

Special Report

State policies and the financing of acquired immunodeficiency syndrome care

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State policies, with respect to the operation of Medicaid programs and the regulation of private health insurance, affect who gets what care, how much is spent, and who ultimately pays. A RAND Corporation study was used to assess States and the District of Columbia in terms of the effects of their Medicaid and health insurance regulations on people with acquired immunodeficiency syndrome and other human immunodeficiency virus-related illnesses. State characteristics are used to explain the individual State policy rankings.

Introduction

A team at the RAND Corporation obtained information on the costs and financing of treatment for acquired immunodeficiency syndrome (AIDS) between fall 1987 and fall 1988 as part of a research project for the Health Care Financing Administration (HCFA), Office of Research and Demonstrations. In each State and in the District of Columbia, the Department of Health, the AIDS coordinating office (if such existed), the office administering the State's Medicaid program, and the agency charged with regulation of private health insurance companies were contacted. Officials were queried as to the nature of the human immunodeficiency virus (HIV) epidemic in that State and on a list of policies believed to affect access to public and private coverage, and reimbursement for HIV-related health care.

Significance of State-level policies

Treating HIV-related illness may cost the United States \$50 billion during the 1990's (Scitovsky and Rice, 1987; Sisk, 1987; and Pascal, 1987). Deciding on how to distribute that cost burden over Federal, State, and local government, employers, third-party payers, and patients poses major problems for our society. Policies that now govern the apportionment of AIDS expenditures were adopted before the onset of the HIV epidemic or in its very

early phases. Critical new policy decisions are impending. Significant initiatives need to be taken to organize and analyze available data in order to inform required policy choices on the financing of AIDS treatment.¹

The distribution of the costs of treating people with AIDS (PWA's) will be much different from that of other catastrophic illnesses. This difference is partly because of the nature of the disease—short survival times and mix of required services—and the demographic and socioeconomic characteristics of the affected population. State and Federal policies on Medicaid and private health insurance coverage influence the combination and amount of inpatient, outpatient, skilled nursing, and in-home services used, and, ultimately, who bears financial responsibility for the costs of these services.

The importance of understanding State policies on Medicaid and private insurance for PWA's becomes clear when we examine the distribution of AIDS expenditures across payers. Pascal (1987) presents estimates of payer shares by that year. He found that about 40 percent of the cost would fall on the Medicaid program under the most likely scenario. Subsequent studies, including Andrulis (1987), Buchanan (1988), California AIDS Leadership Committee (1988), and Sisk (1987), show that the Medicaid share ranges from 20 to 60 percent of patients dying from AIDS and from 10 to 30 percent of all AIDS-related medical expenditures. Substantial cost shares—compared with other major impairments—that fall upon public hospitals (perhaps 15 percent) and on patients and their families (perhaps 20 percent) are discussed in Pascal (1987) and Andrulis (1987).

AIDS will probably absorb about 5 percent of the Medicaid budget during the 1990's (Pascal, 1987). The Hospital Council of New York has estimated that by 1992, HIV-related State Medicaid payouts in New York will have doubled over current levels. California's Medi-Cal increase will probably be almost as large (California AIDS Leadership Committee, 1988). It is not at all unlikely, given these facts and the rapid spread of the epidemic, that many high-caseload States will see AIDS-related increases of 10 to 15 percent in Medicaid expenditures.

Current estimates suggest that public hospitals, funded by State and local governments, are picking up about 15 percent of the treatment costs because many of their patients have no insurance coverage and because State Medicaid systems reimburse only a

¹The National Center for Health Services Research and Health Care Technology Assessment, Public Health Service, is funding a grant and contract research to improve the estimates of the direct and indirect costs of AIDS and other HIV-related illnesses, including the collection of data on out-of-pocket payments and on the costs of treating pediatric AIDS patients.

fraction of true costs (Andrulis et al., 1987). Patients and their families seem to be paying about 20 percent of the costs out of pocket.²

Policy environment

Knowledge of the distribution of AIDS-related expenses is important input to the policy debate on treatment finance. A number of major policy proposals have been offered. For example:

Services covered and reimbursed

- Encouraging more home and community-based waiver programs under Medicaid to discourage "over-hospitalization" and bring down costs.
- Cutting Medicaid coverage for certain services (e.g., intensive care).
- Expanding Medicaid reimbursement for certain services (e.g., nursing facilities and hospices).

Defining eligibility

- Either expanding the definition of presumptive disability to include all symptomatic HIV-infected persons or limiting the definition to only those PWA's with most severe opportunistic infections. (Azidothymidine, for instance, is assumed to significantly reduce and/or postpone disabling symptoms.) Fewer persons will then qualify for Supplemental Security Income (SSI) and Medicaid.
- Further broadening the Centers for Disease Control's official definition of AIDS so as to include more people with serious AIDS-related complex (ARC) conditions.³ This would result in more people eligible for SSI and Medicaid.

Restructuring Federal financing

- Increasing the Federal Medicaid share for AIDS-related claims.
- Allowing State Medicaid systems to pay private insurance premiums for PWA's who cannot continue to pay themselves.
- Permitting "uninsurables" to join State Medicaid programs for which they would be billed through means-testing and subsidized premiums.
- Reducing the Medicare waiting period for chronically ill persons below the current 24 months.
- Developing a Federal "disaster relief" program to assist public hospitals (and local social service agencies) that are disproportionately affected in caring for PWA's.

²The source for these conjectures is ongoing RAND work for HCFA on the cost and financing of HIV-related care, as revealed in interviews with PWA's.

³In 1987, the Centers for Disease Control revised the definition of AIDS, expanding the AIDS population to include some people previously defined as having ARC.

Improving private insurance regulation

- Tightening regulation of health benefits under Employee Retirement Income Security Act (ERISA) of 1974 plans (employer self-insurance). This would lessen discrimination against, and limitations on, PWA's and keep more of them in the private payer system.
- Extending the Consolidated Omnibus Budget Reconciliation Act (COBRA⁴) of 1986 to protect people who lose their jobs with small employers and extending continuation guarantees beyond 18 months to match extension in life expectancy. These changes would also keep more patients in private plans and off Medicaid rolls and/or out of public hospitals.
- Encouraging States to more stringently regulate private third-party health plans, especially multiple employer trusts whose recovery and takeover provisions can result in a situation where workers in small firms have essentially no coverage for serious, chronic illness, including AIDS.
- Promoting (i.e., subsidize) State-managed health insurance risk pools to provide coverage for PWA's.

