Policy & Promise

Learning from Other Urban Public Health Care Settings
Meeting the Needs of Children in Adversity
The Women and AIDS Task Force on Policy
Health Effects of the Gulf War
On the Rust v. Sullivan "gag"
From its inception in 1968, the Health Policy Advisory Center—Health/PAC—has been a unique progressive voice on domestic and international health issues. Through the Health/PAC Bulletin and the books, Prognosis Negative and The American Health Empire, as well as outreach to a national network of grassroots groups, Health/PAC continues to challenge a “medical industrial complex” that has yet to provide decent affordable care.
In this issue of the Bulletin we extend our reach to examine and affirm innovative and sometimes quirky measures that can improve the quality of care individuals receive in the face of institutional and financial disarray—measures that must be devised with increasing urgency and creativity as our federal government retreats from its health care responsibilities. In “City Views” Jack Salmon examines health care in four cities: Dallas, Boston, Seattle, and Milwaukee. He finds that a combination of political leadership and decentralization of health care in these locales provides some cushion both for the uninsured and for city budgets. With “Beyond Financing: The Community View,” Hal Strelnick provides running commentary on three of these cities, Dallas, Seattle, and Milwaukee, that addresses community concerns about municipal policies.

“Successful Strategies: Meeting the Needs of Children in Adversity” by Lisbeth Schorr, examines the elements of effective health care programs for children and highlights the roles that coordination of care and patient participation play in diagnosing and treating the host of interconnected difficulties that poor children face. Her case studies and analysis carry an urgent message: Providers must broaden their programs by questioning the barriers to effective interventions posed by the structures and attitudes of the programs themselves.

We learn, too, from the devastating effects of failed policy. Nowhere is the collapse of services, lack of coordination, and scarcity of provision more evident than in Teresa McMillen’s “Too Little, Too Late.” In this first column of our new regular feature, In Their Own Voice, McMillen describes her frustration as a social worker for a child with AIDS within a health care system replete with service gaps and shortages.

Also in this issue is John Miller’s “Bomb Now, Die Later: The Health Impacts of the Gulf War,” which outlines the health effects of our “surgical” war in Iraq—both those already painfully evident in the gulf region, and those anticipated as the full extent of the environmental disaster unfurls. Finally, we have devoted two pages to the outrageous “gag order” that prevents federally supported clinicians from mentioning abortion to their pregnant clients. One cartoon we saw sums up the state of federal health policy in the Bush administration.

A male doctor says to a patient: “Ah, let’s see. I am supposed to tell you that I am HIV positive and I am not supposed to tell you anything about abortion.... Or, is it the other way around?”

—Sharon Lerner and Nancy McKenzie
City Views
Local Governments, Communities, and Public Health Care

J. WARREN SALMON

Health/PAC requested the following article from Jack Salmon and also asked Health/PAC board member Hal Stelnick to write some short background pieces to accompany Salmon’s article. The information he compiled on Dallas, Milwaukee, and Seattle is included here as sidebars to help contextualize the discussion of those cities.

Over the last few decades, the accelerated, unplanned process of urbanization has had widespread repercussions for the health status of the populations of our cities. Downtown development of business and financial centers has disregarded inner-city communities. Poverty has increased as differences in income and consumption levels have deepened. Prospects for employment are increasingly limited as older industries move out of the cities and give rise to the service economy. Gentrification has reshaped the urban landscape, concentrating the most unfortunate in deteriorating, crime-infested areas.

During the Reagan-Bush 1980s, health resources were never really forced to be efficient. Rather, federal health policy favored greed over need; it fostered competition among providers, cost sharing for consumers, and federal cutbacks, redirecting funds away from unprofitable services, as well as from “unsponsored” patients. As the corporatization of medicine placed profit considerations above charitable mission and professional altruism, access to care became severely restricted for uninsured, underinsured, and Medicaid populations. The private marketplace favors reimbursement for “high-tech” hospital services, which grab the lion’s share of health expenditures, while primary care strategies continue to be neglected.

Vast segments of the urban population in the United States have no regular access to health services. The excess mortality for people in poverty is staggering. Disparities in the rates of major diseases suffered by whites and by blacks and Latinos in cities are growing. The “social epidemics” of AIDS, teenage pregnancy, infant mortality, low-birth-weight and drug-addicted babies, homelessness, trauma, physical and sexual abuse, sexually transmitted diseases, tuberculosis, and more—all indicators of declining standards of living—overwhelm the fragmented, overcrowded public health care providers, as they do the entire social infrastructure. The numbers of people with disabilities, including the mentally distressed, substance addicted, and physically and developmentally disabled, are increasing rapidly, and the elderly segment of most urban populations is also expanding. Such trends portend a monumental demand for public health care services in the 1990s.

In the wake of decades of neglect for public health, priority health problems are forced to compete for diminishing resources.

The ongoing economic crisis of cities has aggravated this situation. As politicians sought to woo business through incentives for development, fewer resources were available for lower priority public health. The change in the federal role in and responsibility for health under Reagan caught states unprepared to do more than attempt to restrain their own outlays, particularly in uncontrolled Medicaid budgets.

In today’s climate, the health needs of our inner cities appear impossible to ameliorate. The overburdening of public providers has coincided with politicians’ lack of interest in health matters, outdated and inadequate public facilities, and the luring away of top talent, both administrative and medical, to more lucrative private sector entities. In the wake of decades of neglect for the public health sector, priority health problems are forced to compete for diminishing resources. Such conditions partially account

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for the inadequacy of local strategies to deal with the health care crisis over the last decade, though individual cities differ in how they prepare for the new public health challenges of the 1990s.

**Not all cities allowed changes in federal policy to devastate local public health care delivery.**

In an attempt to examine these differing responses and to contrast them with the current situation in metropolitan Chicago, three Chicago advocacy groups—the Health and Medicine Policy Research Group, the Metropolitan Planning Council, and the Community Renewal Society—sponsored a series of Urban Public Health Care Systems Study Tours from 1988 to 1990. Presented here are summaries of four of these significant attempts to address mounting urban health needs, with an emphasis on the financial basis of these public health care systems.

**Strategies for Local Public Health Care**

Today it is widely accepted that health care delivery is a local affair, for both the private market as well as the public sector. Although changes in federal policy have significantly affected metropolitan areas in the last decade (from funding cutbacks to Medicare's prospective payment), not all cities allowed such developments to devastate local public health care delivery. The urban examples examined here reveal considerable variation in their evolutionary adjustment to the changing health policy context, yet they share a number of features. The two central ones are political will and community leadership.

Boston, Dallas, Milwaukee, and Seattle are located in separate regions of the nation. Each represents a different historical and cultural legacy, with particular characteristics and capabilities that help to strengthen their respective public health care systems. All four cities are models that seem to be working better than what we find in such cities as Chicago, Los Angeles, or New York City. Their structural and operational strategies have historically shown a degree of flexibility and greater responsiveness to community health needs, although in earlier years they did not evince what one might label visionary planning. Rather, a unique mix of political, civic, community, and public health leadership came together at certain points to push for more comprehensive health services for poor and working citizens. Each city made decisions in favor of more coordinated systems management—although it must be said that the relatively smaller scale of these metropolitan areas makes such management more feasible than in their larger urban cousins.

**Boston: Commitment to Health Care**

Boston has two advantages in providing health care to its poor population: location in a state with a history of commitment to health care and a unique network of neighborhood health centers. Massachusetts was among the first states to implement certificate of need legislation and other cost-control strategies. In 1981, Massachusetts hospitals and Blue Cross were encouraged to implement a prospective payment mechanism, nearly three years before it was implemented under the federal Medicare program. In 1985, the Boston Foundation released *Boston At Risk*, documenting the severe difficulties poor people faced in acquiring health care. In the same year, the first state to establish a free-care pool was more than 20 percent above the national average. However, its strong economy tended to make this expense relatively unburdensome to the public during much of the 1980s.
The new provisions for universal access were designed to be phased in over a period of four years. The estimated cost over the projected four-year time period was between $600 and $800 million. The entire plan has not yet been implemented, however. The law is constructed to tie universal access to increased hospital financing, meaning that the poor will be competing with the powerful hospital industry for what have become scarce state budget dollars. Despite whatever drawbacks the new universal access law in Massachusetts may prove to have, however, health care as a right is a firmly entrenched component of the public discourse, and will be difficult to ignore in future debate.

**Boston's Health System.** The Boston Department of Health and Hospitals was established in 1965, consisting of the Boston City Hospital (a long-term chronic/rehabilitation facility with 151 beds), and Long Island Hospital (a chronic care hospital with 193 beds). The department also administers a school of practical nursing, emergency medical services, and community health services provided by a network of community-owned and hospital-contracting neighborhood health centers. Its major university affiliation is with Boston University.

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The Department of Health and Hospitals is a fully city-administered and financed organization. To administer the neighborhood health centers (NHC), the department receives additional funds from a variety of sources. Much of this money goes directly to the centers themselves ($5.4 million in 1986). Of this, $3.5 million went to the seven Section 330 centers—neighborhood centers that receive direct federal funding.

The health centers received an additional $5.6 million from the State of Massachusetts in 1986, most of which went for maternal-child care. Of that total, approximately half consisted of federal funds, which were matched by the state. The City of Boston provided an additional $3.5 million through the Department of Health and Hospitals, both for centers directly operated by the department and for other affiliated centers, all of which receive some financial support from the city. Additional monies come from philanthropies and other local sources, primarily for capital improvement and building expenses. Before 1974, some federal Hill-Burton construction money had been used in clinic construction, both for hospital-affiliated clinics and for some independent ones. Today, most city money comes from property tax levies, while state funds derive from general revenues.

Patient revenue is, of course, an important source of income for the NHCs. Of the patients seen, about 40 percent are on Medicaid, 40 percent are uninsured (including some privately paid patients whose insurance does not cover all of their care), and 20 percent have Medicare, Blue Cross and other commercial insurance. In 1986, the centers billed Medicaid for $7.6 million and Medicare for $1.6 million. An additional $12.2 million in private insurance, including Blue Cross, was billed, although fully $7.7 million of this was written off in bad debt and free care.

The rates at which Medicaid reimburses care in Massachusetts differ considerably by venue and type of care, according to the League of Community Health Centers, a voluntary association for independent NHCs. Massachusetts is generally considered among the more generous states in Medicaid reimbursement. The centers may now receive increased Medicaid money, since a recent regulation from the federal Health Care Financing Administration stipulates that federally qualified health centers be paid by state Medicaid at 100 percent of full reasonable costs. In Massachusetts, this cost is aggregated from cost reports that the NHCs file with the state rate-setting authority. The current flat rate is approximately $55 per capita for medical services. Under the new regulation, the entire amount should, in theory, be reimbursed.

This source of patient revenue is important because the NHCs provide a great deal of uncompensated care. State mechanisms to assist them have historically been somewhat tortuous. The earlier free-care pools, intended to aid patients receiving hospital care, had included hospital-licensed centers as beneficiaries; the independents received nothing. In 1986, in response to pressure from the League of Community Health Centers, a separate pool was created for all the health centers, and they began to be reimbursed for approximately a third of the free care they had given. The new universal access legislation covers care in health centers as well as hospital care. In addition, hospital-licensed centers are considered departments of the hospitals with which they are associated; thus, patients are covered by any hospitalization insurance for which they are eligible.

The NHCs themselves have been moving toward greater involvement in the payment process. The Neighborhood Health Plan, a community-based health maintenance organization consisting of at least 18 health centers, is being phased in. The plan consisted of 5,000 enrollees in 1990, paid for by the state Department of Medical Security through a combination of trust money from employer contributions and yearly appropriations from the state. The Neighborhood Health Plan administers a program called Center Care, also under the auspices of the Department of Medical Security, under which health centers have been gathering demographic data on their own community populations. Based on these data, a payment structure for the Neighborhood Health Plan is being worked out under a capitation formula.

**Boston's Strength.** The finance mechanism of Boston's system of neighborhood health centers is difficult to summarize. The unusual amount of autonomy afforded individual neighborhood health centers allows them to seek financial support from a wide variety of sources. It must be stressed, however, that basic support derives from the
city Department of Health and Hospitals. Even those clinics affiliated with a private hospital receive needed funds from the city budget. In addition, current initiatives to phase in a managed care system among the centers indicates a move to consolidate resources. Two key strengths of the Boston system have been the ability of individual clinics to tailor day-to-day operations around specific needs of their communities and to maintain historical links with local institutions.

Dallas: Pragmatism and Public Service

In contrast to Massachusetts, Texas can in no way be described as a generous state in assuring basic health and social services to its constituents. Local jurisdictions are virtually unsupported by the state and left fairly much on their own, which makes Dallas particularly unique among urban areas caring for the poor and indigent. Parkland Memorial Hospital, the institution of the Dallas County Hospital Authority, was originally established in 1894. In the 1940s it became affiliated with University of Texas Southwestern Medical College. Throughout the next decade, Parkland made dramatic advances in medical care and technology. After weathering some stressful times and internal conflict in the 1970s, the hospital today is a model of efficiency among the nation’s public health care institutions. Its reputation for medical excellence continues unabated. It is unique in that it is has been successful in attracting significant private-pay patients to its doors. Parkland receives approximately 55 percent of its income from local property taxes; the rest derives from patient revenues. It is also unique as a public entity in seeking philanthropic contributions. Private donations are generally earmarked for specific projects; they are not considered part of the general operating revenue.

Parkland’s businesslike approach to the provision of care to the indigent reflects the pragmatic conservatism of Dallas’s culture and politics. In Texas, a state traditionally tight in its allocation of human services funding, this managerial success in the provision of public health care has won Parkland many accolades.

