whatever shape the participants agree is productive.

The audience for the outcomes of a dialogue process also is determined by the dialogue participants. Often audiences have included colleagues or peers of those participating in the dialogue interested in these issues but not involved in the group's deliberations. Additional audiences are identified as the final product emerges and are those whom the dialogue group believes is most important to receive the information.

- 2. What is the meaning of making a recommendation and what does it mean to sign on to the document?*

A recommendation can be in many forms, from specific policy changes to ideas for research and further exploration. A consensus recommendation means that all participants thought the issue was an important one and, depending upon whether the dialogue group could reach a consensus on a particular approach, could be addressed most effectively in the way suggested.

“Signing on” to a document means that one agrees to the fair and accurate description of the deliberations and any recommendations presented. Also, signing on is an indication of support for the whole package of ideas and suggestions contained within the document. It does not mean

that taken individually, each idea or recommendation is supported, but as a whole package capturing the deliberations and any conclusions, it is supported. "Signing on" does not convey an official endorsement of the document or recommendations.

3. How is credibility assured through participation and representation of diverse interest groups?

One of the most essential components of a dialogue process and product is the composition of the dialogue group. As mentioned, every effort is made to include a broad cross-section of interest groups, organizations, agencies, and individuals who are interested and affected by the issues that will be the focus of the deliberations, while also keeping the total size to one that is constructive and productive. The process for determining who is involved is a very iterative one and includes significant consultation with potential participants.

Some of the federal representatives raised concerns about their capacity to participate in a dialogue that results in policy recommendations directed to the federal government. There followed some discussion about the need for meaningful participation by federal officials while still being able to produce a useful product at the conclusion of a dialogue. Some thought that recommendations broadly defined is essential, while others proposed that discussion of the issues, without recommendations would be most constructive.

Additional comments included the following:

- Recommendations should be directed more broadly than just the federal agencies.
- How well-defined is the problem and does this prevent a constructive dialogue?
- The unique role of a policy dialogue is that it moves toward an outcome in a specified period of time.

Alternatives to a Keystone Policy Dialogue

Additional approaches to a continued effort on these important issues associated with HIV-related financing and service provision systems included the following:

1. Bottom - up approach that begins at the local level, moves to the state level, and eventually to the federal level.
2. National on-line forum to gather information and perspectives more broadly that could then be factored into a policy dialogue discussion.

Problem Statement

The group spent some time discussing a possible problem statement. While there was not adequate time to develop a specific statement, the group did identify the important components of a problem statement.

- Dynamics (epidemic, treatment, demographics, length of life, etc..) are changing. Many people underserved or not served at all by the health care system. The system needs to be assessed and evaluated with the goal of ensuring that all who need care have access to care.
- Problem statement should convey the sense of urgency with which these issues need to be addressed.

Five major shifts of the landscape on which structuring systems:

1. Epidemics are changing.
2. Treatment strategies are changing.
3. Health care financing is changing.
4. Public perception of the government's role is changing.
5. Increased understanding of social inequities are highlighted by HIV.

Objectives

Objectives of any effort that moves forward should include the following:

- Ensure care as early as possible for those with HIV.
- Generally, the best system of care will integrate people into the system as soon as their status is known so that they are able to make treatment choices.
- Create an effective transition phase to move from the current system to an ideal one that best serves people so that no negative impacts occur on services for people with HIV.
- The system needs to assure equity, parity, and inclusion regarding access.

Context and Questions

Additional context for a future effort included the following:

- Focus on federal and state financing strategies for the deliberations, but outline the context of other public, as well as private sources of funding.
- There are problems with the overall health care system, but the dialogue is specifically focusing on issues affecting people with HIV/AIDS.
- An effective system of services is a broad continuum from prevention to early determination of status, through to end stage AIDS care.
- Substance abuse treatment and harm reduction needs to be discussed.

Potential Participants

The group next discussed potential participation and group composition of any effort that moved forward.