Intelligent policy on the framing on HIV care requires good intelligence about the current situation. We need to know how policy changes will shift the burden of caring for those infected with HIV among State, Federal, and private payers.

Medicaid rules and insurance regulations

Each State's⁵ Medicaid policy office, insurance regulation office, and health department were contacted by telephone between October 1987 and September 1988. At least one representative from each agency participated in an interview lasting about 10 minutes; often it proved necessary to interview several people. Followup calls were made to get updates on policy changes. In some cases, it was impossible to find a person who could answer our questions and so the reader occasionally will find "NA" (not available) listed in the tables. When possible, we compared our results with previously published data, and inconsistencies were resolved through further followup calls.

Extent of the epidemic

Data on the extent of the HIV epidemic for all States are shown in Table 1. Also included are data on the magnitude of HIV infection (when State health officers were willing to estimate it), on whether a case

⁴COBRA 1986 extends health insurance continuation coverage at premiums no higher than 102 percent of the previous employer-plus-employee contributions to workers who lose their jobs at employment sites with 20 or more workers.

⁵In what follows, "States" will be assumed to include the District of Columbia.

Table 1
Statistics on human immunodeficiency virus (HIV)-related illness, by State: 1987-88

State	Total number of HIV seropositive 1987-88	ARC report required	AIDS cases		Risk group percent among AIDS diagnosees			State expenditures for AIDS through 1987 in thousands ¹
			Total Dec. 1987	Per million population	Homosexual/bisexual	IVDA	Other	
Alabama	NA	Yes	215	19	79	11	18	\$1,893
Alaska	1,863	No	36	62	75	4	21	498
Arizona	NA	Yes	315	19	79	8	13	0
Arkansas	NA	Yes	87	76	77	11	12	440
California	NA	No	10,954	315	80	13	7	58,033
Colorado	15,000	Yes	521	119	91	4	5	414
Connecticut	NA	No	571	127	NA	NA	NA	4,800
Delaware	NA	No	75	82	65	30	5	36
District of Columbia	NA	No	957	977	96	2	2	3,660
Florida	NA	No	3,623	225	NA	NA	NA	12,539
Georgia	36,000	No	1,078	125	88	NA	12	414
Hawaii	6,000	No	182	121	NA	NA	NA	631
Idaho	200	Yes	16	8	86	14	0	0
Illinois	NA	Yes	1,317	73	NA	NA	NA	3,428
Indiana	846	No	146	26	NA	NA	NA	0
Iowa	NA	No	63	14	NA	NA	NA	8
Kansas	NA	No	103	28	70	12	18	213
Kentucky	1,000	No	109	21	81	9	10	60
Louisiana	26,000	No	670	96	88	3	9	0
Maine	NA	No	59	35	NA	NA	NA	319
Maryland	NA	No	882	124	NA	NA	NA	2,002
Massachusetts	60,000	No	1,038	118	86	8	6	7,591
Michigan	NA	No	463	31	NA	NA	NA	2,500
Minnesota	15,000	No	287	43	90	7	3	1,350
Mississippi	NA	No	89	17	87	8	5	0
Missouri	NA	No	392	43	83	8	7	255
Montana	NA	Yes	13	8	NA	NA	NA	70
Nebraska	142	No	44	15	76	8	16	0
Nevada	NA	No	153	102	85	11	4	0
New Hampshire	NA	No	55	29	87	6	7	59
New Jersey	NA	Yes	3,143	266	NA	NA	NA	7,907
New Mexico	6,750	No	90	42	92	3	5	500
New York	NA	No	13,171	585	58	38	4	39,920
North Carolina	23,800	No	364	34	82	10	8	330
North Dakota	NA	No	46	6	NA	NA	NA	0
Ohio	40,000	Yes	579	27	91	7	2	250
Oklahoma	NA	No	189	32	93	2	5	280
Oregon	14,000	No	279	482	91	4	6	1,980
Pennsylvania	NA	No	1,220	63	92	3	5	350
Rhode Island	NA	No	120	69	NA	NA	NA	389
South Carolina	NA	No	186	37	NA	NA	NA	0
South Dakota	700	No	5	5	75	25	0	0
Tennessee	15,000	No	173	21	87	8	7	0
Texas	NA	No	3,465	150	93	2	5	1,535
Utah	2,000	No	90	40	90	5	5	85
Vermont	1,000	No	24	21	67	23	10	0
Virginia	NA	No	562	72	NA	NA	NA	543
Washington	15,000	Yes	675	99	95	2	3	398
West Virginia	NA	Yes	41	11	65	9	16	0
Wisconsin	NA	No	174	21	80	7	13	543
Wyoming	33	No	8	14	75	8	17	0

¹Does not include Federal share of Medicaid.

NOTES: AIDS is acquired immunodeficiency syndrome. ARC is AIDS-related complex. IVDA is intravenous drug abusers. NA is not available.

SOURCES: The RAND Corporation: Data from the RAND Corporation assessment of Medicaid rules and insurance regulations, 1987-88; (Centers for Disease Control, 1988; General Accounting Office, 1987; Rowe and Ryan, 1988.)

of ARC must be reported to State authorities, on the number of AIDS cases registered,⁶ and on the distribution of cases by transmission group (again, when our respondents were willing to make an estimate). Finally, Table 1 contains some information on the cumulative State spending on medical care for those disabled by AIDS up through the end of 1987.