Parkland recently entered into a contractual agreement with a neighborhood health coalition to provide care in existing community-based, not-for-profit clinics. This agreement is a prototype for a new system of community-oriented primary care (COPC). For the past several years, a factor has been included in the property tax base under the Dallas County Hospital District to fund COPC. This has facilitated initiation of a prototype clinic that was opened this year. Rather than continue to contract out with free-standing clinics, the Dallas County Hospital District has chosen to utilize clinics under its own administrative umbrella, so that it can closely monitor quality and efficiency. In forthcoming years, more clinics will be added and included in Parkland’s overall decentralization scheme.

Sources of Revenue. Aside from the local property tax, Parkland Hospital seeks revenue from a wide variety of contributions. Private donations are generally earmarked for specific projects; they are not considered part of the general operating revenue.

Bluitt-Flowers Health Center in Dallas—Parkland’s community-oriented primary care clinic.
private sources as well. The Texas Foundation for Health Services raised more than $2 million in philanthropic donations in 1989—charitable gifts for maintaining the epilepsy, pediatric trauma, and other specialty services. These gifts are not always in the form of money, but may be equipment, life insurance, artwork for the hospital, real estate or stocks, or arrangements like matching gifts, charitable trusts, or pledges made in multiple installments.

Other ventures are expected to reap financial rewards as well. An on-site McDonald’s restaurant—the largest in Texas—is expected to increase Parkland’s revenue by approximately $300,000 per year. Since 1979, the hospital has committed over $200 million to improve its physical plant and purchase equipment. About $105 million of this was financed through the sale of bonds. The hospital itself financed the rest with operating revenues.

In 1990, it was predicted that Parkland Memorial Hospital would produce over $320 million in inpatient charges, $98 million of which would be collected—$34 million from Medicare; $26 million from Medicaid; $34 million from commercial insurance, including Blue Cross and Blue Shield; and $4 million in patient payments. The rest would be uncollected, due to medical indigence, Medicare or Medicaid contractual disallowances, or bad debt.

**Dedication and Pragmatism.** The Dallas County Hospital District approaches public health care with an unusual combination of dedication to community health needs and business-like pragmatism. Hospital officials stress that current plans to decentralize will both increase access and free the hospital to concentrate on what it does best: provide high-intensity care for those patients who need it most. As much primary care as possible will be allocated to clinics and, eventually, to at least one other community hospital that the district plans to purchase in the future.

Although Parkland, like all public hospitals, labors under the burden of a high percentage of uncollected patient revenue and bad debt, the hospital continues to be enterprising and innovative in its efforts to attract more

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**Beyond Financing: The Community View**

**Dallas**

After San Diego, Dallas-Fort Worth is the fastest growing Consolidated Metropolitan Statistical Area in the United States, having expanded from a population of 2.9 million in 1980 to 3.9 million in 1990. Dallas has now become a majority minority city, with African-Americans (29 percent), Latinos (24 percent), Native Americans, and Asians together outnumbering whites. The county’s population is 40 percent minority. A study of the 64 communities that make up Dallas County identified eight communities (with a total population of 325,000) in desperate need of health services.

Parkland Memorial Hospital, the major facility of the Dallas County Hospital District, first came to the attention of most of the country when President John F. Kennedy was rushed there after being shot. More recently, in the late 1980s, Parkland’s chief officer was on television’s “Sixty Minutes” exposing the widespread practice of patient dumping in Dallas.

Parkland is the major teaching hospital of the University of Texas Southwestern Medical Center, licensed for 940 beds and operating 858. In 1989, Parkland had 40,583 admissions, 14,536 births, 138,355 emergency room visits, and 385,595 ambulatory care visits. Outpatient visits have been increasing by 35,000 new patients per year for the last five years. Parkland found a 700 percent increase in middle- and working-class families’ visits for immunizations just prior to the measles epidemic, which has struck harder here than any other city except Los Angeles.

In 1986, after Parkland’s new outpatient clinic was filled to capacity within one year of opening, the Commissioners Court (which is the Dallas County Hospital District’s board of trustees, with each Dallas County appointing one member) asked Parkland’s Board of Managers to determine the need to decentralize its outpatient services. Waiting times for appointments had jumped from three or four weeks to one year for new adult patients. The board responded that each of the previously mentioned eight neighborhoods needed a comprehensive community-based health center, a plan approved by the Commissioners Court in September 1987.

Parkland adopted the model of community-oriented primary care (COPC) espoused by the Institute of Medicine and began contracting with existing neighborhood clinics, expanding Children and Youth Projects in East and West Dallas into comprehensive COPC centers. The Bluitt-Flowers Health Center, named for two pioneering African-American physicians in Dallas at the turn of the century and serving the predominantly black Trinity/Lisbon/Simpson-Stewart area in the south side of Dallas, opened in July 1991.

The COPC program now operates six health centers and has demonstrated dramatic cost reductions as well as reduced rates of hospitalization, teenage pregnancy, adolescent mortality, and measles. With 30 different sources of public and private funding, the COPC program tries to deliver only comprehensive care. Unfortunately, the rest of the health system in Dallas has largely abandoned its responsibility for the poor. The Medicaid program in Texas ranks 48th in both eligibility and payment.

—H. S.
privately sponsored patients and to operate more efficiently while still providing necessary care for the uninsured. Its connection to the University of Texas Southwestern Medical Center firmly supports these goals.

The Dallas Hospital District has demonstrated that, contrary to popular stereotype, a public sector health care system can be both efficient and effective. Other cities, worried about taxpayers' revolts would do well to look at the example of Dallas and understand that fiscal pragmatism and public service are not necessarily contradictory.

**Milwaukee: Cooperation between Public and Private**

Milwaukee presents a fascinating model for comparison to other older industrial cities such as Chicago. Like Chicago, it is an aging industrial center with long-established “white ethnic” communities that has acquired sizable minority populations. Racial tensions are a part of the day-to-day reality. And, like Chicago, the city as well as the county in which it is located has a long history of providing for the public’s health. Milwaukee, however, has been able to translate this into present-day innovative cooperation between public and private health care providers.

Ethnically, Milwaukee is less diverse than Boston or Chicago. In 1980, the city population was 636,212; 73.3 percent of these citizens were white, 23.1 percent were black, 4.1 percent were of Hispanic origin, and 0.8 percent were Native American.

Milwaukee’s public health care sector is highly centralized in terms of its physical location, its administrative and financial structures, and its concentration of hospital-based tertiary care. Nearly all indigent care for the uninsured in Milwaukee is provided through the Milwaukee County Health Care Plan (MCHCP), established by the county in 1982. Its physical anchor is the Milwaukee County Regional Medical Center. The medical center predates the 1982 legislation that established the independent MCHCP. In 1966, a coalition of community leaders urged the consolidation of several established medical resources into a single, multipurpose health care and research facility. Public and private providers on the grounds of the medical center render the bulk of the care.

The medical center currently consists of the Blood Center of Southeastern Wisconsin, the Children’s Hospital of Wisconsin, the Curative Rehabilitation Center, Froedtert Memorial Lutheran Hospital, the Medical College of Wisconsin, the Milwaukee County Medical Complex (MCMC) and the Milwaukee County Mental Health Complex. The MCMC, the county-owned public hospital, is physically situated adjacent to the two private hospitals, Froedtert and Children’s, and shares some facilities. The medical complex is almost unique among public hospitals; few others derive a significant portion of their revenue from private institutions who refer their patients there.

**Indigent Care under MCHCP.** The Milwaukee County Health Care Plan (MCHCP) serves as a publicly administered HMO to approximately 20,000 “dependent” or “medically needy” county residents. Eligibility criteria are quite strict and succinctly laid out, and financial efficiency is given high priority. People who qualify for MCHCP must be eligible for general relief and not insured by Medicaid, Medicare, or any private third-party coverage. They are automatically enrolled in MCHCP when their general relief case is activated.

Individuals who do not receive general relief from the county but whose medical expenses exceed their available resources are eligible for MCHCP as “medically needy” people. This group is composed of those without available means to pay for their medical expenses. They become eligible with a “spend-down,” which acts as a deductible and is the amount they are required to contribute to the cost of their care. Until they have sufficiently “spent down” to be classified as “dependent,” they are not certified for MCHCP benefits.

In addition, “dependent” or “medically needy” clients who receive emergency care at private hospitals can be reimbursed by MCHCP if the hospitals follow the required notification procedures. Approximately 5,000 of the patients in MCHCP are “dependent”; the remaining 15,000 are “medically needy.”

**Funding and Revenue.** The Milwaukee County Health Care Plan is funded by county property tax and also by a partial reimbursement from the Wisconsin Department of Health and Social Services. About 54 percent of medical expenditures are funded by the tax levy; the remaining 46 percent derive from the Department of Health and Social Services. Limited federal funding has been available under the State Legalization Impact Assistance Grant (SLIAG) program, earmarked for costs of aliens’ medical care.

Of the health care providers on the campus of the Milwaukee County Regional Medical Center, the Milwaukee County Medical Complex (MCMC), the public hospital, is the largest preferred provider of care, accounting for 64.8 percent of MCHCP’s appropriations. It is followed by the Milwaukee County Mental Health Complex (17.8 percent), Froedtert Memorial Lutheran Hospital (14.1 percent), and other private providers (3.4 percent).

The Milwaukee County Regional Medical Center is the location for nearly all care given by the public sector in Milwaukee County, with the exception of the City of Milwaukee public clinics. For the public hospital, Medicare represents 27.3 percent of the Milwaukee County Medical Complex’s patients, while fully 20.1 percent are covered by commercial insurance. MCHCP accounts for 18.4 percent, Medicaid 13.7 percent, and private HMOs
march 6 percent. Approximately 4.8 percent of the complex's patients are classified as self-paying; a significant amount of this is bad debt. An additional 9.7 percent of the medical complex's patient revenue is derived from cross-charges from the nearby mental health complex, Froedtert Hospital, and other private providers, for which the Medical Complex performs certain reimbursable procedures. This revenue from other hospitals that send patients for specific services makes the medical complex quite unique. Few other public hospitals in the nation derive a significant portion of their revenue from private institutions which refer patients.

The Milwaukee County Mental Health Complex receives 32.6 percent of its patient revenue from Medicaid and 19.2 percent from Medicare. MCHCP comprises 12.2 percent; self-pay, 11.1 percent; private insurance, 7.3 percent; and Aid to Families with Dependent Children, 4 percent. An additional 13.6 percent of the Mental Health Complex patients are eligible for benefits through the Institute for the Mentally Diseased, a federal program for clients needing long-term inpatient care. Froedtert, being a private hospital, receives less patient revenue from the MCHCP, although it is a preferred provider.

Milwaukee

Milwaukee, which the New York Times once called a "proud workhorse of a city," lost more than one-quarter of all manufacturing jobs between 1979 and 1983, but now enjoys its eighth straight year of job growth, second in the country only to San Diego. With Bridgeport and Philadelphia all but bankrupt and many other cities close behind, Milwaukee boasted a $58 million surplus in its last fiscal year.

This economic phoenix rising from the dust may also be, according to a University of Chicago study, the most segregated city in the country. The one-third of its population that is minority, predominantly black, but with significant numbers of Latinos and Native Americans, is tightly confined to a near north side ghetto of exhausted and abandoned two-family "flats." Unemployment rates for blacks have risen from three times the white rate (17 versus 5.3 percent) to five times (20.1 versus 3.8 percent) in 1989. Milwaukee's structured economy has left the Black community behind, leading to frustration and anger as well as the resurgence of the Black Panther Militia, led by a militant alderman.

The public hospital that serves the city's poor is located on the 248-acre former poor farm for the indigent in the western suburb of Wauwatosa. The 440-bed former Milwaukee County General Hospital (now Medical Complex) was once the only teaching hospital of the Marquette University Medical School, which became the Medical College of Wisconsin in 1968, when the Jesuits let the state take over its subsidy. A decade later, the medical college moved its campus from downtown to next door to the Milwaukee County General Hospital, where it was joined in 1980 by Froedtert Memorial Lutheran Hospital, a 285-bed private facility that took almost 30 years to build, mired in probate and political controversies. This campus, which became the Milwaukee Regional Medical Center, now includes an eye institute, mental health complex, and rehabilitation center as well as a blood center and children's hospital relocated from downtown. The public hospital boasts the only full-range trauma center in Wisconsin.

Teaching now goes on throughout the Milwaukee Regional Medical Center and also at the local Veterans Administration Hospital, among the VA's largest. General medical and surgical services are fully maintained at both Froedtert and County General, with medical and surgical subspecialties such as urology and cardiology divided equally between the two. Admissions from the county emergency service alternate between the two facilities.

Although Froedtert Hospital officials insist that the city's inner-city poor have easy access to public transportation to the Medical Center, statistics from its Office of Planning and Government Affairs demonstrate that the health care burden of the poor has been falling upon the inner-city hospitals, Mt. Sinai and Good Samaritan. Almost 60 percent of these two hospitals' patients live in the ten central city zipcodes, while only 40 percent of the Medical Center's do. In 1989, half of Mt. Sinai's admissions and 46 percent of Samaritan's were Medicaid patients or were medically indigent, while just over one-third of the Regional Medical Center's and 30 percent of Froedtert's patients were; in 1990 Froedtert's percentage fell to 26 percent. Two other Milwaukee hospitals, St. Joseph's and St. Michael's, had less than ten percent of such poor patients. One central city zipcode had only one primary care physician serving 14,547 people. Although a network of mental health clinics are tied to the Regional Medical Center, the city (not the county) administers five traditional public health clinics and two comprehensive health centers. A family practice residency program also serves the central city.