There was considerable discussion of how to assure appropriate and meaningful inclusion of consumer voices in a dialogue. Various options were explored, including expanding consumer representation in the dialogue itself, as well as convening focus groups, town meetings, Presidential Advisory Council hearings, and other ideas. This issue is an important one and will need significant additional consideration should a dialogue effort move forward. The following list of groups were identified as possible additions, some of whom already were present or were part of the invitation list. Time did not allow for much discussion of the list or any conclusions about the development of a participant list.

- People with HIV (women, people of color, drug users)
- Immigrants and those who provide services to immigrants
- Private payers\managed care (e.g. National Health Insurance Association)
- Those who provide services to families
- Physicians
- Treatment experts
- Native Americans
- Governors' Association
- People who are from outside the beltway
- Those familiar with Medicaid and Medicare
- Social Security Administration
- Service providers for women with alcohol and/or drug problems
- Community-based organizations
- Criminal justice system representatives
- Adolescent/youth representatives
- Treatment skeptics
- State alcohol and drug abuse system representatives
- Community leaders

Next Steps

At the conclusion of the exploratory session, the group agreed that a working group, formed from a subset of volunteers from this larger group, should be convened to develop a more specific proposal for an initiative to move forward on these important issues. The proposal would be circulated to the larger group for comment and reaction, and next steps would be determined accordingly.

The meeting adjourned at approximately 4:00 p.m.

**Keystone Exploratory Session on Public HIV-Related Health Care Financing
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**KEYSTONE NATIONAL POLICY DIALOGUE ON PUBLIC
HIV-RELATED HEALTH CARE FINANCING AND SERVICE PROVISION SYSTEMS**

Draft Proposal
April 7, 1997

Meeting Aug 7, 1997

The advent of new therapeutics and associated treatment strategies to combat HIV disease has prompted development of new principles of care. This change has occurred at a time when those needing care are increasingly minorities, women, and injection drug users, all of whom traditionally have been underserved by the health care system. The HIV-related health care financing and service provision systems must respond to both of these developments in order to meet the promise of these new treatments to not only prolong life, but to delay, or intermittently end, the disability of people with HIV. The Presidential Advisory Council on HIV/AIDS highlighted the need for such revisions of the health care financing and service provision systems during their December, 1996 session when they recommended that the Administration,

“Assess the implications for the service delivery system of this changing standard of care (as well as the systemic evolution toward managed care)--as it affects Medicaid, Medicare, and Ryan White CARE Act programs.”

Further, and more specifically, the Advisory Council recommended that, “...a mechanism [be created] for the public sector, private sector, and the community to engage in a formal, facilitated dialogue process on how to set priorities for HIV care and services that assures the best use of resources and recognizes a context of shifting demands for services.”

Proposal: The Keystone National Policy Dialogue on Public HIV-Related Health Care Financing and Service Provision Systems would convene approximately forty key decision makers critical to developing and implementing changes in policy on these issues to engage in an eight month to one year consensus-building effort. This dialogue process will involve representatives from the key federal agencies (Public Health Service, Office of Management and Budget, Health Care Financing Administration, Health Resources and Services Administration, Office of National AIDS Policy, Presidential Advisory Council), state agencies, community service groups, advocacy organizations, managed care organizations, private payors, physicians, and members of academia.

This timely effort will contribute to addressing some of the challenging issues surrounding appropriately and effectively structuring the health care financing and service provision systems for people with HIV in light of a new standard of care. Because of the complexities of the financing and services structure and the various levels at which decisions are made and services provided, this policy dialogue will serve as a first important step toward realigning this structure. Additional, separate efforts must take place among other decision makers at the community, state, regional and national levels to insure that this transition is effective and is supported by the many interest groups involved in and concerned about these issues.

The Dialogue group will conclude its work with the development of a final report containing consensus recommendations and present their findings to high-level policy makers. The budget for this one year effort will be approximately \$420,000.