Examination of these results suggests that data with respect to HIV infection and ARC are only scantily available. Where the distribution by means of transmission is known, more than 75 percent of cases to fall into the homosexual and bisexual male group.⁷ Interestingly, it is in the Eastern States (e.g., New York, New Jersey, Delaware, Vermont, and West Virginia) that drug abusers and others form a sizeable share of AIDS patients. Cumulative expenditures, as one would expect, are highly correlated with the AIDS caseload. (The simple correlation coefficient is 0.92.) The most striking anomalies in these data are the high spending in Massachusetts (where we would have expected about \$3.5 million instead of \$7.6 million) and the low spending in Texas (where we would have expected about \$10.7 million instead of \$1.5 million).⁸ Although this analysis is muddled in that we compare State-Medicaid-only spending with total AIDS caseload, it probably also reflects the lenient Medicaid environment in Massachusetts as compared with the restrictive environment in Texas.

Medicaid policies

State Medicaid programs vary with respect to eligibility and coverage. Our conversations with Medicaid offices in each of the States produced useful information on both eligibility standards and provision of services.

Eligibility standards

Generally, individuals qualify for Medicaid in one of two ways:

- They may be members of a "mandatory group," such as those receiving benefits under Aid to Families with Dependent Children (AFDC), Supplemental Security Income (SSI), or various poverty-level groups, including pregnant women and infants.
- They may be members of "optional groups," such as the medically needy, who are required to meet all the criteria for cash assistance under AFDC or SSI, except that their income and assets may be above the AFDC or SSI maximum.

⁶We have substituted data released by the Centers for Disease Control, Public Health Service, for the data we tried to collect from the individual States. The former source proved substantially more complete and reliable.

⁷More current and complete information on transmission mode is available from the surveillance files of the Centers for Disease Control, Public Health Service, in Atlanta.

⁸For the list of States, spending runs about \$5,000 per AIDS case, when the two variables are regressed by ordinary least squares.

Currently, all those with an AIDS diagnosis meeting the requirements established by the Centers for Disease Control are "presumptively disabled" and thus eligible for SSI. States typically impose income and asset maxima that govern qualification.

We first include data on a general indicator of Medicaid eligibility: the ratio of the Medicaid population to the poverty population in the State. The higher that measure, the easier eligibility for Medicaid would appear to be.

The higher a State's SSI income eligibility standard, the sooner a person becomes eligible for Medicaid. The SSI income eligibility criterion for a single person in most States falls within the range of \$4,000 to \$5,000 per year, but several States have cutoffs outside this range. Generally, one must be unemployed to receive Medicaid coverage through SSI. In order to significantly increase Medicaid's share of AIDS costs, the income and asset requirements would have to be raised to a level consistent with income from a full-time job at the minimum wage—about \$7,000 a year. Only two States—Alaska and California—have standards this high, and none of our respondents indicated that their State was planning to raise its standard to such a level.

Many States have a medically needy program that employs a more generous (i.e., compared with SSI) income eligibility standard based on the difference between income and medical expenditures. Thus, in some States, individuals with income or assets too high for Medicaid eligibility under SSI, but with substantial medical expenses, will qualify under the medically needy program. Also, individuals with HIV-related health problems, but who do not (yet) have AIDS, can become eligible through medically needy programs.⁹

Thirty-four States have such indigent care programs, providing some medical services to people who do not qualify for Medicaid. There is no Federal funding for these programs. These programs are an important source of care for HIV-seropositive individuals who have depleted their own financial resources yet cannot qualify for Medicaid. The services available under indigent care programs vary across States and from county to county within some States. Generally, people dependent upon this assistance program are limited to receiving inpatient care in county hospitals only, and often have limited coverage for skilled nursing facility care, outpatient prescription drugs, and mental health services.

Data indicating ease of eligibility for the various State Medicaid systems are shown in Table 2. Column 4 of the table contains the results of a simple scoring scheme devised to assess the differences in Medicaid eligibility. The State received 1 point if its ratio of Medicaid beneficiaries to its poverty population exceeded 1, an additional point if the eligibility income cutoff exceeded \$5,000, and a third point if

⁹Most States allow a maximum of \$2,000 in assets in addition to a home and one car.

Table 2
Indicators of access to State Medicaid systems, by State: 1987-88

State	Ratio of Medicaid beneficiaries to poverty population (1)	Income cutoff for eligibility (2)	Medically needy program to accommodate HIV + s (3)	Medicaid access score (4)
Alabama	0.46	\$1,416	No	0
Alaska	0.42	8,880	No	1
Arizona	0.55	2,304	No	1
Arkansas	0.50	2,304	Yes	1
California	1.28	7,404	Yes	3
Colorado	0.58	5,052	No	1
Connecticut	0.91	6,060	Yes	2
Delaware	0.65	3,720	No	0
District of Columbia	0.51	4,200	Yes	1
Florida	0.34	3,024	Yes	1
Georgia	0.45	3,072	Yes	1
Hawaii	1.20	5,616	Yes	3
Idaho	0.35	3,648	No	0
Illinois	0.83	4,092	Yes	1
Indiana	0.44	3,072	No	0
Iowa	0.59	4,572	Yes	1
Kansas	0.65	4,524	Yes	1
Kentucky	0.65	2,364	Yes	1
Louisiana	0.51	2,280	Yes	1
Maine	1.11	6,432	Yes	3
Maryland	0.73	4,140	Yes	1
Massachusetts	1.57	5,712	Yes	3
Michigan	0.95	5,388	Yes	2
Minnesota	0.81	6,384	Yes	2
Mississippi	0.47	4,416	No	0
Missouri	0.58	3,348	No	0
Montana	0.44	3,984	Yes	1
Nebraska	0.42	4,200	Yes	1
Nevada	0.32	3,420	No	0
New Hampshire	0.58	4,668	Yes	1
New Jersey	0.96	4,848	Yes	1
New Mexico	0.38	3,096	No	0
New York	1.03	5,964	Yes	3
North Carolina	0.46	2,952	Yes	1
North Dakota	0.36	4,452	Yes	1
Ohio	0.75	3,624	No	0
Oklahoma	0.65	3,720	Yes	1
Oregon	0.82	4,764	Yes	1
Pennsylvania	1.15	4,380	Yes	2
Rhode Island	1.31	5,292	Yes	3
South Carolina	0.50	4,560	No	0
South Dakota	0.31	4,392	No	0
Tennessee	0.44	1,860	Yes	1
Texas	0.33	2,208	Yes	1
Utah	0.45	8,316	Yes	2
Vermont	0.83	6,372	Yes	2
Virginia	0.51	3,492	Yes	1
Washington	0.69	5,904	Yes	2
West Virginia	0.72	2,988	Yes	1
Wisconsin	1.06	6,528	Yes	3
Wyoming	0.31	4,320	No	0

¹This is the income cutoff for an AFDC (Aid to Families with Dependent Children) family of 3; it does not apply specifically to people with AIDS. A better measure for the income cutoff might have been the combined Supplemental Security Income level but data on that measure were not readily available to us.