In January 1985, after experimenting in Madison and Marshfield, the state of Wisconsin began the mandatory enrollment of 110,000 Milwaukee AFDC recipients in nine health maintenance organizations (HMOs) under its Preferred Enrollment Initiative. Despite the financial success of the HMOs, they face certain problems that are not unique to Milwaukee. While Medicaid hospitalization rates plummeted, the state has been unable to monitor utilization or health status. Many existing physician-patient relationships were disrupted, and only one-third of beneficiaries seeking to switch HMOs succeeded. As capitation rates (the amount allocated for each patient's care) are tightened, and the HMOs seek to tighten their own belts, the barriers to treatment that patients face are likely to increase.

—H. S.
The Clinic System. The clinic system of the Milwaukee City Department of Health consists of two comprehensive primary care facilities and five public health clinics that administer traditional services (immunization, well-baby treatment, treatment under the federal Women, Infants, and Children program, etc.). The city manages the physical plans of the two comprehensive clinics; other providers—both public and private—provide the medical care.

Some of the city clinics receive federal grant monies. The Robert Wood Johnson Foundation, which made the initial grant to start the two comprehensive primary care clinics, continues to provide some funding for their operation. City clinics are funded through municipal tax dollars. There is also some federal maternal-child health money and other, smaller grants like the SIA program and federal money for Southeast-Asian refugees.

Many of the services in the city clinics, being preventive, are not reimbursed. Some patients have private insurance, but little is collected. Thus, the public health clinics are essentially fully tax supported. The patient mix at the two comprehensive clinics is about 50 percent Medicare, 20 percent Medicaid, and the rest uncompensated. Coordination between county and city health programs is beginning to be addressed.

A Strong Socialist Tradition. As befits a community with a strong socialist and labor tradition, Milwaukee has taken an active role in the provision of public goods for its citizens. The Milwaukee County Health Care Plan utilizes a preferred provider organization model that private sector purchasers of care have adapted with increasing frequency.

Milwaukee County has also succeeded in devising a strategy whereby both publicly and privately sponsored patients make extensive use of cooperating facilities. Efficiency is a major goal, as its adoption of preferred providers by the MCHCP for financing demonstrates. The “spend-down” requirements for poor patients are quite strict; one must be nearly destitute to be “dependent” under state criteria and thus qualify for entirely free care under the MCHCP. Yet this, combined with the high-quality reputation that enables the Milwaukee County Medical Complex to draw privately insured patients from other hospitals to seek specialized care, has ensured its long-range financial viability. Cooperation between public and private providers, based on this case on a position of strength and a reputation for quality in the public sector, has enabled the Milwaukee system to grow and expand its scope in a way that is unique among the cities visited.

Seattle: Community Clinics

Seattle symbolizes to many people the evolution of a community from frontier roots to a 21st-century future. Rich in Native American heritage and rustic tradition, the city is now a leader in aerospace research and high-tech development.

Like other cities examined here, Seattle has a long history of providing for the public health of its citizens. The city’s first health officer was appointed in 1878. At that time public health was seen as a problem affecting the entire population. In 1949, after years of debate over whose responsibility it was to attend to the local public health, the city and county health staffs were merged by state legislative decree. In 1951, the Seattle-King County Department of Public Health was formed. The city would administer the agency; funding was allocated to the governments on the basis of population served. Finally, in 1980, administrative responsibility was transferred to King County because of the increasing population. It is now, both in budget and scope, one of the single largest health departments in the country.

Today, this model health department works with both hospitals and community clinics to provide affordable health care. A network of community clinics, formed during the 1960s and 1970s, has established links with city government to become an effective not-for-profit system, complementing the public endeavor in an unusually amicable private-public partnership.

In an unusually amicable private-public partnership, Seattle’s community clinics have established links with city government to become an effective not-for-profit system.

Seattle’s network of community health centers did not start out as a coordinated effort, however. Rather, volunteers and community residents in the late 1960s and early 1970s participated in the “free clinic” movement, responding to expressed neighborhood needs. There was no centralized source of funding; staffing was mostly by volunteer physicians and nurses through the mid-1970’s.

The clinics began to receive federal funding in 1976, eight years after the first Seattle clinic was started. At that time, community clinics had begun organizing themselves into consortia to facilitate the development of administrative and financial links to one another. Also, beginning in 1977, several Seattle communities were designated Health Manpower Shortage Areas by the federal government, making Seattle the first urban site in the United States eligible to receive personnel from the National Health Service Corps.

The mid-1970’s were an important period of activity and growth for Seattle’s community health centers. After the election of Mayor Charles Royer in 1977, the Seattle Health Department was reorganized into the Seattle-King County Health Department; the Seattle division was created to oversee public health in the city. Whereas previously there had been no relationship between the city and the clinics, the Seattle division began to establish one. In the years directly following, as Reagan-era cutbacks began to deprive the local system of the federal support that had largely sustained it, the City of Seattle began to
allocate increasing amounts of dollars for community services, including the health centers. That funding has continued: the 1990 Seattle division budget called for $6.1 million in local funds and $4.8 million in federal block grant money for human services; of that, nearly $4 million was to go to community health centers.

In recent years, both the State of Washington and the County of King have shown growing interest in keeping the clinic system viable. Over 20 percent of Seattle’s residents receive care from the clinics. A recent state initiative to plug gaps in the safety net unfilled by Medicaid was a 1985 allocation directly to community health centers located in Washington, including those in Seattle. The state also granted $950,000 to cover medical services for low-income residents who were not eligible for Medicaid (i.e., the medically indigent). This was expected to increase to $2,550,000 by 1990 as part of Governor Booth Gardner’s state health initiatives. It should be noted that payment for dental services, often overlooked in both private and public insurance, is included. More recently, the “First Steps” program has increased Medicaid eligibility for pregnant women and infants up to 185 percent of the poverty level and for children through age 8 up to 100 percent of the poverty level.

Additional state legislation includes the 1987 Washington Basic Health Plan, a demonstration project designed to provide health insurance to 25,000 currently uninsured low-income residents. The plan is managed care, although at one site there will be an option for a certain amount of fee-for-service medicine.

Seattle

With its magnificent geography between Puget Sound and the Olympic and Cascade Mountains, Seattle has developed a reputation for supporting serious cultural efforts, in addition to having a pedestrian-friendly downtown. The city’s population was just above a half-million in 1990, and the Seattle-Tacoma Consolidated Metropolitan Statistical Area was among the five fastest growing in the nation during the 1980s. About 80 percent of Seattle’s population is white, 10 percent is black, 7.5 is Asian, 2.5 is Latino, and 1.5 is Native American.

Health care has long been an important civic issue in Seattle. The city can claim one of the nation’s first prepaid group practices, the Group Health Cooperative of Puget Sound, founded after World War II by local labor unions and community groups. Still one of the only consumer-controlled health maintenance organizations in the country, it was featured recently in the New York Times as their model for a national health program. When the Reagan administration closed the nation’s Public Health Service hospitals, Seattle’s community health centers organized to maintain theirs. Although the Public Health Service hospital eventually closed, in 1987 the city passed a bond issue to build more clinics.

Since the state legislature established a health care commission last year, which is debating employer-mandated versus community-based health insurance (see “Campaigning for Health Care Reform,” by David West, Summer 1990), Governor Booth Gardner has been seeking a state health plan that he could showcase when he hosted the National Governor’s Association in August 1991. Without a state income tax, however, little is expected.

Seattle is facing financial problems, anticipating a $14 million deficit in 1991 and a $20 million deficit in 1992, and has been looking to other levels of government for help. The city’s economy is dominated by Boeing’s aerospace and Weyerhauser’s lumber production, with fishing and tourism just behind. While Weyerhauser has maintained a low political profile, Boeing self-insures its own employees and has actively opposed broadening health coverage for others.

Another important player on the local health care scene is the University of Washington, nationally renowned for its departments in family and internal medicine and pediatrics. Providence Hospital serves Seattle’s hilly inner city of one- and two-family houses and provides backup services for many health centers. Group Health has its own hospital and even residency training programs.

In 1981 the Seattle-King County Public Health Department developed the Seattle Health Policy plan, which immediately ran into stiff community opposition. Although the plan identified health goals for each age group in every Seattle neighborhood, the development process did not include community groups or providers, and the plan proposed to redistribute resources based on its findings. The City Council eventually adopted only some of the report’s principles. With that lesson in mind, the Seattle division of the county health department developed a strategic plan in 1988 that recognized both its direct service delivery and community health planning roles and adopted community-oriented primary care as its model.

Eight independent community health center organizations with 13 sites, serving 52,000 patients annually, coordinate their work with the County Department of Public Health’s two comprehensive primary care clinics, five pediatric clinics, and several specialized clinics, serving 100,000 patients. According to Jack Thompson of the Seattle-King County Department of Public Health, the community clinics and health department are meeting to “sort out roles” and decide “what the community clinics want to do” in trying to achieve the Department of Health and Human Services’ goals known as “Healthy People 2000.” The Health Department is organizing and sharing its demographic and epidemiological data with the neighborhood centers and health facilities in order to promote their community orientation. There are also plans to include the hospitals in this process.

—Hal Strelnick
The County of King has also increased its attention to health care for the poor. The expansion of clinics throughout King County will be facilitated by a recently passed Regional Health Facilities Bond Initiative ($15 million), which also provides capital financing for two regional hospitals, in an era when public support for health care has been dwindling nationwide.

**Finance Structure.** The city of Seattle currently contributes approximately 30-35 percent of the clinic system's revenue; the clinics receive an additional 35 to 40 percent from various federal government programs; and third-party payments (mostly Medicaid) account for 15 percent. The remaining 10 percent comes directly from King County, the state of Washington, and other sources.

The three city-owned health centers receive 50 percent of their funding from general funds from city sales and business and occupational taxes. The next biggest source of income derives from state pass-throughs from federal programs, and an additional 10 to 15 percent comes from third-party payments.

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**Over 20 percent of Seattle’s residents receive care from its community clinics.**

The patient payment breakdown in the Seattle clinics varies, depending on their location. In North Seattle, 10 to 15 percent of the patients seen are sponsored by Medicaid; in Southeast and West Seattle, Medicaid patients account for fully 50 to 60 percent of the patient load. Also included are growing numbers of working poor who are medically indigent and eligible for the Basic Health Plan.

**Cooperation.** Like Boston, Seattle has found success in a decentralized, largely unregulated system of clinics whose effectiveness in caring for the city's poor and indigent has led them into increasing cooperation with public officials. It should be stressed that federal money and programs were not the initial life-blood of Seattle's system; it originated from volunteer efforts and community support.

Historically, the Seattle clinics have succeeded by entering into coalitions with one another. They have maintained their separate administrative authority, however. As city and county officials take more interest in administering and funding the clinics, a certain amount of political centralization will evolve; a similar phenomenon is under way in Boston.

**Constraints on State Policy**

Each of the urban settings described sought means to strengthen their public health care over the last two decades. Local innovations have varied in governance, overall structure of service providers, joint public-private initiatives, and interorganizational linking of primary care and hospital care. In each case, however, the roles of city and county governments, user constituencies, and public health and civic leadership significantly affected the development of local systems within externally imposed constraints. Financing varied also, but in each of these cases, there were innovative strategies to enhance funding of public services.

How state governments have facilitated or limited local public health care varies as well. Although Massachusetts, Wisconsin, and Washington have historically provided substantial support for health services for the poor and indigent, Texas has not, and has no plans to do so. Cities in the first three states have been able to a degree to replenish resources slashed under Reagan-Bush health cutbacks. In Dallas, the clear lack of state support forced Parkland Memorial Hospital to depend on local funding and encouraged its businesslike approach to cost-effectiveness to justify budget increases.

State support for local public health care comes chiefly through the Medicaid program. When Medicaid cost-containment policies (or a state’s historical stinginess) limit such support, local public health care systems cannot easily flourish. Among the cities studied here and across the nation, Dallas remains an exception to what has generally evolved in its reliance on property tax revenues for expanded programs. There is a wide variability in generosity among the states which, when coupled with the lack of uniform determinations for poor families, affects the development of local systems quite unevenly. Medicaid benefit packages vary for each state as well, as does utilization of specific service benefits. Each jurisdiction has different patterns of spending its Medicaid dollars for different types of services, such as physicians, hospitals skilled nursing facilities, and the like.

As Medicaid continues to erode state budgets nationwide, it appears less likely to serve as a means to buttress either the public or private urban health care sectors.

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**The Seattle clinics have succeeded by entering into coalitions with one another.**

States were expected to spend $25.2 billion in 1990 to cover about 22 million Americans, far fewer than the actual number of people living in poverty. The federal government’s contribution to Medicaid may total $35 billion, pending budget cuts. The new federal mandates on maternal and child health and nursing home care improvements, enacted over the last several years, will continue to demand greater expenditures from the economically depressed states. For states that have historically supplemented Medicaid with general revenue funding to target special urban health initiatives, significant pressures will build for further fiscal curtailments.
Such external financial constraints within state governments will directly affect the development of the local health sector in each city. Stronger cost-control initiatives may need to be imposed, especially by the more generous states, such as Massachusetts. The trend for local public health care to become a repository for greater numbers of patients who increasingly are unwanted by private health providers will be exacerbated.

Lessons

A 1977 survey of public health departments found them substantially involved in the delivery of personal medical services, although these services often suffered from inadequate financial support. In a follow-up investigation, Miller and Moos found that personal medical care services, rather than preventive services, consumed the greatest share of expenditures among the 15 local health departments they studied across the nation. These expenditures were directed mainly to the poor and other disadvantaged groups. It should be noted that as greater resources are demanded for personal medical care services, the focus on traditional public health and environmental surveillance recedes, a tendency that has increased in the 1980s as disease prevention and earlier treatment strategies have been severely compromised.

In an overcrowded, underfunded system, activities of outreach and screening, immunization, control of sexually-transmitted diseases, tuberculosis, and other communicable diseases, maternal and child health, mental and dental interventions, and family planning traditional

The roles of city and county governments, user constituencies, and public health leadership significantly affected the development of local systems.