Objective: To collaboratively develop recommendations for current public HIV-related health care financing to more appropriately align service provision systems with the new treatment regimens and currently underserved populations. A group of decision makers with diverse perspectives will identify and articulate key principles and imperatives associated with a new standard of care; assess the current public care, financing, and service systems against these needs; and develop recommendations for adjustments to the health care financing and service provision systems as appropriate.

Background: People with HIV/AIDS are disproportionately dependent on the public system for access to care. HCFA estimates that approximately 53 percent of adult Americans and 90 percent of children living with AIDS receive their medical coverage through Medicaid. A growing percentage are becoming eligible for Medicare. A 1992 AHCPR study estimated that only 15 percent of people with AIDS have private health insurance. More recent data from the Centers for Disease Control (through December 1996) suggest this percentage has held over the years.

The bulk of public sector spending is in the Medicaid (\$1.8 billion federal share; \$1.5 billion state share) and Medicare (\$1.3 billion) programs, with additional federal resources contributed through the Ryan White CARE Act (almost \$1 billion) and the Veterans Administration (\$350 million). When combined with other state resources, total public spending on HIV-related primary care and services in FY 1997 is estimated to be over \$6 billion. (There are estimated to be 650,000-900,000 people living with HIV in the U.S.; approximately 223,000 have a diagnosis of CDC-defined AIDS, i.e., a seriously compromised immune system and/or opportunistic infections.)

Despite this huge commitment of resources, many people with HIV are not accessing appropriate care. This is due, in part, to the fact that access to the major programs -- Medicaid and Medicare -- usually require that an individual be disabled by HIV disease *before* being able to access publicly funded care.

In the early years of the epidemic, when treatment for HIV generally occurred in later stages of HIV disease progression, this was problematic but not too far from the standard of care. Today, as we are entering an era where the standard of care is fast becoming intervention at the earliest possible moment after infection with HIV -- long before an individual becomes symptomatic, let alone disabled -- we must examine how we can redeploy the current \$6 billion public commitment to HIV-related care so as to create a system of care that *prevents* disability, rather than treating it. This objective is made more challenging by the fact that HIV is increasingly a disease that disproportionately affects minorities and injection drug users; populations that historically have had less access to systems of care.

There are many legal and programmatic restrictions on and historical commitments to funding specific kinds of services for people with HIV that must be assessed and potentially altered -- through policy changes and/or administrative or legislative action -- to accomplish this goal. Hence, this Dialogue.

Critical Questions:

A) How are current resources deployed? Based on what principles of care/treatment?

(In advance of the start of the dialogue, it is planned to have a white paper available that will outline for participants how current public dollars are being spent -- describing the mechanisms, the restrictions on those mechanisms, what kinds of services (primary care, home care, pharmaceuticals, case management, etc.) are being purchased, what proportion of funding is going to those services, and how many people are accessing those services. While some of these data may not be available, the best possible estimates will be made so that all participants will have a common grounding on this baseline question.)

B) What are the new principles of care/treatment strategies?

(The basis for this discussion will be the current PHS effort to define the standard of care, as well as the participation in the dialogue of clinicians and researchers active in the field.)

C) What do these changes mean for service provision?

D) What possible options might align service provision with the new treatment needs?

(These two questions are the main focus of the Dialogue; they seek to identify the programmatic changes needed to assure access to the care and services needed under this new standard of care, both in terms of the populations that must be reached and the service demands imposed by the new standard of care.)

E) What are the changes needed in the existing care-related programs to achieve this realignment?

(The answer to this question would outline the practical steps that might be necessary -- in terms of policy, administrative or legislative changes -- to bring about this realignment.)

Process: Determining how best to adapt the public health care financing and service provision systems will require the participation of those involved from the various interested and involved agencies, groups, and organizations. Given that much of the financing comes from the public sector, representation from the key agencies is critical. These informed representatives must discuss and reach a common articulation of the need for change to the financing and service

provision systems; determine how progress, or lack thereof, affects the overall approach to treating people with HIV; assess the various options that could most effectively meet these needs; and develop consensus recommendations for consideration by key policy makers.