NOTE: HIV + s is human immunodeficiency virus seropositives.

SOURCES: The RAND Corporation: Data from the RAND Corporation assessment of Medicaid rules and insurance regulations, 1987-88; (General Accounting Office, 1987; Urdman and Wolf, 1988.)

Table 3

Services provided to people with acquired immunodeficiency syndrome under Medicaid, by State: 1987-88

State	Reimbursement for AZT ¹ (1)	Hospice services covered (2)	Home care waiver applied for (3)	Increasing reimbursement for nursing home services (4)	Unlimited inpatient days covered (5)	Medicaid service score (6)
Alabama	No	No	No	No	No	0
Alaska	Yes	No	No	No	Yes	2
Arizona	Yes	No	No	Yes	Yes	3
Arkansas	No	No	No	No	Yes	1
California	Yes	UR	Yes	No	Yes	3
Colorado	No	NA	No	No	Yes	1
Connecticut	Yes	Yes	No	No	Yes	3
Delaware	Yes	Yes	No	No	Yes	3
District of Columbia	Yes	No	No	NA	Yes	2
Florida	Yes	Yes	No	Yes	No	3
Georgia	Yes	No	No	No	Yes	2
Hawaii	Yes	No	Yes	No	Yes	2
Idaho	Yes	No	No	No	No	1
Illinois	Yes	UR	No	No	Yes	2
Indiana	Yes	No	No	No	Yes	2
Iowa	Yes	No	No	NA	Yes	2
Kansas	Yes	Yes	No	No	Yes	3
Kentucky	Yes	Yes	No	Yes	No	3
Louisiana	Yes	No	No	No	Yes	2
Maine	Yes	No	No	NA	Yes	2
Maryland	Yes	No	No	Yes	Yes	3
Massachusetts	Yes	UR	No	No	Yes	2
Michigan	Yes	Yes	No	No	Yes	3
Minnesota	Yes	Yes	NA	NA	NA	2
Mississippi	Yes	No	No	No	No	1
Missouri	Yes	No	No	No	Yes	2
Montana	Yes	No	No	NA	Yes	2
Nebraska	Yes	No	No	No	Yes	2
Nevada	Yes	No	No	No	Yes	2
New Hampshire	Yes	UR	No	No	Yes	2
New Jersey	Yes	UR	Yes	Yes	Yes	4
New Mexico	Yes	Yes	Yes	No	Yes	4
New York	Yes	Yes	No	Yes	Yes	4
North Carolina	Yes	Yes	Yes	No	Yes	4
North Dakota	Yes	Yes	Yes	No	Yes	4
Ohio	Yes	Yes	Yes	Yes	Yes	5
Oklahoma	Yes	No	No	No	Yes	2
Oregon	Yes	No	No	Yes	No	2
Pennsylvania	Yes	No	No	No	Yes	2
Rhode Island	Yes	No	No	No	Yes	2
South Carolina	Yes	No	Yes	NA	Yes	3
South Dakota	Yes	Yes	No	Yes	Yes	4
Tennessee	Yes	Yes	No	No	No	2
Texas	Yes	No	No	No	No	1
Utah	Yes	No	No	No	Yes	2
Vermont	Yes	Yes	No	No	No	2
Virginia	Yes	No	No	No	Yes	2
Washington	Yes	No	No	Yes	Yes	3
West Virginia	Yes	No	No	No	No	1
Wisconsin	Yes	No	No	Yes	Yes	3
Wyoming	Yes	No	No	Yes	Yes	3

¹Currently only Alabama does not reimburse for azidothymidine.

NOTES: NA is not available. UR is under review.

SOURCES: The RAND Corporation: Data from the RAND Corporation assessment of Medicaid rules and insurance regulations, 1987-88; (Buchanan, 1988; General Accounting Office, 1987.)

people with AIDS are automatically eligible for its medically needy program. The range is thus 0 to 3. The States with the broadest eligibility criteria are California, Hawaii, Michigan, New York, Rhode Island, Maine, Massachusetts, and Wisconsin followed by Connecticut, Minnesota, Pennsylvania, Utah, Vermont, and Washington (Table 2).

Services provided

How States differed in terms of coverage of and reimbursement for services used by PWA's is shown in Table 3.

PWA's, like some other chronically ill Medicaid beneficiaries, face problems of obtaining care because many providers do not accept Medicaid, and many States place limitations on the maximum amounts of certain services covered by Medicaid. (These problems may be compounded by the general reluctance on the part of providers to serve individuals with HIV infection.) Moreover, PWA's need a unique blend of inpatient, skilled nursing, and home care services. Our questionnaire results focused on some basic means by which States could expand access to care for PWA's.

According to a recent survey, approximately one-half of the AIDS and HIV patients on alternative care status would benefit from skilled nursing home care (New York Department of Health, 1988). Ideally, by increasing Medicaid nursing home reimbursement rates for PWA's, States can provide an incentive for these facilities to accept PWA's who generally require more nursing care than the average patient.¹⁰ This aspect of service is covered in column 4.

Medicaid waivers for home and community-based services (State policies are shown in column 3) can be used to provide coverage for home care as an alternative to inpatient care. Hawaii, New Jersey, New Mexico, Ohio, and California have received approval from HCFA for these waivers, and approval is pending on waiver applications from South Carolina. A number of other States reported that they did not apply specifically for waivers covering the AIDS population because they already utilized 2176 waivers for the disabled, which can include PWA's. Additionally, many home services can be covered through waivers for hospice care, for which 13 States provide Medicaid coverage¹¹ (Jones, 1988.)