This study, along with the more rigorous investigation by Miller and Moos, recognized that local circumstances are key to successful strategies for developing and strengthening the public health care sector. On a programmatic level, it can be seen from the example of these few cities that decentralization can become a way of improving the identification of and response to specific neighborhood health needs. This approach can also produce longer term efficiency in management when sufficient resources are allocated to the neighborhood level. An ambulatory care system also offers a greater degree of flexibility and adaptability in formulating strategies for health promotion. Such a shift in the locus of services responsibility from centralized hospitals to community-based ambulatory systems can include a broader range of services from the not-for-profit providers. The aim should not be to merely accommodate the private sector (mainly hospitals), but rather to integrate public and private efforts, as in Milwaukee, through innovative arrangements that break down historical barriers.

Moreover, all such efforts must take place within a framework of substantial community participation. Without a concomitant opening up of the public health care system to mechanisms for community empowerment, progress in wresting the devastation from the social epidemics is unlikely.

5. Ad Hoc Committee on Medicaid, Including the Poor: Health Policy


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**Join us for a Health/PAC Panel**

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**Women, Health & Power**

Moderator: Linda Lowe, Georgia Legal Services

The Medicalization of Adolescent Sexuality
Judith McCabe, University of Colorado

Women, Power and Community Control
Byllye Avery, Founding President, National Black Women’s Health Project

Reproductive Technology and Abuse
Loretta Ross, Center for Democratic Renewal

The Fetal Protection Movement
Jacqueline Berrien, Women’s Right’s Project, American Civil Liberties Union

Women and Access to Basic Care
Rita Salain, Georgia Department of Human Resources

Mental Health Services for Women in the Public System
LaRay Brown, Health and Hospitals Corporation, New York City.

Monday, November 11, 1991
Continental Breakfast 9 am, Panel 10 am
at the Best Western American Hotel
160 Spring Street, Atlanta, Georgia
Meeting the neglected and often urgent needs of poor children in today's climate of scarce and dwindling resources is a significant challenge, and it is intensified by the fact that simply expanding existing programs would have only limited impact. After eight years of studying successful interventions in the fields of health, mental health, education, child care, and social services that have actually improved long-term outcomes for children who are growing up in adversity, it has become clear to me that we must do more than improve access to existing services. We must also bring about profound changes in the content and provision of those services. If we are concerned with how the health and well-being of disadvantaged children can be significantly improved, we must begin by thinking anew about just what it is that these children need access to.

We must do more than improve access to existing services. We must also bring about profound changes in those services.

Comparing successful and unsuccessful health programs for disadvantaged populations, it becomes apparent that the health needs of children that are not being well met tend to have certain characteristics. They are not exclusively biological; they don't inhere entirely within the child; they require collaboration between pediatricians, other professionals, and parents; and they require continuity in care-taking and the investment of time. Of course, these issues don't even arise for children who lack access to the system, who are excluded from entry by financial and other barriers.

Two examples may help to clarify these points. The first illustrates the prevailing approach to health care for the poor, and how it fails disadvantaged children even when services exist for them.

**Gail: How Health Care Fails**

Gail was 13, shy, and soft-spoken. While being teased by schoolmates on the playground, she fatally stabbed an 11-year-old boy. She wandered away from school, and, several hours later, confused as to her whereabouts, telephoned her grandmother to pick her up. Later, she had no memory of the stabbing, and only vaguely recalled the boy pointing a knife at her. Witnesses said the boy had been pointing a pencil at Gail when she stabbed him.

Some weeks later, an official of the juvenile court reviewed Gail's medical records at the local hospital. They showed that Gail had been seen there more than 30 times for problems ranging from sore throats to recurrent headaches. The juvenile court reviewer discovered, in the midst of the fat file, an inconspicuous note by a resident physician saying that Gail had twice lost consciousness for no apparent reason while being examined. The resident recommended an electroencephalogram to determine whether Gail was suffering from seizures. None was performed until after Gail had killed her schoolmate.

Gail's family, with little education and overwhelmed by other problems, had no idea what Gail's examination had shown or that follow-up neurological tests had been recommended. There had been no single professional with continuing responsibility for making sense of the many complicated factors in Gail's background. Until after the killing, no one took the careful history that revealed that Gail had been the product of a long labor and traumatic delivery, that her mother had had syphilis during her pregnancy, that Gail's behavior since kindergarten had oscillated between withdrawal and fighting, that Gail often flew into a rage for no apparent reason. Following such outbursts, Gail would feel tired and have to sleep—a history that might have suggested a psychomotor symptomatology. Subsequent to the stabbing, neurologists concluded that Gail probably suffered from a psychomotor disturbance, and that the killing may have been associated with a seizure. No one, of course, can say today how Gail's behavior might have been different had she had proper medical attention.
Mrs. Cross and Jeffrey: Services That Work

The second story, a happier one, illustrates many of the elements of programs that intervene successfully with disadvantaged children. It comes from a pediatric group affiliated with Sinai Hospital in Baltimore, where the staff prides itself on meeting needs beyond the biological, that extend beyond the individual child, that involve collaboration across professional lines, and that require time-intensive, flexible, and non-episodic responses.

I met Mrs. Cross, a fiftyish grandmother, and her grandson, 2½-year-old Jeffrey, when the pediatric group suggested I learn about their work by meeting with some of the families they serve. The pediatric group enrolls every baby born at Sinai Hospital whose family has no other source of care, and takes responsibility for providing comprehensive services for that baby. Jeffrey's mother had been diagnosed as schizophrenic some time before he was born.

"From the minute that baby was born, from the first second, they showed concern for him," was how Mrs. Cross began her conversation with me. "Everyone, starting with Dr. Straus [the group's medical director, who became Jeffrey's pediatrician at birth], knew what the situation was from the beginning. My daughter couldn't have had a doctor who paid her any more attention or cared more about that baby." With Mrs. Bruce, the outreach worker, and Mrs. Polen, the social worker, "it's really been like a chain of concerned people," said Mrs. Cross. "Whenever I saw a problem, I got on the telephone and called Mrs. Bruce and she came right out. I felt confident, knowing she would do that. And I'm sure she relayed what was going on to the doctor, because everybody at all times knew what was going on. We didn't have to always start over again, and repeat everything, like at other hospitals."

Mrs. Cross described her daughter Lena's recurrent hospitalizations and her deteriorating ability to care for Jeffrey. She consulted with Dr. Straus about Lena's refusal to let Jeffrey take the antibiotics ordered for him, to let water touch him, or to feed him anything other than pizza and grits, and about whether it was safe to leave Jeffrey alone with his father when he came to visit. "It strengthened me," said Mrs. Cross, "to know that I could get professional advice from someone I could trust and who was aware of the situation. After a while, I came to see that much as I'd like to think Lena could care for her own baby, it was wishful thinking."

What was described as "a chain of concerned people" goes far beyond some mechanistic coordination of services.

Mrs. Bruce came and talked to Lena about feeding Jeffrey properly and about his health and cleanliness, to no avail. The Department of Social Services sent somebody who told Mrs. Cross that "if Lena remained at home they would have to take the baby and put him in a foster home."

Step by step, Mrs. Cross reviewed how the clinic's outreach worker and social worker helped her get her daughter back into hospital care and get temporary guardianship of her grandson—a painful process that she could never have managed, she said, without the help of
the pediatric group. "All these people know that this is a child that really needed special attention. Dr. Strauss, you know, he really knows Jeffrey! And Mrs. Bruce, she really became like a member of the family. She was like Jeffrey's...I would say she was like Jeffrey's appointed mother from the hospital. She always came. One day we opened the door and the snow was knee high and icy, but there she was. She never, never failed to keep an appointment."

Who is to say which of the services the pediatric group provided to Mrs. Cross are medical services, which should be considered mental health services, which are social services, and which are really family support services? We do know that less than six months after this conversation, the heroic Mrs. Bruce had to be let go because there was no money to support outreach activities. We do know that what Mrs. Cross describes as "a chain of concerned people" goes far beyond some mechanistic coordination of services. And it would probably be safe to guess that the residents being trained in that pediatric group have a radically different definition of the content of high-quality health care from that of most physicians, in or out of training.

The Elements of Successful Programs

The Sinai Hospital pediatric group has many elements in common with other successful programs. In my study, I identified these elements through a detailed examination of 18 such programs in the domains of family planning, prenatal care, child health, family support, preschool, and elementary education. These programs had succeeded in lowering the incidence of what I labeled "rotten outcomes"—teenage childbearing, dropping out of school, and delinquency—or in preventing antecedent risk factors. I called these "rotten outcomes" because of their lifelong consequences and the enormous toll they take on the youngsters, their families, and society as a whole. Although none of the three outcomes is strictly a health outcome, poor health and poor health care are implicated, both as precursors and as consequences.

A second attribute that marks successful programs is active collaboration across professional and bureaucratic boundaries. These programs are able—usually through heroic efforts—to overcome the fragmentation that results from separate funding streams, separate and often conflicting regulations, and separate disciplinary approaches. Successful programs, whether they are built around health clinics, social agencies, settlement houses, or schools are somehow consistently able to remove some of the most burdensome barriers to the receipt of coherent services. In these programs, no one says, "This may be what you need, but helping you get it is not part of my job," or "This is outside this agency's jurisdiction."

A third attribute of successful programs is that they deal with the child as part of a family and with the family as part of a neighborhood and community. These programs take into account the real world of those they serve and recognize the centrality of strong family support in the life of a young child. The successful school enlists parents in collaborative efforts to give children reasons to learn. The clinician treating an infant for recurrent diarrhea sees beyond the patient on the examining table to whether the family needs help from a public health nurse or social worker to obtain non-medical services. A rural health clinic in Mississippi actually delivers clean water to families that can't get it any other way.

Finally, in successful programs, staff have the time, training, and skills necessary to build relationships of trust and respect with children and families. Professionals in these programs say they work in a setting that allows them to provide services respectfully and ungrudgingly, in an atmosphere of mutual trust. They stress their informal and collaborative posture, and emphasize the importance of one-to-one relationships, listening to parents and adolescents, and exchanging information rather than merely instructing.

In successful programs no one says, "This may be what you need, but helping you get it is not part of my job."
Obstacles to Implementation

A number of troublesome paradoxes inhere in these critical attributes of success and represent obstacles to the widespread implementation of similar programs. Understanding these paradoxes helps to explain why successful models so often remain isolated and unreplicated, and why many efforts to build on past successes fail.

The most obvious obstacle is that the key attributes of programs that are successful in improving outcomes for disadvantaged children (comprehensiveness, intensity, flexibility, front-line discretion, informality, emphasis on personal relationships, and dealing with individual children in the context of family and community) are at odds with the dominant ways that most large institutions and systems function. Indeed, many institutions and systems, both public and private, have recently demonstrated an upsurge of interest in providing more effective and coherent services to children at risk and their families. Many are even prepared to modify long-standing traditions and rules governing the division of labor and turf among various professions and various agencies and systems. However, the needed changes strike them as so complicated, profound, and far-reaching that practitioners and administrators as well as policymakers seem to have a hard time moving beyond rhetoric.

Although these groups may in fact recognize that fragmentation of services interferes with the provision of effective services, they find it exceedingly difficult to overcome because it is typically the product of legitimate pressures such as the need for accountability or the demands of political forces—including single-issue advocacy—that are themselves becoming ever more fragmented as well as the exigencies of a reward system that puts a premium on ever-greater specialization.

In the crisis atmosphere created by scarce resources, years of budget cutbacks, the increase in the social disruption of families, the increased incidence of AIDS, drug addiction, child abuse, and childhood poverty, moreover, it is almost impossible to persuade beleaguered administrators and politicians to address issues of long-term change—change that promises few, if any, immediate pay-offs. Operating agencies fear that efforts at cooperation could diminish their already inadequate resources.

Politicians—and advocates—may also recognize the need for broad, systemic changes, but know that their success depends on being identified with crisply defined, easy to understand, incremental steps designed to reach clearly circumscribed, manageable goals.

The distinctive forms of programming that improvements in services to the truly disadvantaged often require constitute another obstacle to their implementation. There is a tremendous discontinuity not only between the needs of the most disadvantaged and those of the rest of society, but also between the services and programs that would meet those needs and what actually exists. For example, the staples of middle-class prenatal care—routine laboratory tests and regular monitoring of blood pressure and fetal growth—are not enough when the patient is a teenager who is poor, frightened, depressed, suffering from a venereal disease, and perhaps addicted or without a permanent home. We try to gloss over these differences in order to provide equity in benefits and services and to maintain broad political support for our efforts to serve these populations, but our failure to face up to the distinctive needs of those at greatest risk may have become counterproductive.

Possibilities for Change

Obviously, when we focus specifically on health needs and health services, the obstacles to devising large-scale programmatic responses to the broad spectrum of needs of poor children and their families are no less formidable. Many of the problems are similar; others are even harder
to solve in the health policy context.  
The predominant view of medicine, in which a problem is seen as medical and therefore within the physician's proper purview only if it can be approached by the theory and techniques of biomedical science, may help to explain why children and families at risk often derive little benefit from their encounters with the health system, even when they have them.  
In the hierarchy of values or priorities in health, social services, and education, disadvantaged populations rank low; preventive services rank low; and, in medicine, the non-technological services essential to many successful preventive interventions rank low. When it comes to professional status and economic compensation, direct provision of basic services to the least powerful carries little prestige. There are no prizes for being willing and able to respond "transmedically" to what David Rogers describes as the "great untidy basketful of intertwined and interconnected circumstances and happenings" that often all need attention if a health problem is to be overcome.

The key attributes of successful programs are at odds with the dominant ways that most large institutions and systems function.