There is a growing realization that the changes in treatment strategies spurred by new therapeutics, will require a corresponding change in health care financing service provision systems. The challenge of reaching agreement on how to most effectively modify these systems will require a collaborative, consensus-building effort, the first step of which is proposed to be a dialogue focused at the national policy level. The Keystone Center, an interested but uninvolved and objective organization, will organize and facilitate a policy dialogue focused on successfully meeting this challenge. This effort will involve leaders of the different constituencies to encourage building agreement on how to adapt the current public HIV-related health care financing structure to more appropriately align service provision systems with the new treatment regimens.

A Keystone National Policy Dialogue on Public HIV-Related Health Care Financing and Service Provision Systems will bring together a core group of experts, including those representing key federal agencies, state agencies, community service groups, advocacy organizations, managed care organizations, private payors, physicians, members of academia, and Congressional staff. This Dialogue group will collaboratively work through the key questions and issues; develop a common base of information; and develop consensus recommendations to further progress in this area of policy. Recommendations could include options with associated advantages and disadvantages evaluated.

The dialogue process will consist of four phases: 1) Convening; 2) Problem Description and Issue Identification; 3) Agreement on Recommendations and Finalization of Report; and 4) Presentation of Report and Recommendations.

The first, or convening phase of this project would involve extensive discussions with representatives of diverse stakeholders interested in and affected by these issues to assist with identification of key issue areas and potential Dialogue participants. This phase would be concluded with an organizational or steering committee meeting to more specifically define the substantive focus, goals, and objectives of the effort. In addition, discussion of ground rules governing the Dialogue, identification of other key participants, and sources of funding also would be discussed. This phase will be about four to six weeks.

The Problem Description and Issue Identification phase will be initiated when the full Dialogue is in progress, involving the diverse participation of approximately forty key decision makers. This phase will continue through multiple plenary and work group sessions, conference calls, and development of collaborative writing assignments. Critical issues will be highlighted and recommendations for options to address these issues will be developed by the Dialogue group. This is the longest phase of the project, taking approximately six to seven months.

The Agreement on Recommendations and Finalization of the Report phase involves reviewing, discussing options, and collaboratively selecting the options that the Dialogue group determines

are the most appropriate to address the key issues and meet the objectives of the effort. Once consensus is reached, the report outlining the Dialogue group's deliberations and conclusions is finalized. This phase is approximately four weeks.

Presentation of the Report and Recommendations follows immediately the finalization of the consensus report. All preparations are conducted during the previous phase so that the recommendations presented are as timely as possible.

Outcomes: The Dialogue group will be tasked with completing a final report containing an overview of the issues and consensus recommendations for adapting the current public HIV-related health care financing and service provision systems in accordance with the new standard of care. The report and recommendations will be presented to those additional key decision makers not involved in the project who are critical to implementing the proposals, including policy changes, dedication of resources, or forming collaborative alliances, to enhance the impact of the final report. The important elements for assuring that the Dialogue group recommendations have a beneficial impact include the quality of the proposals and recommendations, their support by the diverse constituencies that developed and agreed to them, and the presentation of the recommendations to those who are important to their timely and effective implementation. The report and recommendations also will serve as groundwork for the separate, broader discussions and efforts that should take place to fully align the health care financing and service provision systems comprehensively and effectively.

Funding: Financial support for this project will be secured from public and private entities, including private foundations, companies and government agencies. Given the federal government's key role in these issues, it is anticipated that a significant portion of the budget, totaling approximately \$420,000, will be contributed by the primary agencies. The diversity of funding sources, however, will emphasize the interest in and support for resolving these issues by a diverse group of stakeholders.