States cite additional reasons for declining to apply for the waivers. First, several States prefer the flexibility inherent in serving people through State-only programs not subject to Federal regulations. States on their own can also prior-authorize coverage for special services, thereby precluding the need for an

AIDS-specific 2176 waiver. Secondly, to receive waiver approval, the State must prove that the waiver plan is budget-neutral. This requires research expenditure, an undertaking unlikely in a State with a low caseload. Third, the 2176 waiver applies only to PWA's who continuously require a steady level of care (e.g., in an institution). But the typical PWA goes through periods of wellness during which he or she will descend to a lower service-need level and lose valuable benefits (e.g., case management and counseling) (Rosansky, 1988). Although the 2176 waiver can reduce overall costs of treatment, some States feel they can achieve similar savings through other policies.¹²

We have supplemented our results with information on other State-specific Medicaid policies relevant to PWA's. This supplementary information relates to coverage for azidothymidine (AZT), a drug useful in suppressing and/or delaying symptoms common to the HIV-infected shown in column 1, coverage of hospice services in column 2, and limits on inpatient days for Medicaid eligibles in column 5.

We calculated a Medicaid service score based on the number of "Yes" answers. Given the variables we examined, the most generous Medicaid programs are in Ohio, followed by New Jersey, New Mexico, New York, North Carolina, North Dakota, and South Dakota.

Private health insurance policies

Policies with respect to the regulation of private health insurance encompass the securing of coverage and the protection of benefits for those covered. These were difficult data to collect. Particularly in the low-AIDS-incidence States, many of the regulations applicable to health insurance policies have never been applied to PWA's so that our respondents had to speculate on a hypothetical situation.

States regulate only third-party plans operative in their jurisdictions. Eighty percent of American workers are covered by self-insured plans that may be administered and/or reinsured by an insurance company, but the plans are regulated by the U.S. Department of Labor under ERISA. With respect to third-party plans, it has been alleged that the Labor Department regulation of ERISA plans is less stringent than is the practice among the States (California AIDS Leadership Committee, 1988).

Securing coverage

When HIV-infected individuals are excluded from private health insurance coverage, Medicaid bears a greater share of the AIDS treatment costs. PWA's

¹⁰States granting increased reimbursement still report access problems as a result of long waiting lists, shortage of single bed rooms, and the lack of facilities for infectious disease control within the nursing homes. Florida, on the other hand, has recently opened chronic care facilities that could serve PWA's.

¹¹However, fewer than six of these States have received HCFA approval for hospice care and thus, presumably, do not receive a Federal matching share for that coverage.

¹²Even a "waiver-covered" PWA may find that not all of his outpatient service needs are reimbursed. In California, for example, the waiver will provide for \$1,300 worth of services per month. At a cost of \$15 per hour for some home health attendants, the round-the-clock care needed by some patients would be reimbursed for fewer than 4 days per month.

will spend down to Medicaid eligibility levels at an earlier point in their illness than if they had private health insurance coverage at the time of diagnosis. Also, many of the infected, uninsured individuals with early symptoms will be burdened with out-of-pocket expenses because they will require regular medical attention but probably do not qualify for disability status. Uncompensated expenditures (e.g., in public hospitals) arise as these individuals can no longer pay bills out of pocket but lack the necessary AIDS diagnosis to immediately become eligible for Medicaid.

According to a recent survey of commercial health insurers, all of them rated PWA's as uninsurable, 99 percent rated individuals with ARC as uninsurable, and 91 percent said they would not knowingly cover anyone who is HIV seropositive (Intergovernmental Health Policy Project, 1988). Insurers seek to identify this last group, the asymptomatic infected individuals, by asking applicants to submit to an HIV antibody test. Insurers are primarily interested in testing applicants for individual health insurance policies and those in small groups (fewer than 50 members); large groups have experience-rated policies in which the current year's premium reflects the previous year's payout, protecting the underwriter against risk. Historically, large-group, employer-sponsored plans have not attempted to screen covered employees.¹³

Only a few States proscribe use of an HIV antibody test in the underwriting process.¹⁴ Insurers have been known to use T-cell helper counts blood tests to identify immune system abnormalities. The T-cell count is not an accurate means of identifying the HIV-infected because some infected individuals have normal T-cell counts and occasionally T-cell counts can drop below normal in uninfected individuals. Insurers recognize the drawbacks of using the T-cell count in underwriting and are lobbying heavily for the right to use the antibody test, at least in underwriting individual health insurance policies. Antibody testing has become common practice in the issuance of life insurance policies.

We also asked State insurance regulators whether insurers in their State were permitted to screen applicants on the basis of sexual preference, a device allegedly used to deny coverage to people "at risk" for HIV infection.

Finally, we attempted to obtain information on the existence of assigned risk pools in each State. These could be used by people with HIV-related illness who cannot secure individual health insurance coverage.

¹³It may, however, be the case that self-insured employers attempt to screen out HIV positives, or those suspected to be at risk for HIV infection, in order to control health insurance costs.

¹⁴Even States that do not forbid the use of HIV testing may attempt to protect the rights of HIV positives. Vermont, for example, places strict limits on the circumstances under which insurers can request the test and on the circulation of test results. Florida, New Hampshire, and Rhode Island have passed laws that attempt to balance the interests of insurers and the insured. Washington, and the District of Columbia, on the other hand, may be forced by Congress to stop precluding HIV testing for insurance purposes.

The replies were difficult to interpret because many respondents were uncertain of the legal status of assigned risk plans and of their applicability to HIV positives or PWA's. We gave a State a "Yes" on this item only when the respondent answered unambiguously in the affirmative.

The results of this portion of our research are shown in Table 4.

No State has a perfect score of 3 with respect to access to private health insurance. The States scoring 2 on this item are California, Washington, District of Columbia, Massachusetts, Michigan, Minnesota, New Jersey, New York, North Dakota, and Wisconsin.

Protecting benefits

State policies designed to provide access to private health insurance are identified in Table 4. How States attempt to protect the benefits of those who do secure private coverage are shown in Table 5. We asked respondents about three different policies—"mini-COBRA's", preexisting condition exclusions, and payout caps.