Moreover, the reforms in health policy and health financing that are currently under consideration are unlikely to solve the health problems of truly disadvantaged children. Proposals to eliminate financial barriers to health care by creating a universal entitlement to insurance would alleviate some portion of the problems that disadvantaged families encounter in obtaining health care. But, as Eli Ginzberg has pointed out, "quantity and quality would continue to depend on the availability of physicians, support personnel, bed capacity, equipment, and other critical inputs."  
To the extent that rationing or spending ceilings are imposed (through a national health financing system or through state programs), the health services that will flourish will probably continue to be biomedical responses to biologically defined problems, because they are at the core of what the medical profession values most.  
Medicaid reforms that expand eligibility and improve reimbursement are even less likely to benefit the truly disadvantaged in the future. Fossett and colleagues concluded on the basis of their Chicago study that, even with such reforms, because of the increasing concentration of the poor and specifically low-income minority women in areas of concentrated poverty, the choice of providers for this population (in the absence of other kinds of interven-

tion) will be increasingly limited to a small number of high-volume Medicaid practices, "where there is cause for concern about the quality of care."  

If health system reforms now on the horizon are unlikely to bring solutions, are there other avenues that could lead to substantial improvements in the health care of disadvantaged children? Leaders in the health field might do better to make common cause with forces outside the health system that are working to improve a wide range of services and institutions on which poor children and their families depend. A profusion of scattered efforts are now getting under way in school systems, human service agencies, child care, and family support programs and within state and local governments that are aimed at reducing the mismatch between successful services of all kinds and the traditional workings of large institutions. These may offer a more forceful wave of change to ride than the wave of health system reform.  
It is clear from the findings already discussed that if the health care, schooling, and social services and supports that could change the prospects of these youngsters are to reach those who need them most, they must be coordinated and coherent, and provided with enough flexibility and skill to be responsive to the needs of individual families and the circumstances of individual communities. This cannot be done in large numbers of communities to serve large numbers of families without changes in the way money flows to local programs.

A Modest Proposal

An idea that may merit further exploration is the creation of a sort of flexible superfund, to support flexible intensive services for children growing up in areas of highest need. An initiating agency (which could be a state, the federal government, or even a large city) would attempt to persuade other agencies and jurisdictions to join it in earmarking a certain proportion of expenditures (including funds that currently support health services, social services, schools, preschools, and the like), to support comprehensive, neighborhood-based services.  
Together with similarly targeted funds from foundations, businesses, and nonprofit agencies and institutions (which may not be large in comparative dollar magnitude, but would provide additional flexibility and public support), these funds would flow, unencumbered by the usual restrictions, into neighborhoods characterized by high rates of poverty and social need. To guard against the misuse of these funds, it would be essential to provide intensive and highly competent technical assistance and training to all eligible participant agencies and to maintain accountability through the rigorous use of outcome measures. Assessing effectiveness by measuring real-world outcomes rather than processes would help in making continuing mid-course corrections and in assuring funders that the program's purposes are, in fact, being accomplished.  
The target population would be defined geographically to minimize the barriers to access created when eligibility is determined by such criteria as income, assets, or family status, and to take into account the powerful neighborhood-level influences—positive and negative—that affect children's well-being. The definition of eligible target areas could be made at a federal, state, or local level,
possibly by census tract. Criteria would include high rates of poverty, unemployment, school dropout, teenage childbearing, welfare dependence, and single-parent families. A neighborhood focus would also make it possible to combine efforts to improve a broad range of effective human services with simultaneous efforts to improve housing, job training, public safety, and community and economic development.

A massive infusion of new funds to support a parallel service delivery system for the poor (which is how many of the early Office of Economic Opportunity programs surmounted systems barriers) is unlikely, as is massive and rapid systemic change to accommodate comprehensive, transdisciplinary, flexible, responsive services. This proposal however, would keep the scale of the effort relatively modest by limiting it to support for services to children and their families living in areas in which the truly disadvantaged are concentrated. Because the initiative would be targeted only a fraction of the poor, it would not be as threatening to scarce resources and to prevailing administrative and professional arrangements as a proposal involving larger numbers.

Although the proposed initiative would be relatively small in scale, it would hardly be trivial, because it would target the populations at greatest risk, in greatest need of high-quality services, and yet least likely to receive them under present circumstances. Furthermore, it would tackle the broad sweep of barriers to the improvement of services for disadvantaged children. It would also represent a sufficiently bold departure from "business as usual" that it might attract the kind of talented and committed individuals who could make an initiative like this work.

The rewards to local communities of participating in the program would be only partially in the form of new funds. The additional attraction would be in the more favorable conditions under which funds would be made available. High-quality technical assistance and continuing consultation would have to be made available on terms that would assure that virtually every neighborhood that qualified under the definition of need could participate.

A host of important questions would have to be answered before such a proposal could enlist widespread support, including the difficult issue of what kind of local agencies could become recipients of these funds and who would be responsible for the requisite planning and coordination. In addressing such questions, the rich experience drawn from both successes and failures of attempts to improve outcomes among disadvantaged children during the last 25 years should prove invaluable, and could be expected to minimize the chances of repeating the mistakes of the past.

The significance of this proposal is not in its particulars. Rather, it should be seen as one among many attempts to find fresh answers to the agonizing question of how systems and institutions can be helped to meet the increasingly urgent needs of America's disadvantaged children, and thereby the needs of all Americans.

There is now increasing agreement about the high stakes as well as ample knowledge and experience on which successful interventions can be built: It is time to combine income supports, economic policy, and housing and community development with action to assure that the best schooling and health and social services the nation can provide will, at long last, reach the children and families who need them most. Then the children growing up without hope today will stand a real chance of becoming full participants in thriving American communities of tomorrow.

2. Findings from longitudinal research on risk factors as well as the experience of practitioners suggest that a focus on the period between the mother's pregnancy and the child's entry into elementary school may be the most auspicious and economical time to intervene. I found a handful of risk factors that seemed susceptible to reduction or prevention through outside intervention. These included being born unwanted or to a teenager mother, low weight at birth, untreated childhood problems, failure to develop trusting relationships with reliable and protective adults early in life, and lack of language and coping skills at school entry.

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Bomb Now, Die Later
The Health Impacts of the Gulf War

JOHN M. MILLER

In the celebratory atmosphere following the end of the war in the Persian Gulf, the media has treated the devastation of Iraq and Kuwait sympathetically but uncritically as the unintended but unavoidable results of a war that was the cleanest in the history of human violence. In reading Miller's summary of the effects of the war on the health of the population, we must keep in mind what many commentators have pointed out: that the devastation inflicted by U.S. bombs on the civilian populations of Iraq and Kuwait was not "collateral" damage. It was the deliberate result of "surgical" strikes intended to, as James Ridgeway wrote in the June 18, 1991, Village Voice, "knock out key installations of Iraq's civilian infrastructure, denying electricity, water, heat, and medical services to the civilian population."

What does it mean that, as Jost Hiltermann of Physicians for Human Rights told the Guardian (June 12, 1991), "They have refined these weapons to the point that the mass death doesn't come until after the war"? It means, as Miller shows, that civilians—particularly children—bear the brunt, and, since the war is long over, no one gets the blame.

"We refer to this as a bomb now, die later kind of war," Dr. H. Jack Geiger of Physicians for Human Rights told the press after touring Iraq. "This is a slow-moving catastrophe of immense proportions...The four horsemen of the apocalypse are riding through Iraq right now."

The exact number of those who died during the 42-day Persian Gulf War may never be known. The Pentagon has little interest in body counts these days. The number of those who died before the war because of the tight sanctions against Iraq or because of Iraq's invasion of Kuwait is also unknown. Still more casualties have come after the war from refugee flight, burning oil wells, and the collapse of Iraq's infrastructure. The health aftermath of this war will linger, and civilians will be the ones to suffer. If the worst fears and predictions of relief workers and climatologists come to pass, many more in Iraq and elsewhere will die as a result of the "hyper war," as the quick and intense conflict has been referred to by some Pentagon officials, than were killed directly by the bombing or ground war.

Greenpeace calculates that as of early May 1991, over 200,000 lost their lives as a result of the Gulf crisis. Among the dead: 100,000 to 120,000 Iraqi troops and nearly 76,000 civilians, most in the civil war and refugee flight that followed the temporary ceasefire. Between 2,000 and 5,000 Kuwaitis were killed during the seven-month Iraqi occupation. Other estimates of the casualties vary, but whatever the exact figures and however surgical the U.S. air strikes, Greenpeace contends, "the patient was skillfully carved and disemboweled..." The social and economic fabric of the society was completely disrupted.

Health and the Infrastructure

A United Nations mission to Iraq soon after the war found that the recent conflict has wrought near-apocalyptic results upon the economic infrastructure of what had been, until January 1991, a rather highly urbanized and mechanized society. Now, most means of modern life support have been destroyed or rendered tenuous. "Iraq has, for some time to come, been relegated to a pre-industrial age, but with all the disabilities of post-industrial dependency on an intensive use of energy and technology."

The destruction of Iraq's infrastructure was so systematic that even without the ongoing sanctions it would take years to rebuild.

Subsequent investigations have essentially confirmed this conclusion, as have internal assessments by the U.S. government. The destruction of Iraq's infrastructure was so systematic that even without the ongoing sanctions it would take years to rebuild. A lack of electricity and fuel is preventing Iraq from meeting many of its people's basic needs. Transportation and communications remain crippled, hindering coordination and distribution of relief goods. Describing the destruction of sanitation, waste

John M. Miller is coordinator of the International Clearinghouse on the Military and the Environment in Brooklyn, New York, a project of the Arms Control Research Center.
Telecommunications building in Baghdad hit on several days by U.S. planes.

A lack of electricity and fuel is preventing Iraq from meeting many of its basic needs.

short-term fixes and remedies” that are sustaining the Iraqis “will probably deteriorate in the months ahead.”

if Iraq is allowed to pay for food assistance with its oil, the destruction of irrigation systems in the war, the lack of imported seed, fertilizers, pesticides, and fuel for agricultural vehicles, and the diversion of agricultural labor to the war means this year’s harvest will be poor, and next year’s doesn’t promise to be much better.

Children are especially vulnerable. A Harvard study team found that infant and child mortality had doubled, and severe acute malnutrition was rampant. The team’s report conservatively “projects that at least 170,000 children under five years of age will die in the coming year from the delayed effects of the Gulf Crisis....The immediate cause of death in most cases will be water-borne infectious disease in combination with severe malnutrition.” A UNICEF survey of 430 children under age 6 in southern Iraq found nearly 10 percent were severely malnourished, and a recent UN-sponsored mission by Tufts University specialists in nutrition confirmed the seriousness of the problem.

Those water-borne diseases that are not preventable because of the destruction of water purification and sewage treatment systems would still be treatable if the Iraqi medical systems were still functioning. But only a fraction of Iraq’s health system—which before the war “was well equipped to meet the needs of children and their families”—is operating. Many hospitals and clinics were severely damaged during the bombing or in the uprisings that followed. In addition, many facilities “lack reliable clean water, sewage disposal, and electrical
power.”13 There is a shortage of health workers; many were foreign workers who left Iraq. Common laboratory tests cannot take place because of a lack of power.

The public health crisis is directly linked to the destruction of nearly all of Iraq’s electrical generating capacity. “Without electricity, water cannot be purified, sewage cannot be treated, water-borne diseases flourish and hospitals cannot cure treatable illnesses,” concluded the Harvard study.14 The New York Times reported that three months after the war, 80 percent of the nation’s power grid was still down.

International sanctions have made the situation worse. Dr. Eric Hoskins, medical coordinator of the Gulf Peace Team, an international group that has been in the region since before the war, reported in May 1991 that since August [1990], less than one-thirtieth of Iraq’s medicine requirements have been met. All medicines—including vaccines, insulin, anesthetics and antibiotics—have been in short supply since late 1990. Iraq’s child immunization program has been suspended since September for lack of vaccines. Already, cases of paralytic polio are on the rise, and outbreaks of measles are likely.15

Almost no food has entered Iraq—which has historically imported 70 percent of its food—since August 1990. Although the UN authorized the unfreezing of Iraqi assets in March to buy food and medicine, the process for importing them is extremely cumbersome. Iraq is not allowed to buy supplies needed to repair and rebuild essential infrastructure. To buy food commercially, Iraq needs to earn foreign exchange by exporting oil, which is also not allowed. President Bush opposes any easing of sanctions until Saddam Hussein is overthrown.

Unexploded Ordnance

In common with many other battlefields of this century, Iraq and Kuwait are now littered with unexploded bombs and mines that will long pose a threat to human life. Iraq emplaced some half a million mines in and near Kuwait. Over 90,000 tons of bombs were dropped on Iraq and Kuwait. Many were cluster bombs, which disperse hundreds of small bomblets. Artillery, naval ships, and tanks fired additional shells. Not all of this ordnance exploded: “At least 600 bombs, rockets and artillery shells dropped or fired every day of the war will have failed to explode and thus constitute a continuing hazard somewhere in the war theater,” one U.S. expert told the Washington Post.16

While many of the leftover mines and munitions in Kuwait are being destroyed, buried explosives will continue to cause causalities in that country and elsewhere. Over 100 soldiers have been injured since the war ended.

Survivor of “mistaken” bombing of civilian Kadahmiya neighborhood in Kuwait.
Along the Iran-Iraq border, many Kurds have been injured by land mines and unexploded munitions, and several of the tent cities were located in areas that had been heavily mined. GIs in northern Iraq have been told not to give children presents because Kurdish culture requires them to reciprocate, and some children have been wounded when picking up shiny cluster bomblets to give as gifts.

Special equipment and training are needed to find and render harmless many of the sophisticated weapons the United States rained down on Iraq and Kuwait. Some areas, especially those away from populated and industrial areas, may ultimately have to be fenced off.