**Keystone Exploratory Session on Public HIV-Related Health Care Financing
and Service Provision Systems**

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Keystone

9/2

Conv. w/ Teije Anderson

TS: Concerned about proposal - overemphasis on rec's as outcome

~~TS~~ Problem w/ Jeff as "co-chair" - he should be involved, though

TA: Going to call (Abbie) & (Jeff) → lower his profile

↙
how much control does KS have
as opposed to Jeff

Keystone

8/20/97

Jeff
Aloby
Ernest
Mariella
Katie O'Neill

Out of last meeting

Dialogue is necessary
Work-group should meet

TS: confusion about Keystone as the process

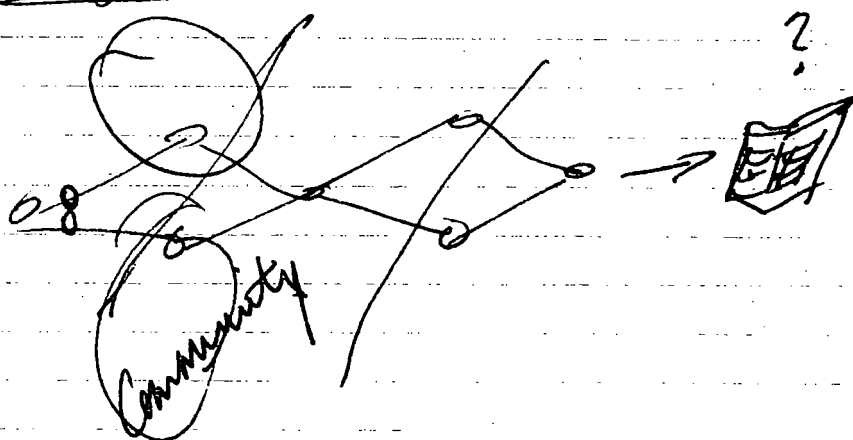
EH: - thought there was agreement around as carrying process
forward
- doesn't want to spend a lot of time searching the universe
for possible processes

① - { where they are
where they want to be } longer term input mechanism

② different dialogues

Marsha → Services Committee as convener

Dialogues



Keystone Work Group Meeting

August 20, 1997

Agenda

- 1) Goals and Objectives of the Work Group Meeting
- 2) Development of a Problem Statement and Objectives of a Future Effort
- 3) Structure of an Effort
- 4) Participation
- 5) Next Steps

Problem Statement

- Dynamics (epidemic, treatment, demographics, length of life, etc..) are changing. Many people underserved or not served at all by the health care system. The system needs to be assessed and evaluated with the goal of ensuring that all who need care have access to care.
- Problem statement should convey the sense of urgency with which these issues need to be addressed.

Five major shifts of the landscape on which structuring systems:

- 1) Epidemics are changing.
- 2) Treatment strategies are changing.
- 3) Health care financing is changing.
- 4) Public perception of the government's role is changing.
- 5) Increased understanding of social inequities are highlighted by HIV.

Objectives

- Ensure care as early as possible for those with HIV.
- Generally, the best system of care will integrate people into the system as soon as their status is known so that they are able to make treatment choices.
- How do we create an effective transition phase to move from the current system to an ideal one that best serves people.
- The system needs to assure equity, parity, and inclusion regarding access.

Context and Questions

Additional context for the dialogue included the following:

- Focus on federal and state financing strategies for the deliberations, but outline the context of other public, as well as private, sources of funding.

- There are problems with the overall health care system, but the dialogue is specifically focusing on issues affecting people with HIV/AIDS.
- An effective system of services is a broad continuum from prevention to early determination of status, to end stage AIDS care.
- Substance abuse treatment and harm reduction needs to be discussed.