State "mini-COBRA's" do one of two things. They either extend "COBRA-like" protections to workers who had been affiliated with small employers, or they extend COBRA continuation protections beyond the 18 months stipulated in the Federal law. States with mini-COBRA's will retain more people under private coverage.

Some States have policies that prevent or discourage new policy underwriters from denying reimbursement for preexisting conditions such as HIV infection or AIDS.¹⁵ Because there is substantial turnover in health insurance underwriting, the absence of bans on exclusions for preexisting conditions can result in the loss of coverage and the shift of patients to Medicaid and/or public hospitals.

Almost all State regulators permit insurers to limit or cap certain treatments or services (e.g., dental care, psychiatric care, and ophthalmological care). Some States, however, do not permit insurers to limit reimbursement for specific diseases or conditions. Queries on this last policy constituted the final item in our questionnaire of State regulation of private health insurance benefits. The findings are shown in Table 5.

The score for private insurance benefits shows some States registering higher than was the case on the previous items. For example, California registers a 3, as well as Georgia, Kansas, North Carolina, and Pennsylvania. On the other hand, Michigan, New Jersey, New York, and Wisconsin—States that tended to score high on past items—registered scores of only 1 for private health insurance benefits.

¹⁵After the data were collected, we discovered the complexity of "recovery and takeover" provisions in the health insurance business, especially as these relate to Multiple Employer Trusts, often used by groups of small employers. As a result, we feel that reimbursement for preexisting conditions is problematical in many States that answered "Yes" (Table 5).

Table 4
State policies to provide private health insurance access for
human immunodeficiency virus (HIV)-affected populations, by State: 1987-88

States	Insurers cannot question about HIV test	Insurers cannot deny on basis of sex preference	Provides risk pool applicable to AIDS/HIV patients	Access score
Alabama	No	No	NA	0
Alaska	No	No	No	0
Arizona	No	Yes	NA	1
Arkansas	No	No	NA	0
California	Yes	Yes	No	2
Colorado	No	Yes	No	1
Connecticut	No	No	NA	0
Delaware	No	Yes	No	1
District of Columbia	Yes	Yes	NA	2
Florida	No	Yes	NA	1
Georgia	No	Yes	No	1
Hawaii	No	No	NA	0
Idaho	No	No	No	0
Illinois	No	Yes	NA	1
Indiana	No	No	Yes	1
Iowa	No	Yes	NA	1
Kansas	No	Yes	No	1
Kentucky	No	No	No	0
Louisiana	No	No	No	0
Maine	Yes	No	NA	1
Maryland	No	Yes	NA	1
Massachusetts	Yes	Yes	NA	2
Michigan	Yes	Yes	NA	2
Minnesota	No	Yes	Yes	2
Mississippi	No	No	No	0
Missouri	No	No	NA	0
Montana	No	Yes	NA	1
Nebraska	No	No	NA	0
Nevada	No	Yes	No	1
New Hampshire	No	No	No	0
New Jersey	Yes	Yes	NA	2
New Mexico	No	No	Yes	1
New York	Yes	No	No	2
North Carolina	No	No	NA	1
North Dakota	No	Yes	Yes	2
Ohio	Yes	No	No	1
Oklahoma	No	No	No	0
Oregon	No	Yes	NA	1
Pennsylvania	No	Yes	No	1
Rhode Island	No	No	NA	0
South Carolina	No	No	Yes	1
South Dakota	No	Yes	NA	1
Tennessee	No	Yes	NA	1
Texas	No	No	NA	0
Utah	No	No	No	0
Vermont	No	No	NA	0
Virginia	No	No	No	0
Washington	No	No	NA	0
West Virginia	No	No	NA	0
Wisconsin	Yes	Yes	NA	2
Wyoming	No	No	NA	0

NOTES: AIDS is acquired immunodeficiency syndrome. NA is not available.

SOURCE: The RAND Corporation: Data from the RAND Corporation assessment of Medicaid rules and insurance regulations, 1987-88.

Table 5

State policies protecting the benefits of human immunodeficiency virus and acquired immunodeficiency syndrome (HIV/AIDS) patients, by State: 1987-88

State	Provides extended COBRA protection	Insurers cannot use HIV/AIDS to exclude preexisting conditions	Insurers cannot cap specific diseases	Benefit score
Alabama	No	No	No	0
Alaska	No	No	Yes	1
Arizona	Yes	No	No	1
Arkansas	Yes	Yes	No	2
California	Yes	Yes	Yes	3
Colorado	Yes	No	Yes	2
Connecticut	Yes	No	No	1
Delaware	No	Yes	Yes	2
District of Columbia	NA	Yes	NA	1
Florida	NA	Yes	Yes	2
Georgia	Yes	Yes	Yes	3
Hawaii	Yes	No	NA	1
Idaho	No	Yes	Yes	2
Illinois	Yes	No	No	1
Indiana	No	No	Yes	1
Iowa	Yes	Yes	No	2
Kansas	Yes	Yes	Yes	3
Kentucky	Yes	No	No	1
Louisiana	No	No	Yes	1
Maine	Yes	No	NA	1
Maryland	Yes	Yes	No	2
Maine	Yes	No	Yes	2
Michigan	NA	Yes	NA	1
Minnesota	Yes	Yes	No	2
Mississippi	NA	NA	NA	0
Missouri	No	NA	No	0
Montana	NA	Yes	Yes	2
Nebraska	Yes	No	NA	1
Nevada	NA	No	No	0
New Hampshire	Yes	No	Yes	2
New Jersey	No	No	Yes	1
New Mexico	Yes	No	No	1
New York	No	No	Yes	1
North Carolina	Yes	Yes	Yes	3
North Dakota	Yes	No	Yes	2
Ohio	Yes	No	No	1
Oklahoma	Yes	No	No	1
Oregon	Yes	No	No	1
Pennsylvania	Yes	Yes	Yes	3
Rhode Island	Yes	No	Yes	2
South Carolina	NA	NA	No	0
South Dakota	NA	Yes	NA	1
Tennessee	Yes	Yes	No	2
Texas	NA	No	Yes	1
Utah	Yes	No	Yes	2
Vermont	Yes	No	No	1
Virginia	Yes	No	Yes	2
Washington	Yes	No	No	1
West Virginia	Yes	No	Yes	2
Wisconsin	NA	No	Yes	1
Wyoming	No	No	No	0

NOTES: COBRA is Consolidated Omnibus Budget Reconciliation Act of 1986. NA is not available.