**Oil Fires**

Pollution resulting from the war will cause health problems for years to come. A soot-filled cloud of toxic smoke has spread well beyond Kuwait, where hundreds of oil wells are in flames. Putting out all the fires, the bulk lit by retreating Iraqis, will take a year or more. Should the fires burn long enough and the smoke go high enough, some scientists fear that the summer monsoons over India could be disrupted, triggering famine. In the meantime, the fires are creating a health crisis on the ground.

The smoke consists of nitrogen and sulphur oxides (major causes of acid rain), soot particles, unburned oil, heavy metals, and toxic chemicals such as benzene, toluene, and xylene that can cause cancer, birth defects and genetic mutations. The fires are also a major source of carbon dioxide, the major greenhouse gas and a cause of global warming. A recent analysis of the smoke by the National Toxic Campaign found additional chemicals that with long-term exposure can cause damage to the liver, kidneys, and respiratory system.

Soot produced by the fires has been detected as far away as Hawaii. Acid rain and an oily “black rain” from the fires have fallen over 1,000 miles from the Kuwait, contaminating water sources and fields in Iran. The smoke and soot “are affecting sunlight, crops and health, according to Robert R. P. Chase of Analytic Sciences Corporation.” It is clear from satellite studies that people as far east as India and Ethiopia are breathing soot from the Kuwaiti oil fires. Some of these particles are of cancer-causing compounds, such as benzene.” Chase predicts that the densest smoke will cause health emergencies for up to 200 people per 100,000, primarily among the very young and people with lung problems. “What this means is that some of these people will have to be hospitalized and put on oxygen if they are exposed for 24 hours or more,” he says.

Kuwaiti hospitals and clinics report increased admissions for lung problems. Long-term exposure to the smoke can cause cancer, respiratory illnesses, and birth defects. Healthy individuals exposed to the smoke complain of coughing, shortness of breath, headaches, and raw throats. Kuwait’s doctors have urged people with asthma to leave the country. The World Health Organization has advised people with heart or respiratory problems to stay indoors while the smoke cloud is overhead.

Much specific data about the makeup of the smoke has yet to be released, but an Environmental Protection Agency team detected levels of particles up to “10 times the permitted amount under U.S. regulations.” Even as it sought to downplay the impact of the fires, a U.S. government Interagency Air Assessment Team report acknowledged that “emissions from oil fires may have the potential of causing health effects of both an acute and chronic nature,” particularly for “susceptible subpopulations, such as individuals with asthma and chronic obstructive lung disease.” During the summer, thermal inversions will trap the pollution for days over Kuwait.

The pollution is already affecting water supplies and irrigation for crops. Scientists from the British Meteorological Office who have measured the smoke cloud report that agriculture in Iraq and Iran are at greatest risk from acid rain, which can contaminate the soil and eat away at crops and trees, stunting their growth. Other toxic substances in the smoke, along with the millions of barrels of spilled oil, may, after entering water ecosystems, become concentrated higher up on the food chain, poisoning birds, fish, mammals, and the humans who eat them.

Other wartime sources of airborne toxin include tires burned in Iraq’s cities to mislead allied bombers; uranium dust from hardened shells in the U.S. arsenal, used to attack bunkers and tanks; and fires at petroleum and petrochemical storage facilities in Kuwait and Iraq.

**Chemical Spills**

The amount of toxins released by the bombing of military and industrial chemical facilities, petrochemical plants, and other industrial infrastructure is unknown. During the air war, traces of chemicals, presumably from the bombing of stored chemical munitions, were detected along the Saudi-Kuwait border. While there are no reports of Bhopal-like mass deaths from chemical releases, the incomplete burning of nerve agents and mustard gas would leave toxic by-products, such as dioxins, which would persist in the environment and accumulate in living organisms.

Al Picardi, an environmental scientist who has looked at the impacts of controlled incineration to destroy chemical weapons stockpiles in the United States, says the results of bombing chemical weapons facilities “would be many orders of magnitude worse, because it is uncontrolled open burning.” The lower temperature of such fires would allow the release of more waste products of combustion and volatilization and of the chemical agents themselves.

Chemicals from industrial facilities, such as those producing and storing pesticides, chlorine for water purification, and petrochemicals were released in massive quantities.
Burning of the chemicals have polluted the air and spills have contaminated soil, nearby bodies of waters, and groundwater. These chemical and their by-products can often be immediately lethal and over the long-term cause cancers, birth defects, and other illnesses.

The war has had an impact on health services in the United States as well. Many small communities temporarily lost their doctors or other health workers as reservists were called up. And this war, which may yet be resumed—so popular and fought with so few U.S. casualties—may embolden this and future administrations to further military adventures, in which resources needed to solve and treat health and environmental problems at home and abroad would be squandered by creating further human tragedies in the Third World.

3. Ibid., p. 8.
4. Letter dated March 20, 1991, from the United Nations Secretary General to the President of the Security Council (S/22366), enclosing report by Under-Secretary-General Martti Ahtisaari.
10. Mayer, op. cit.

Refugees wait in long lines and sweltering heat to receive rations of bread, yogurt, and water in hastily constructed camps in the no man's land along the Jordanian and Iraqi frontiers.
In Her Own Voice

Too Little, Too Late: A Child with AIDS

by Teresa McMillen

I met Joanna and her family during their second visit to the clinic in June 1990. Joanna was brought to the clinic by her mother, Ana, and her aunt Mildred. Her 6-year-old brother, Tommy, was an uncontrollable ball of energy, running in and out of rooms, up and down the halls, propelled by a force that no one could contain, although Joanna often tried. Ana was in a daze, having just found out that Joanna had tested positive for HIV infection; she barely spoke and seemed isolated from those around her. Mildred expressed her concern about how Ana, as a single mother, would manage with Joanna sick, Tommy out of control, and Ana herself eight months pregnant. The family lived in a one-bedroom, rat-infested apartment. I promised to make a referral to the city’s Division of AIDS Services with requests for home care and housing.

I learned that Joanna had had a pretty normal life until her 11th birthday, when she began to get very ill. Ana said Joanna had frequently had fevers and ear infections, but no one thought to look for HIV infection as a possibility until Joanna came down with candida esophagitis, one of the opportunistic infections associated with AIDS, in May 1990. At our first interview, Ana told me she did not believe the diagnosis. She wanted Joanna to be tested again. And, since the only possible risk factor was perinatal transmission, we asked Ana to be tested as well.

When both tests came back positive, Ana had to come to terms with the severity of Joanna’s illness. She had to accept her own infection as well, and face the guilt she felt at the unmanageable. It was impossible for Anna to follow through on referrals because the burdens of caring for un-
possibility that she had infected her then newborn son, Jason. She anguished over her daughter's suffering and felt additional guilt that she herself had remained so healthy. She worried constantly that Jason would become sick and that one day only Tommy, who was HIV-negative, would be left, with no one to care for him. She was also afraid of dying.

Joanna was enrolled in a controlled treatment trial for children. The protocol involved monthly intravenous infusions of about 2½ hours each. As I spent time with the family during these monthly infusions, a connection began to develop between us. I was impressed with Joanna's maturity, intelligence, and sense of responsibility. She was a tremendous source of strength and companionship to her mother as Ana struggled to raise her children alone. Joanna had goals for her life. She was an honors student and valedictorian for her sixth grade class. She wanted to live.

We were able to provide many services, but just as often Joanna's illness was several steps ahead of our efforts.

Time Running Out

From the perspective of a service deliverer, caring for a child with AIDS is a difficult and frustrating task that requires the coordination and involvement of many agencies. The doctors, nurses, and social workers at Einstein contacted at least 40 different agencies in attempts to secure needed services or materials for Joanna's family. We were able to provide Joanna and her family with many important services that eased their suffering, but just as often her illness was several steps ahead of our efforts.

In July we invited Joanna to come with a group of children from the hospital to the Hole in the Wall Gang Camp in Connecticut, a camp for children with chronic illnesses. She desperately wanted to go, but already her time was running out. The day before we were to leave, she was hospitalized for severe abdominal pain at Bronx Municipal Hospital Center. (Every time Joanna needed to be hospitalized, the pediatric unit at Einstein was full. It was extremely frustrating.) This was the first warning we had that the deadly Mycobacterium intracellulare infection had found Joanna. We knew then that she had less than a year to live.

We all tried to bring as much comfort, compassion, and joy to Joanna's life as possible. After her bitter disappointment at missing camp, we made a referral to Starlight Foundation, which fulfills the requests of terminally ill children. They granted Joanna's wish for a TV and VCR. Joanna was unable to attend school that September. A home tutor came to Joanna every day and tried to brighten her spirits with jokes, games, or just companionship when she was too ill to study.

The Division of AIDS Services was finally able to provide a homemaker for Ana in mid-October. She had waited for 4½ months, but it was a great relief to finally have some help. The homemaker's hours were from 8:00 am to 4:00 pm. She helped with housework and stayed with the other children when Ana had to bring Joanna to the hospital.

There were several crises when the homemaker wasn't available and Ana had to rush Joanna to the hospital. Her friends helped sometimes, but often Ana was forced to struggle alone with one child in severe pain and two others demanding her attention in a crowded hospital emergency room. It was a nightmare for her. We requested increased hours for the homemaker but were never able to get them.

Tommy was confused and disturbed by his sister's illness. As often happens in families of chronically ill children, the well children are overlooked or emotionally neglected in many ways. Tommy became the main expresser of anxiety in the family. His hyperactivity and reckless, impulsive behavior became almost
Thousands of families are facing similar tragedies compounded by nonexistent, overloaded, or inadequate services.

unmanageable. It was impossible for Anna to follow through on referrals for counseling for very long because the burdens of caring for Joanna were too overwhelming.

Joanna’s condition deteriorated rapidly. She was in constant, often severe, pain. She was suffering from seizures. She had numbness and tingling on her right side, her foot dragged when she walked, and her mouth contorted when she tried to talk. She was terrified by the changes in her body. I stayed with her as she cried over and over, “Why me? Why is this happening to me?” I squeezed her hand and tried to calm her when the doctor drew her blood. She screamed, as she did each time an IV was inserted or blood was taken. Every needle stick was a torturous affront to the fragile body that she was desperately trying to keep intact. The virus was destroying her body, but to Joanna the procedures she was put through were equally terrifying and destructive.

Around Thanksgiving I went to Joanna’s home. She was suffering from diarrhea and could no longer walk. Still, she was open to talking. She talked about her helplessness, her frustration at not being able to walk, her regrets about the things in life she had missed out on, her embarrassment at needing to wear diapers. I tried to comfort her by telling her that someday she would have a different kind of life. I said that sometimes our bodies just don’t work right anymore. I tried to convey to her my sense that our spirit—or everything that makes us who we are, how we think, feel, and act—lives in our bodies. I expressed my belief that when our bodies get too sick or injured, God invites us to live in his house so that we can have a different, more beautiful life. I felt that Joanna understood.

In early December, Joanna had to be admitted again, this time to North Central Bronx Hospital with pneumocystis carinii pneumonia (PCP). From the time of her admission until the day of her death on January 4, the nurses from Einstein’s Comprehensive AIDS Family Care Center, who were very close to Joanna, frantically worked to obtain the nursing services that would allow her to be discharged and cared for at home. Einstein’s doctors also worked closely with those from North Central Bronx to coordinate her care. Numerous agencies were contacted. Only one of them could help, but not in time.

Joanna begged every day to go home. She was often alone in the hospital in the evenings and at night because the family did not have enough support and Ana had no one to take care of her other children. The nurses and social worker from Einstein visited several times a week. At Christmas, Joanna found the strength to open a number of gifts from the Children’s Hope Foundation.

Anger, Frustration, and Death

The last visit I had with Joanna during which she was aware of my presence was two days before her death. Her room was filled with toys that she would never play with and could bring her no more joy. The Christmas decorations were incongruous next to the suffering in her room. Joanna was wearing an oxygen mask. She removed it only long enough to point out the IV in her ankle, which must have been even more frightening to her than the usual insertions she hated so much, and to indicate her swollen wrists. Then she panicked and put the mask back on her face.

As I drove home, I cried because I did not understand a medical sys-

tem that dictates that some form of treatment must be provided even when there is no hope. Joanna’s mother had struggled with and finally signed the “do not resuscitate” order weeks earlier. Why did they continue to draw blood, to put an IV in her little ankle, to take needless X-rays that were only going to tell us that she would die soon? Why couldn’t Joanna be allowed to die with dignity at home? I was angry and frustrated by a home health care system that requires that a referral cross many desks and receive multiple approvals before someone actually shows up to help. I was angry at Ana’s family and friends for not rallying to support her in any way they could. I was angry at myself for not knowing more about how to negotiate the health care system. No dying child should have to spend even one night alone in a hospital.

I can take you no further with Joanna than the door of her room the night she died. As Ana, her nurse from Einstein, and I waited at her bedside for her suffering to end, Joanna was blessed with unconsciousness.

Time has not eased Ana and Tommy’s suffering over the loss of Joanna. Ana often feels sad. She is apathetic about life and sometimes thinks dying would be easier. Tommy is worried about everyone in his family getting sick. He is haunted by the memory of his sister. At 8 years of age, he is burdened with guilt and regret born of not treating his sister better when she was alive.

The struggles of Joanna’s family are not unique. I have met many courageous people like them who have taught me about life, about hope, and about what is important. They have given me strength to pass on to others in need.

Across the nation thousands of families are facing similar tragedies compounded by nonexistent, overloaded, or inadequate services. Access to services must be facilitated more quickly, and more skilled home care workers must be hired to meet the overwhelming needs of these families. One of the things I learned most clearly from Joanna’s experience was that AIDS waits for no one, least of all the children.
Title X: A Supreme Nightmare

CATHERINE TEARE

It's hard to know which is worse: the recent Supreme Court Title X decision, or the near-certain knowledge that the same five member majority (Rehnquist, White, Kennedy, Scalia and Souter) will overturn Roe v. Wade at the first opportunity.