Potential Participants

- People with HIV (women, people of color, drug users)
- Immigrants and those who provide services to immigrants
- Private payers\managed care (e.g. HIAA or AAHP)
- Those who provide services to families
- Physicians
- Treatment experts
- Native Americans
- Governors' Association
- People who are from outside the beltway
- Those familiar with Medicaid and Medicare
- Social Security Administration
- Service providers for women with alcohol and/or drug problems
- Community-based organizations
- Criminal justice system representatives
- Adolescent/youth representatives
- Treatment skeptics
- State alcohol and drug abuse system representatives
- Community leaders



The Keystone Center

MEMORANDUM

To: Terje Anderson, Mariella Cummings, Ernest Hopkins, Jeff Levi,
Christine Lubinski, Miguelina Maldonado, Katie O'Neill, Todd Summers,
and Lorraine Teel

From: Abby Dilley

Subject: Work Group Meeting/Conference Call

Date: August 14, 1997

Thanks to all of you for volunteering to participate in developing a proposal to the larger group for continuing discussions on HIV-related health care financing and service provision systems. In order to take advantage of the momentum generated by last week's meeting, I hope we can schedule a work group meeting as soon as possible.

Having talked with several of you, the best date appears to be next week **Tuesday, August 19th**. We will meet for about four hours, from **1:00 p.m. until 5:00 p.m. eastern time**. Those of you located in Washington, D.C. will meet at our offices at 1001 G Street NW, Suite 430W. We are right over Metro Center, accessible by the red, orange, and blue lines. Those of you from out of town will participate via conference call. As soon as we confirm that this schedule is possible for the majority of you, I will send additional logistical information, such as a conference call number and access code. **Please confirm your participation by close of business Friday, August 15th by phone (202)783-0248 or fax (202)783-0328.** I will send out a meeting summary to all of you for review and comment prior to sending a proposal to the full group. Those of you who cannot participate in the call at all or miss portions of it will be briefed on the work group discussion. If this date does not work for the majority of you, we will reschedule as soon as possible.

The purpose of the meeting will be to develop a proposal for continuing discussions on these important issues. The agenda will include development of a project statement and determination of project objectives, structure, participation, and next steps. If this work group can reach general agreement on a proposal with one or a few different options for proceeding, we will circulate this to the larger group for reaction. If the larger group is enthusiastic about the proposal, we will move forward with the next steps. If a general proposal cannot be agreed to by the work group, we will inform the larger group of the discussions and reasons for disagreement.

Again, thank you for your time and enthusiasm. I look forward to working with you.

713\01\025apd



The Keystone Center

MEMORANDUM

To: Terje Anderson, Mariella Cummings, Ernest Hopkins, Jeff Levi,
Christine Lubinski, Miguelina Maldonado, Katie O'Neill, Todd Summers, and
Lorraine Teel

From: Abby Dilley

Subject: Work Group Meeting/Conference Call

Date: August 18, 1997

After talking with several of you about meeting to continue discussions on HIV-related health care financing and service provision systems it was clear that, Tuesday, August 19th was problematic for a majority of the group. Although it is difficult to match every schedule, I would like to reschedule the meeting for **Wednesday, August 20, 1997** so that more of you are able to participate in the discussions. The meeting time of **1:00 p.m. until 5:00 p.m. eastern time** and the agenda will remain the same.

Those of you located in Washington, D.C. will meet at our offices at 1001 G Street N.W., Suite 430 West. We are right over the Metro Center station, accessible by the red, orange, and blue lines. Those of you from out of town will participate via conference call. To access the conference call dial 1-800-477-1232, tell the operator you are calling to participate in the Keystone Center conference call and that the moderator is Abby Dilley.

For Miguelina and Lorraine, who are unfortunately unable to participate in the meeting due to scheduling conflicts, I will follow-up with them to brief them on the discussions of the work group and any proposals that we developed. Their comments will be incorporated prior to sending any materials to the larger group.

If you have any questions, please call me at 202-783-0248. I look forward to meeting with you on Wednesday.