SOURCE: The RAND Corporation: Data from the RAND Corporation assessment of Medicaid rules and insurance regulations, 1987-88.

Table 6
Definitions, descriptions, and sources for variables

Variable	Mean	Standard deviation	Minimum	Maximum	Source
POP—State population (in thousands)	4,616	4,732	402	23,667	(Bureau of the Census, 1988)
INC—State per capita income (\$)	10,417	1,533	7,483	14,090	(Bureau of the Census, 1988)
SOUTH—State located in South	.333	.476	0	1	(Bureau of the Census, 1988)
CASES—Number of AIDS cases, December 1987	650	1,776	2	10,289	Table 1
EXPPAT—State Medicaid expenditures/cases through 1987 (dollars in thousands)	3.7	4.9	0	25.2	Table 1
MEDELI—Medicaid eligibility score	1.196	.939	0	3	Table 2
MEDSER—Medicaid services score	2.392	.981	0	5	Table 3
MEDTOT—Combined Medicaid score	3.588	1.388	0	7	MEDELI + MEDSER
PVTACC—Private insurance access score	0.765	0.737	0	2	Table 4
PVTBEN—Private insurance benefits score	1.412	0.829	0	3	Table 5
PVTTOT—Combined private insurance score	2.176	1.228	0	5	PVTACC + PVTBEN
SUMTOT—Combined Medicaid and private insurance score	5.765	2.233	0	11	MEDTOT + PVTTOT

NOTE: AIDS is acquired immunodeficiency syndrome.

Table 7
Correlations among variables

Independent variable	MEDELI	MEDSER	MEDTOT	PVTACC	PVTBEN	PVTTOT	SUMTOT	EXPPAT	CASES	POP	INC	SOUTH
MEDELI	1.0000											
MEDSER	0.0451	1.0000										
MEDTOT	0.7080	0.7375	1.0000									
PVTACC	0.2704	0.4618	0.5092	1.0000								
PVTBEN	0.2798	0.0434	0.2198	0.2272	1.0000							
PVTTOT	0.3511	0.3065	0.4541	0.7536	0.8113	1.0000						
SUMTOT	0.6334	0.6272	0.8716	0.7313	0.5830	0.8325	1.0000					
EXPPAT	0.4132	0.2335	0.4444	0.4067	0.1904	0.3726	0.4813	1.0000				
CASES	0.3860	0.2506	0.4381	0.3762	0.1232	0.3090	0.4424	0.9234	1.0000			
POP	0.3039	0.2178	0.3595	0.3726	0.2067	0.3632	0.4233	0.7583	0.7820	1.0000		
INC	0.3532	0.2229	0.3964	0.3682	0.1013	0.2894	0.4057	0.3768	0.3657	0.2799	1.0000	
SOUTH	-0.2835	-0.2426	-0.3631	-0.2279	0.0507	-0.1026	-0.2823	-0.1219	-0.0737	0.0058	-0.2877	1.0000

NOTE: Explanations of variables are given in Table 6.

SOURCE: The RAND Corporation: Data from the RAND Corporation assessment of Medicaid rules and insurance regulations, 1987-88.

Table 8
**Factors associated with State Medicaid and private health insurance outcomes:
Results of multivariate analyses**

Independent variable	Dependent variable							
	MEDELI (1)	MEDSER (2)	MEDTOT (3)	PVTACC (4)	PVTBEN (5)	PVTTOT (6)	SUMTOT (7)	EXPPAT (8)
CASES	.322	.188	.448	.120	-.094	.043	.491	.810
POP	.055	.095	.133	.132	.190	.402	.534	.097
INC	.030	.073	.091	.104	-.067	.054	.145	.032
SOUTH	-.550	-.504	-.927	-.277	.112	-.225	-1.152	-.088
MEDELI		-.140						
MEDSER	-.120							
MEDTOT								-.017
PVTACC					.183			
PVTBEN				.135				

NOTE: Explanations of variables are given in Table 6.

SOURCE: The RAND Corporation: Data from the RAND Corporation assessment of Medicaid rules and insurance regulations, 1987-88.

Explaining the outcomes

The outcomes, as measured by the scores calculated in Tables 2 through 5, do not tell the whole story. In some cases, we could not obtain responses from a particular State. In other cases, our informant may have been misinformed, or State policy may have changed between the time we collected our data and this article appears.¹⁶ There were questions about AIDS care, coverage, and reimbursement that we did not ask because of resource limitations. There are also cases where local government provides a service to PWA's that is not generally available at the State level. Nonetheless, the scores discussed provide useful summary measures of State-by-State policies and their impact on those infected with HIV.

We hypothesized several background factors that we thought might be associated with the scores. The various factors are described in Table 6.

We first report the correlation coefficients between the various score variables and State characteristics, together with the intercorrelations among the characteristics. Table 7 is a complete listing of correlation coefficients for all the variables used in the analysis.

For the Medicaid scores, there is not much basis for distinguishing among the State characteristics in terms of the strength of their associations—they are of roughly similar size. In the case of the private insurance score variables, the size of the association with income and with southern location is diminished.

In Table 8, we report the results of multivariate analyses (ordinary least squares regressions) that attempt to portray the independent statistical relationships between the scores and various State characteristics. Multiple regression provides a convenient technique for expressing the underlying associations between two variables, holding constant the association with other related variables. We do not indicate standard errors or *t*-statistics, or coefficients of variation because the underlying data are more in the nature of a census than a sample. We have, however, standardized the independent variables (i.e., divided the values for each State by the standard deviation for the variable)¹⁷ so that regression coefficients indicate the relative magnitude of the various independent factors in terms of their association with the scores (Table 8).