The Title X restrictions are a thinly-veiled attempt to limit the number of abortions in this country by tying federal family planning dollars to restrictions on medical care providers' freedom of speech. The best-known provision of the regulations specifies that "a Title X project may not provide counseling concerning abortion or referral for abortion as a method of family planning." Any pregnant woman requesting abortion information at a clinic that receives any Title X money will be told (according to the Department of Health and Human Services' official script): "This project does not consider abortion an appropriate method of family planning and therefore does not counsel or refer for abortion."
The only exception to the policy is in cases of "imminent peril" to the woman.

The regulations impact poor women—the primary clients of Title X clinics—unfairly. They are the latest in a series of income-based restrictions to access. In Maher v. Roe (1977), the Supreme Court ruled that federal Medicaid funding could not be used to pay for abortion. The 1989 Webster case upheld a Missouri law forbidding abortion in any public facility, including hospitals built on state-owned land.

Rehnquist argued in Rust v. Sullivan that Title X regulations do not burden poor women unfairly, since they leave them the same options as if the government had never funded family planning services at all. This reasoning is cruel and specious. Incorrect and incomplete information causes real harm to women, and the "same options" amount to no options at all: appropriate medical care is denied to women who cannot pay.

A second provision of the regulations, which has received less press but is equally dangerous, prohibits any Title X grantee from engaging in activities that encourage, promote or advocate abortion as a method of family planning. These activities include, lobbying, developing or distributing materials related to abortion, providing speakers, taking any legal action to increase abortion availability, and paying any dues to an organization that advocates abortion. Pending legislation that would overturn the ban on abortion counseling and referral does not address this second provision, which threatens recipients of Title X monies, which has a 1991 grant budget of $144 million, and conduct programs in over 4,000 clinics. One-third of these programs' clients are adolescents, and most are low-income women.

Things can hardly get worse. Overturning Roe v. Wade is merely a formality for a court that has effectively made abortion unavailable to women who cannot pay for it themselves. We must redouble our efforts to regain some of the ground we have lost through the actions of the Rehnquist court.

Rust v. Sullivan

JUSTICE HARRY BLACKMUN DISSENTING

Rust v. Sullivan, the case which resulted in the Supreme Court's recent "gag ruling," was decided by a vote of five to four. Following are excerpts from Justice Harry Blackmun’s dissent, in which he was joined by Justice Thurgood Marshall. Justices Paul Stevens and Sandra Day O'Connor wrote separate dissenting opinions. Justices White, Rhenquist, Scalia, Kennedy, and Souter formed the majority.

Casting aside established principles of statutory construction and administrative jurisprudence, the majority in these cases today unnecessarily passes upon important questions of constitutional law. In so doing, the Court, for the first time, upholds viewpoint-based suppression of speech solely because it is imposed upon those dependent upon the government for economic support. Under essentially the same rationale, the majority upholds direct regulation of dialogue between a pregnant woman and her physician when that regulation has both the purpose and the effect of manipulating her decision as to the continuance of her pregnancy. I conclude that the Secretary's regulation of referral, advocacy and counseling activities exceeds his statutory authority, and, also, that the regulation violates the First and Fifth Amendments.

By far the most disturbing aspect of today's ruling is the effect it will have on the Fifth Amendment rights of the women, who, supposedly, are the beneficiaries of Title X programs.

Both the purpose and the result of the challenged regulations is to deny women the ability voluntarily to decide their procreative destiny. For these women, the government will have obliterated the freedom to choose as surely as if it had banned abortions outright. The denial of this freedom is not a consequence of poverty but of the government's ill-intentioned distortion of information it has chosen to provide.

In its haste further to restrict the right of every woman to control her reproductive freedom and bodily integrity, the majority disregards established principles of law and contorts this Court's decided cases to arrive at its preordained result. The majority professes to leave undisturbed the free speech protections upon which our society has come to rely, but one must wonder what force the First Amendment retains if it is read to countenance the deliberate manipulation by the government of the dialogue between a woman and her physician. While technically leaving intact the fundamental right protected by Roe v. Wade, the Court...once again has rendered the right's substance nugatory...This is a course nearly as noxious as overruling Roe directly, for if a right is found to be unenforceable, even against flagrant attempts by government to circumvent it, then it ceases to be a right at all. This, I fear, may be the effect of today's decision.
Briefly Noted

The Task Force on Women and AIDS Policy Document

An article in the New York Times recently announced that women are being overlooked in the AIDS epidemic. The Centers for Disease Control's definition of AIDS, it went on to report, does not reflect the course of HIV in women, often leaving HIV-infected women without benefits and proper care. To practitioners who were working with high-risk women even before the AIDS epidemic, this particular story on the neglect of women with HIV did not come as news.

The Task Force on Women and AIDS is born of such long-term commitment to women. The group was originally convened by Dr. Helen Rodriguez-Trias, and has about 50 members, mostly women, most of whom work directly with HIV-infected women as providers and health care advocates. The remaining members have come to the Task Force from law, health care administration, and a variety of other backgrounds. They have been meeting regularly in New York City since 1988, and share an urgent concern for the particular needs of women in the HIV epidemic. All agree that these needs have gone largely unmet. Their self-appointed task has been to articulate these needs, focusing on how to provide "culturally appropriate, accessible health and social services that foster women's abilities to manage their own health and prevent infection."

The group has recently produced a 41-page paper entitled "The Task Force on Women and AIDS Policy Document," which summarizes their current analysis of and solution to the variety of problems plaguing women affected by HIV. The Task Force plans to offer a regular update, calling the policy paper a document-in-formation in the face of the ever-changing position of women in the epidemic.

The Task Force grew out of a recognition of how health and service institutions systematically exclude and dismiss women both within and beyond the HIV epidemic. The members of the Task Force thus faced their task with an acute sense of own responsibility not to exclude. And their document is decidedly inclusive of both a wide range of medical, social, and ethical issues that affect women infected with HIV, as well as a diversity of themselves. Such inclusiveness, they state in their introduction, is based upon a perception of women's roles as mothers, partners, and caregivers, distinguishes between various groups of infected women, and includes female family members of infected individuals, as well as other populations that may be affected and overlooked in the future.

Format and Formulations

The paper treats medical, ethical, and social policy issues separately from population groups, so that sections of the paper can be easily excerpted and updated. This format makes for some duplication, as in...
the overlapping sections on housing and the needs of homeless women, and the separate sections on drug treatment and the needs of drug-using women. Policy issues are frequently reiterated—they are outlined first in the abstract and later resurface as concerns of specific groups. But any blurring of theoretically distinct concerns in the document is a reflection of the real and terribly intimate interconnection of forces, including racism and class bias, that have ushered HIV and AIDS into women’s lives. And even as the Task Force tries to do justice to this complex reality of HIV in all women, including those traditionally marginalized, such as women in prison, lesbians, sex workers, homeless women, immigrants, adolescents, and women who are mentally ill, developmentally disabled, and abused—they unapologetically emphasize the primacy of gender in the predicaments of all HIV-affected women.

Issues and Answers
The Task Force document approaches each of its 21 sections on issues and population groups with a summary, followed by an outline of the Task Force’s recommendations. The assessments range from broad-based overviews of women’s issues that predate the HIV epidemic, such as reproductive autonomy and access to primary health care, to examinations of topics that are specific to the HIV epidemic, such as the mechanisms at work in effectively excluding women from clinical trials, implications of the definition of AIDS for women, and confidentiality and partner notification.

These assessments resound with a clarity and descriptiveness wrung from the Task Force’s collective years of direct experience with and commitment to their clients—women who have experienced various other kinds of jeopardy as women, as well as those who are now HIV-infected. Understanding the real implications of mandatory testing for women, they slice through testing jargon to condone only voluntary HIV testing with counseling. Having witnessed firsthand the failures of existing drug treatment, they point to the scarcity and inadequacy of drug treatment in general, and the overwhelming lack of drug treatment for polyaddicted and pregnant women. The authors also recognize the nature of drug use itself as symptomatic of social and economic problems. Knowing well the fragmentation of the health care system in poor urban neighborhoods, they describe unsparingly the scarcity of gynecological, drug treatment, and infectious disease services and the lack of coordination among existing services.

Recommendations
The Task Force has created this document as its own forum for presenting women’s needs, and as a result it is free from the budgetary constraints, political reality, and polite tiptoeing that can set the tone of recommendations written for other purposes. The recommendations portion of the document, also clearly informed by the Task Force’s years of direct service, makes simple, sweeping demands. This section may shock a reader dulled by too many timid, budget-bound requests. However, it is hard to miss the value of the visionary nature of the Task Force’s demands: this document does not ask what we can afford to spend on women, but rather demands the full range of women’s rights and entitlements (in the true sense of the word), including adequate housing; conveniently located, accessible drug treatment; legal services; primary and preventive health care; and attention from scientific researchers both to the natural history of HIV in women and to the more general dearth of information on women’s biology.

The women who make up the Task Force on Women and AIDS have invaluable resources: the knowledge and experience to humanly treat, slow, and, as quickly as possible, stop the HIV epidemic from spreading in women. Unfortunately, like others on the front line, they have neither the time nor the finances to ensure that their recommendations receive the attention and support of policymakers. We hope that funders and officials draw on the HIV policy suggestions put forth in this document—suggestions guided by a Task Force that has distinguished itself by addressing the practical complexity of HIV in women within the context of the history of gender discrimination.

—Sharon Lerner

Task Force on Women and AIDS Policy Document is available for $3 from the National Women’s Health Network, 1325 G Street, NW, Washington DC 20005, (202)347-1140.

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Learning Pride After Activism


by Nancy McKenzie

The issues subsumed under gay rights have broadened beyond political and institutional discrimination and the conditions associated with AIDS to the validation of gay and lesbian experience, including the health and mental health consequences of stigmatization and isolation; the mating and marrying of homosexuals; and the bating and bashing of us.

As psychiatry, like much of the medical establishment, has become more irrelevant to the basic health needs of Americans, the discussion of gay life, like discussions of childhood experience in mental health circles, has become more commonsensical and less academic. The hegemony of the American Medical Association has receded and left discussions of health and mental health needs to social workers, counselors, and individuals in support groups, many of whom are gay and lesbian and many of whom, as social activists, have had to understand oppression from within themselves and their patients.

Cures: A Gay Men's Odyssey, written with the health care community in mind, reflects America’s recent coming of age with respect to the personal experience of oppression and abuse and its place in social change. Like few other books, Cures reflects not so much the external struggles for power, equality, and rights as a struggle for self-love and permission to live as a homosexual. This is not a book about marginality. It is, rather, a book about recognizing the oppression one has suffered and internalized. It’s an uncommon story of an uncommon man—a courageous man, whose integrity led him from achievement and political participation back to himself, whence all things must ultimately spring.

Martin Duberman is an outstanding scholar and prolific writer, thinker, and activist. Active in the civil rights struggles and the anti-war movement, an innovative teacher, avant-garde writer for Broadway and Off-Broadway, historian of black culture and black activism, and founding board member of the many early gay and lesbian rights organizations, Duberman’s personal struggle to gain some sense of himself sexually parallels struggles for feminist and gay and lesbian rights. It also hearkens back to another struggle, one to find the relevance of the mental health profession in times of upheaval and social change. Cures is both a book about Duberman and about America in the years of social justice activism that excluded the plight of homosexuals. These were years in which a person like Duberman could devote his life to the liberation of other Americans and yet find himself personally humiliated and tormented by the view imposed by his powerful and manipulative therapists that his homosexuality was a particularly overt form of immaturity.

Duberman was born on the other side of Stonewall, the side where homosexuality was hidden as an issue of social justice. As a historian at the most elite of academic institutions (Yale, Harvard, Princeton), Duberman pointed out in his writing and in his teaching how the extent to which a people articulates their power depends on struggles both organized in the street and voiced by particularly courageous individuals who have the power to make change within established institutions. Duberman was one of those individuals, both inside and outside academia. And yet, as much as Duberman understood the oppression of others, he was, as he admits, blind to his own—one might even say systematically blind, since he spent the better part of 20 years, mostly in therapy, methodically watching and probing his psyche for the source of his inability to have relationships.

One of the most powerful implications of Duberman’s story is about how marginality imposed by race, sex, and class might be a help in coming to terms with the self-hatred that goes with being gay, whereas privilege and power can make one heartless toward the basic human need for intimacy. The book is ultimately about compassion, particularly Duberman’s, and its absence within the elitist mental health establishment, which actively sought to control the emotional lives of homosexuals in the years before Stonewall.

Cures begins with Duberman’s first academic position at Harvard...
and runs to his help in establishing the Lambda Legal Defense and Education Fund and the National Gay and Lesbian Taskforce. It treats the roughly 20 years prior to the American Medical Association’s re-designation of homosexuality as a sexual preference. It highlights Duberman’s influence on the civil rights movement and ends with the impact of civil rights on his life. While thematically it is a book about the arrogance and heterosexism of psychiatry, it is mostly a book about the life of a country in one of its most tumultuous and exciting eras—one in which an uncommon man played a diversity of roles working for the rights of others and came to terms with the love of himself. This is a book for anyone who remembers America in the early days of rage and vision. It is for those who care to see those days through the personal candor of an American man, scholar, and political leader who, among thousands of others, was “of the sixties” but with the additional personal anguish of a hidden and tormenting homosexuality. It is, finally, the story of how activism helped ultimately to end his torment and that of thousands of others.