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THE KEYSTONE CENTER

DATE: July 17, 1997 **NUMBER OF PAGES (INCLUDING COVER SHEET):** 8

TO: Sandra Thurman, 202-632-1096

FROM: Abby Dilley

PROJECT: 7130

PROJECT/OVERHEAD CODE: 0000

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The Keystone Center

July 17, 1997

Sandra Thurman
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Dear Ms Thurman:

I have tried to reach you by phone to update you on what has been happening with regard to the potential Keystone dialogue project on Public HIV-Related Health Care Financing and Service Provision Systems which we discussed several weeks ago. Hopefully, this is a more convenient way of providing you with information, though I would very much appreciate the opportunity to talk with you about any comments, suggestions, or concerns you may have about this effort. I also hope that you can attend an organizational meeting scheduled for Thursday, August 7th to determine whether a consensus-building effort on these issues is appropriate at this time.

After several conversations with many of the key interest groups, organizations, and agencies, there seems to be significant interest in moving forward with a collaborative effort. The next step is to convene a cross-section of decision makers, reflective of the group that would participate in a dialogue project, to determine collectively whether a consensus-building effort is desirable, on what specific issues, and with what particular goals and objectives. While the proposal offers a framework for such an effort, the participants are the ones who ultimately define these most critical aspects of a dialogue project. If on August 7th the group does conclude that a consensus-building effort on a set of issues is appropriate, then several procedural considerations need attention, including a meeting schedule, identification of any additional participants, funding, and determination of materials useful to inform and enrich the discussion.

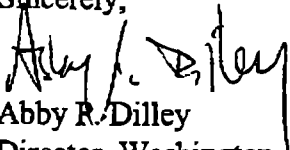
Response to the organizational meeting has been strong. Enclosed is a tentative participant list, including those to date who have been contacted to attend. The list is continuing to evolve and most, but not all, have confirmed participation. I am very encouraged by the response and commitment of time and attention to this meeting focused on public HIV-related health care financing and service provision systems, that there is substantial interest in a collaborative dialogue project. We will see if this is true on August 7.

Letter to Sandra Thurman
July 17, 1997
Page Two

Again, I hope that you are able to attend this important meeting. Your contribution to shaping and participating in such an effort is critical. Additional materials regarding logistics and a meeting agenda will be forthcoming. The first portion of the meeting will concentrate on defining the set of issues and questions of a consensus-building effort and whether or not there is agreement that a dialogue project should proceed. If the group does agree to move forward, the remainder of the meeting will focus on the procedural issues. If your schedule is difficult for that day, perhaps attending the first portion would not be too prohibitive.

Please let me know if you can attend the meeting, and any comments, questions or ideas you have about the potential project would be welcomed.

Sincerely,



Abby R. Dilley
Director, Washington, DC Office
Vice President, The Keystone Center

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**Keystone Exploratory Session on Public HIV-Related Health Care Financing
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8/7/97

Is a policy dialogue an appropriate mechanism for addressing potential changes in HIV/AIDS service delivery system?

Others who need to be part:

- substance abuse providers & SAMHSA
- mental health service providers
- people living with HIV/AIDS
- treatment advocates & NIH

Bill Corr

- HHS doing analysis of AIDS programming
- can't continue all that we have done, and do all that needs to be done ~~that~~

FORMAL PROCESS?

Out of box

Christine

- build capacity in other systems
MH, SA

Mark Gerson

- intersecting policies making it harder

- homeless ~ federal \$

- ~~are~~ animosity toward substance users & immigrants

Bill Corr

- because we've been paying for services
doesn't mean that we've been successful

- devolution/decentralization
- legislated social agenda

Keystone

8/7/97

(2)

- Missing charts

torpedoes, not iceberg
not yet in the boat
1500's map

"The Least of the Very Broken"

by David Boyer

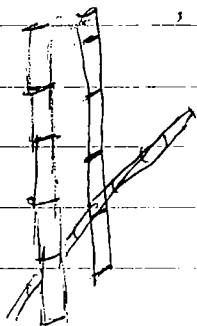
What does Keystone process look like?