Medicaid eligibility and services

Other things equal, States with more "generous" Medicaid regulations with respect to eligibility score (MEDELI) ought to be the ones with higher caseloads (a proxy, perhaps, for political pressure), higher per

capita incomes (more easily affordable), larger populations (generally more progressive), and locations outside the South (a region known for having a more stringent Medicaid environment) (Andrulis, 1987). As shown in Table 8 the hypothesized factors are indeed associated with the Medicaid eligibility scores. The heavily impacted, larger States outside the South score higher on Medicaid eligibility. Affluence appears to have a limited, though positive, association with the Medicaid scores.

We added the Medicaid services score (MEDSER) to the equation on the grounds that States with easy eligibility should have extensive services, (i.e., that both would be affected by a liberal Medicaid environment).¹⁸ As can be seen in Table 7, the simple correlation is positive, though small. However, the measure of independent association between Medicaid eligibility and services is actually negative. A similar set of factors is associated with the outcomes for Medicaid services, MEDSER. The third column shows multivariate regression results for the sum of the two Medicaid scores (Table 8).

Private insurance access and benefits

The column headed private insurance access score (PVTACC) presents results of an attempt to find the factors associated with high State scores on access to private health insurance. Our hypothesis is similar to that for Medicaid eligibility—large caseloads and populations, high income, and location outside the South are associated with high access scores. The signs of the coefficients shown in Table 8 are as hypothesized. State population appears to have a strong relationship with access, and the two private insurance scores are, as expected, related.

The associations with private insurance benefits score (PVTBEN) (HIV-related benefits for holders of private health insurance policies) were the least expected of all those for various scores or score combinations. Even the signs for the caseload, income, and regional variables are the reverse of what might have been anticipated. The larger, richer, non-Southern States appear to provide most protection to PWA's in terms of regulation of health insurance underwriters, as shown in the combined private insurance score (PVTTOT) (Table 6).

Explaining overall State performance

We combined both Medicaid and private insurance scores into SUMTOT and regressed it against all of the background variables with the results as shown in the penultimate column (Table 8). Population,

¹⁶The continuing coordination between the States and the Federal Government for reimbursement for AZT therapy is a good example of emerging policy, as is the increasing use of Medicaid's case management option by the States.

¹⁷Except for the regional variable (South/non-South), which is binary, i.e., 0, 1.

¹⁸Estimates of coefficients were also made for cases in which the equation did not contain the companion score, (i.e., MEDELI and MEDSER and, below, PVTACC and PVTBEN). Invariably, the effect of dropping the other score variable was to slightly lower the estimated coefficients for the remaining exogenous variables, but not to change the relative magnitudes.

caseload and, especially, region appear to be more strongly associated with State policies affecting PWA's than is per capita income.

Finally, we sought to discover the factors associated with Medicaid spending per AIDS patient across States (EXPPAT).¹⁹ Table 8 contains the results of a multiple regression estimate of the factors associated with State expenditures per patient. Per patient expenditures are more strongly associated with the size of the caseload than with population and region. State per capita income is a distant fourth in magnitude of association. Curiously, there is only a weak association between spending and the State's "generosity" with respect to Medicaid eligibility and services. In fact, the association with MEDTOT is negative. A possible reason for this outcome—although care needs to be taken with a conclusion based on such sketchy evidence—is that the kind of services upon which the MEDSER element of the MEDTOT variable is based (Table 3), actually reduce expenditures through the use of hospices and home-based services. It is also possible that States with good Medicaid services scores may have relatively high non-Medicaid, AIDS caseloads, which would tend to reduce spending per patient, as measured in Table 8.

Table 9

Average scores, by caseload volume classes

Dependent variable	Number of AIDS cases, end of 1987		
	<1,000 ¹	1,000-10,000 ²	>10,000 ³
	Average score		
MEDELI	1.0	1.4	3.0
MEDSER	2.4	2.3	3.5
MEDTOT	3.4	3.7	6.5
PVTACC	0.6	1.1	2.0
PVTBEN	1.3	1.9	2.0
PVTTOT	1.9	3.0	4.0
SUMTOT	5.4	6.7	10.5

¹All States other than those listed under ² and ³ below.

²Florida, Georgia, Illinois, Massachusetts, New Jersey, Pennsylvania, and Texas.

³California and New York.

NOTE: Explanations of variables are given in Table 6.

SOURCE: The RAND Corporation: Data from the RAND Corporation assessment of Medicaid rules and insurance regulations, 1987-88.

High, medium, and low caseload States

In terms of caseload, the States fall, rather naturally, into three groups (Table 9). California and New York together account for a large fraction of total cases and form our high caseload class. Then there are a number of States we call medium caseload, between 1,000 and 10,000 cases by the end of 1987. This group contains Florida, Georgia, Illinois, Massachusetts, New Jersey, Pennsylvania, and Texas. The low caseload group contains all the other States. We were interested in how scores for the dependent

¹⁹This is a crude estimate of spending per patient. It is the quotient of the State share of Medicaid reimbursements for AIDS patients during 1987 and AIDS cases alive at the end of 1987 and thus does not measure actual spending on Medicaid-qualified PWA's.

variables differed among these three classes of States (Table 9).

Conclusions

The RAND Corporation contacted State Medicaid programs, AIDS coordinating agencies, and health insurance regulation officials between the fall of 1987 and the fall of 1988. The interviews probed the nature of the HIV epidemic in each State, policies that affect access to public and private insurance coverage, and reimbursement for HIV-related health care. State scores were constructed for four domains of activity: Medicaid eligibility, Medicaid services, access to private insurance, and benefits protected under private insurance.

The most generous States in the Medicaid realm were California, Hawaii, Maine, Massachusetts, Michigan, New Jersey, New York, North Carolina, North Dakota, Ohio, Rhode Island, South Dakota, and Wisconsin. For private insurance policies, California, the District of Columbia, Georgia, Kansas, Massachusetts, Michigan, Minnesota, New Jersey, New York, North Carolina, North Dakota, Pennsylvania, Washington, and Wisconsin scored highest. Large caseload, location outside the South, big population, and high per capita income were found to be associated with high scores.

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