Let the Women Speak: On Women, AIDS, & Activism


by Mary Beth Caschetta

It is somewhat worrisome that—

Women have mobilized: Anti-war and abolition; health and labor reform; the green movement; anti-violence; cancer; and now AIDS. Whatever the cause, we were there organizing and we were writing it down (when we knew how to write). Because of the real need to chronicle our struggles and because of the basic failure of AIDS education in the United States today, Women, AIDS & Activism, an effort of ACT UP/NY’s Women and AIDS Book Group, is a must read for all women, for all health providers, and for all people involved in the AIDS movement.

A collection of essays, this fine resource book pulls together the disparate elements of women and HIV: information, criticism, personal accounts, political insight, and passion. Although the editors do not always make the complicated connections between essays to complete their analysis, each essay stands solidly on its own.

Names and stories emerge from the personal accounts of particular, amazing warriors: Iris de la Cruz, for example, an HIV-positive activist and ball of fire, whose most famous line to those who knew her was, “I guess I’m too much of a bitch to die.” Iris died this Spring. Or Melinda Singleton, whose essay is an honest account of living with HIV, sums up every act of lobbying and protesting for AIDS and women in the past decade. Or DiAna DiAna, who turned her South Carolina hair salon, DiAna’s Hair Ego, into an AIDS education center for her community—condoms piled next to the curlers.” And Cynthia Acevedo, who recounts her struggle over safer sex with her HIV-positive lesbian lover. They didn’t win the struggle. Instead, they stopped having sex altogether. Her lover, Acevedo writes, felt like a germ. There are also several HIV-positive women who write with anonymity.

The personal as political works most brilliantly in this collection. More accounts by more women living with HIV and their advocates would only have added strength to the narrative and given more power to this volume.

It is somewhat worrisome that—over a year and several reviews since the book’s publication—Women,
AIDS and Activism has not been more generously received, especially by other feminists and activists. However, it is only mildly surprising. After all, the single most important and terrifying message in AIDS education is still aggressively resisted in this country: The people closest to us are those who put us at most risk. That is to say, it is not the dentist, or immigrants invading our country, or people living on other continents. It is our lovers and those with whom we share needles. Until people understand this point then no one will believe that women get AIDS and die. We cannot hate the people who put us at most risk, because they are us.1 We must discard hatred as our only model for understanding this epidemic and create a new one. Reading Women, AIDS and Activism points us in that direction.

The criticism of the AIDS portion of the book is somewhat puzzling. Many reviewers seem preoccupied with the idea that the information in the collection has become outdated, even before it was published. But it is a myth that AIDS information has a shelf life and spoils. Even if that were true, what information do we actually have concerning women? We do not have any studies about women and HIV that dictate treatment regimens. We have barely begun to understand how the virus expresses itself in the female body, and how, exactly, to convince intransigent researchers and policymakers that the disease is, in fact, different in women. The studies we use to bolster arguments about women’s health are decades old, and sometimes not even based on women’s bodies.

Additionally, the epidemiological criteria and tracking methods for women with AIDS do not reflect the reality of women’s lives or bodies. The point is made vehemently in the very first essay, “What Numbers Mean” by Risa Denenberg. So what is outdated? If anything the book’s essays, “How Do Women Live?”, “Safe Sex is Real Sex,” “Prostitution and HIV Infection,” “Treatment and Trials,” “Race Women and AIDS,” and “Lesbians in the AIDS Crisis,” to name a few, need to be continually republished everywhere. Repetition is one useful way to undermine the public denial of women’s health issues, including AIDS.

As for the activism of the title, the authors made an unfortunate choice not to tell their own stories as organizers and leaders in the movement. Maxine Wolfe’s essay, “Transformation of Our Movement,” comes closest to detailing a history from an activist’s point of view. It is a bravely honest moment in the anthology. “I no longer feel like I’m on the periphery of the periphery,” she writes. “I feel I’m helping build a movement that is mine rather than trying to fit into someone else’s,” raising the question, by and for whom was Women, AIDS and Activism written?

The authors identify themselves with the introduction as white and Jewish women. They explain that they chose diverse contributors, acknowledging that 73 percent of women with AIDS are women of color. In a late chapter, entitled “Translating Issues into Action,” and in the book’s conclusion they explain activism as any action, no matter how small. They offer practical advice for the journey to political action, starting by breaking the silence by telling a friend about women and lesbians with HIV, for instance.

Is the book then meant to be a tool for activists? Is it successful as such? These are the criteria with which most health workers and women activists with whom I spoke measured Women AIDS and Activism. I myself see the book as a testimony to the world in which women live and the place that HIV holds therein. The collection contains problems. For instance, wouldn’t the book have been more honest if women with HIV and women of color had taken part in the editorial process, rather than appearing only as invited guests? There are also a few gaps in courage—what about the safety issues for women who practice S/M? I am confident, however, that these flaws will be worked out by the time the next edition of Women AIDS and Activism appears in print. I look forward to the day. For now I am grateful that this book exists, and I believe we need to read it as a gift.

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1. AIDS educator and activist, Sally Cooper, is responsible for this idea, which she shared in one of our many conversations concerning the writing of this review.
McCormack has worked in the eligibility system for more than 20 years and served for five years as entitlements advocate at the Whisman-Walker Clinic in Washington, DC. He worked for years reporting on and formulating federal health policy. His experience shows. He is committed to preparing the person with AIDS for the worst features of the American way of sickness. Those features are apparent from the table of contents. Every agency/procedure and its acronym—SSI, SSDI, SSPs, AFDC, EA, FS, TEFA, VA, AZT, Medicare, Medicaid, Hill-Burton—and all the issues—from mental health, to money, food stamps, drugs, housing, homecare, death, and taxes—come across to the reader as they do to the sick, as so many moves in the game of health jeopardy. McCormack writes in such a way that he is right there with the PWA, guiding, joking, cajoling, ironic, outraged, and always knowledgeable, strategic and effective.

After a chart of major benefits programs, the book gives a key to the logic of most of the entitlement offices and then goes on to address each of the programs, their requirements, benefits, how-to-apply instructions—and, importantly, the appeals process and special problems.

The second section of the book deals with ways to improve service delivery in the reader’s state and outlines the income and medical issues most in need of change. The recommendations are excellent and offer specific ways to influence the system. The last section of the book includes directories of programs, from AZT trials to vital statistics agencies, as well as reprints of all important entitlement forms so that readers can see just what they are in for. There are reprints of crucial documents such as the Social Security Administration’s “Claimant/Physician Functional Capacity Report,” and a step-by-step set of instructions for coping with the Social Security Disability determination process. There are a number of charts on documents needed, a glossary on Medicare coverage of drugs, a resource guide, a general glossary, and an extensive bibliography.

The poor cannot navigate the public entitlement system without advocates. In fact, some of us believe that its user-unfriendliness is the most efficient cost-containment strategy of a nation disdainful of public programs. With this book any user of the public entitlement system can become his or her own advocate. Bravo for The AIDS Benefit Handbook and Bravo for Thomas McCormack for spending years breaking the code and sharing his knowledge.

Dear folks at Health/PAC,

Your Summer 1991 issue is GREAT! Well-researched, well-written, bone-chilling articles, cover to cover. I’ve already made copies of “Contagious Urban Decay,” “Young Adults,” and “The Slave Health Deficit,” and shared them with colleagues at work. I hope that someone decides to test the hypothesis proposed by the Wallaces on other urban areas in the U.S. I think we might find that it holds up all too well. Certainly Hartford fits the pattern.

As always, the question we now face is “What do we do about it?” The talk among members of Congress, business and other labor leaders about the need for a national health care system, while welcome after all these years of silence, doesn’t begin to touch the real problems of poverty and racism identified in this issue. How low do we as a nation have to sink before a critical mass of people demand alternatives? Do enough members of the progressive community now possess the skills, power, and focus to provide the needed leadership?

I’m sorry I won’t be at the APHA Annual Meeting this fall to discuss some of these issues with other Health/PAC people. I’m hoping you’ll use the Bulletin as a forum for consideration of strategies to get us out of this mess, before there’s nothing left to save.

DONNA BIRD

Boston, MA
Vital Signs
Two Steps Back on Measles Epidemic

In 1979, the Surgeon General predicted 1990 would be the year of "no more than 500 cases of measles nationally," according to the Children's Defense Fund's May 1991 special report, "Vaccine Supply and Low Income Children: Barriers faced by Community and Migrant Health Center Patients." The 25,421 cases of measles reported nationally in 1990 proves this estimate grossly inaccurate and attests to the greatly narrowed concern for the health of low-income populations during the past decade.

The current measles epidemic has received some media attention because Americans know, as one doctor put it, "if we can't prevent measles we might as well quit." The Children's Defense Fund report is meant to place blame where blame is due.

CDF found shortages of measles vaccine supplies at 96 percent of the nation's federally funded community and migrant health centers that responded to their survey. These health centers are responsible for the primary health care of 6 million low-income patients, 3 million of whom are children under age 18, living in severely medically underserved urban and rural communities. According to CDF, the centers are plagued by "spot" shortages of vaccines for measles and the other eight vaccine-preventable childhood diseases. Often these "spot" shortages become "routine," forcing health centers to purchase supplemental quantities privately at much higher prices. Purchasing the vaccine on the market leads health centers, in turn, to channel federal grants allocated for other purposes toward the costs of the vaccines. Their financial crises are further compounded by Medicaid's inexplicable failure to reimburse the health centers for Medicaid-eligible patients' vaccines. Staff shortages at the health centers create additional barriers to immunization for low-income patients, preventing the staff from coping with "the poverty, homelessness, and lack of transportation experienced by [their] patients."

CDF's solutions include allocating an additional $30 million beyond the levels recommended by the National Vaccine Advisory Committee to expand the system of bulk purchase of vaccines from the Centers for Disease Control (CDC); providing the health centers' clinical staff with technical assistance from the CDC to make their immunization programs more efficient; requiring Medicaid to reimburse health centers for vaccines given to eligible children; passage of pending bills required to revitalize the existing health care system; and Medicaid benefits be denied to families that do not have their children vaccinated. Such suggestions, characterized as "irrationally punitive" by CDF, seek to avoid addressing the systemic problems of health care provision and shift the blame for the current measles crisis to parents. If appropriate corrective measures are not undertaken immediately, the possibility is great that the other eight childhood preventable diseases will follow the course set by measles in reaching epidemic proportions. According to CDF, $3 billion dollars, or "about 0.5 percent of what the nation spent on health care in 1988," is required to revitalize the existing health clinics and to establish new ones in all other medically underserved urban and rural communities.

While the country is debating a step forward toward a national health system, this seems little enough to spend to keep from moving two steps back.

—Anita Malkani

The "If-You-Have-to-Ask-You-Can't-Afford-It Department"

Blue Cross/Blue Shield, traditionally known as the "insurer of last resort" is quickly moving toward insuring only those unlikely to need the coverage. The "Blues" were founded on the principle of community rating, making insurance available to all at the same price, regardless of health status, which has earned the Blues public approbation as well as tax exemptions and state-approved discounts in the rates they pay out to hospitals. But today only about a dozen of the country's 30 Blue Cross associations still function on a community-rating basis. Not unlike their private coun-
terparts, these companies are employing various strategies to cut their costs as well as to reduce their public responsibility while retaining their privileged status.

In New Jersey, a coalition of community groups that formed two years ago in opposition to New Jersey Blue Cross/Blue Shield continues its fight. Last year the coalition won a precedent-setting court decision against the company’s discriminatory rate hikes (see “NJ Citizens Stop Blue Cross Discrimination,” Vital Signs, Winter 1991). More recently, the mammoth insurer proposed premium increases for subscribers with full (not supplemental) policies, which would bring the average increase in rates for these subscribers to 70 percent over the past three years, during which there has been a 90 percent reduction of primary subscribers as well as a sharp rise in the number of uninsured in New Jersey. Under the proposed increases, a couple with preexisting conditions would have had to pay $11,000 out of their household budget for their “last resort” coverage.

The revitalized community coalition held a press conference focusing directly on affordability of the policies in addition to working behind the scenes with state officials, according to Donald Light of the New Jersey Public Health Association. They were successful in holding the increases to 9.9 percent, saving community-rated subscribers $150 million, while the settlement extracted another $50 million from businesses with commercial policies.

Meanwhile in New York, Empire Blue Cross/Blue Shield, the nation’s largest nonprofit health insurer, recently dropped group coverage of professional and trade associations and fraternal orders. These groups accounted for more than 100,000 people, many of whom cannot get any other group plan and will now be left with extraordinarily expensive individual policies as their only option.

In a still more drastic departure from its perceived role as universal insurer, Empire has proposed a 50 percent rate increase for 300,000 individuals holding individual policies and 120,000 employees of small businesses who are considered bad risks. At the same time, Empire would reduce rates for people in the so-called good-risk group. This move to risk rating guarantees that only those who are likely to minimally utilize their insurance will be able to afford it, even from the “insurer of last resort.” And the numbers of uninsured in the state are sure to surge if the rate changes go through.

While some associations are crying poverty to justify their rate increases, others are raking in profits (see “Blues Getting Greener,” Vital Signs, Spring 1991). It is unclear where the shortfalls are occurring, how much bad management is a culprit, and how often bad financial ventures are paid for by the public. Yet, according to Light, Blues are shifting funds among their corporate and public accounts to disguise the true source of the losses in their investments.

As we go to press, a coalition of cancer, disability, AIDS, and women’s issues groups (not unlike the New Jersey coalition), appears to be forming in opposition to Empire’s regressive proposals, including risk rating, and in favor of universal coverage. At a hearing held in August, New Yorkers heard about Blue Cross’ rating plans, which include gender-based rating (women under 60 are considered risky), and learned that even under the proposed risk rating scheme, Blue Cross expects that payments made by lower risk populations will subsidize the expenses of the more costly policies by $40 million. Contact Herb Semmel at (212) 727-2270 for further information regarding the coalition.

—Sharon Lerner and Ellen Bilofsky

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