- 1) collaborative consensus-building
- 2) creative, constructive policy recommendations

? Redundancy -

- Develop a broader standard of care, with steps as to how to make that standard available to as many PWAs as possible.

Public official participation - finance issue until the end



Problem Statement what does this mean?

(Dynamics (treatment, demographics, length of life)
changing - many people under-served or unserved -
need to look at system to insure

- how best to serve
- equity, parity & inclusion
- urgency
- focus on fed-state financing strategies
- early integration (once status known) into care

**Keystone Exploratory Session on Public HIV-Related
Health Care Financing and Service Provision Systems**

The Omni Shoreham Hotel

Washington, DC

August 7, 1997

Agenda

- 8:00 a.m. Coffee and Informal Discussion
- 8:15 a.m. Welcome, Introductions, Meeting Background, Meeting Objectives, Ground Rules, and Agenda Review
- 9:30 a.m. Comments by William Corr, *Chief of Staff, Office of the Secretary, Department of Health and Human Services*
- 9:45 a.m. Context for a Potential Policy Dialogue Questions
Nick Bollman, *Chair, Services Committee, Presidential Advisory Council for HIV/AIDS and Senior Program Director, The James Irvine Foundation*
- 10:30 a.m. Break
- 10:45 a.m. Policy Dialogue Questions:
1) Does the context create a compelling case for reviewing and discussing the current public financing and service provision systems to consider what, if any, modifications are appropriate?
2) If yes, then what are the key issues and questions that would shape this review and discussion?
- 12:00 p.m. Lunch
- 1:00 p.m. Continuation of Policy Questions Discussion:
3) What does a policy dialogue look like?
4) Would a collaborative, consensus-building policy dialogue be a constructive vehicle for conducting this discussion and developing policy recommendations?
- 2:00 p.m. If a consensus-building policy dialogue is determined to be appropriate and desirable, then several issues need to be addressed:
1) Dialogue goals and outcomes
2) Key questions or issues to frame the dialogue
3) Participants
4) Ground rules
5) Background materials
6) Funding
7) Time frame and meeting schedule
- 3:15 p.m. Next Steps
- 4:00 p.m. Adjourn

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The Keystone Center

MEMORANDUM

To: Participants of the Keystone Exploratory Session on HIV-Related Health Care Financing and Service Provision Systems

From: Abby Dilley and Debbie Eakin

Subject: Update

Date: November 14, 1997

As you will recall, during the exploratory session held in August a subset of volunteers from the full group was tasked with developing a proposal for a focused effort on issues associated with HIV-related health care financing and service provision systems. The participants of this group included Terje Anderson, Mariella Cummings, Ernest Hopkins, Jeff Levi, Christine Lubinski, Miguelina Maldonado, Marsha Martin, Katie O'Neill, Todd Summers, Lorraine Teel, and Deborah von Zinkernagel (for Eric Goosby). Before being circulated to the full group, the subgroup needed to reach agreement on a model to propose.

After three sessions and several drafts of proposed options, two issues have become clear: 1) there is continued interest in having a constructive discussion on HIV-related health care service provision and financing systems; and, 2) a satisfactory model for moving forward with these discussions has not been identified. The subgroup made a strong effort to identify and develop a model that could be circulated to the larger group for consideration, but for various reasons, could not reach agreement on a single model that is appropriate for this group to pursue. Therefore, at this time, this exploratory effort is concluded. We thank you for your time and your patience with allowing the subgroup to do their work. If in the future an opportunity arises that is more timely and appropriate for a dialogue project to be useful, we will look forward to working with you.

In the meantime, other initiatives are underway. The Department of Health and Human Services has indicated that they are organizing a national discussion concerning HIV-related health care service provision systems. Additional information about this effort will be available at the end of this month. Other organizations and groups also are considering whether and how to continue discussions surrounding these critical issues.

Again, thank you for your time and interest in this exploratory effort. We hope there are other opportunities in the near future to work with you.

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