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On the Question of Maternal Age

To the Editor:

Phyllis Kernoff Mansfield documents methodically this clinician's observation that intelligent, decision-making women, who are in excellent physical condition but who have delayed childbearing into their 30s and 40s, become completely intimidated by their obstetricians. They are easy victims to a professional jargon that is derogatory and terrifying. Words such as “elderly” and “premium baby” are used to justify massive intervention, including cesarean section rates as high as 63 percent for primiparas. Much of the literature simply documents that these women are at high risk from their obstetricians and not their age.

At the Midwifery Associates of Roosevelt Hospital, N.Y.C. during the years 1977-1981, 13.5 percent of the client population were women between 35 and 42 years of age. In my “Pregnancy in Gravidas Over Age 35 Years,” Journal of Nurse-Midwifery, Jan. 1983, we researched the outcomes of these pregnancies. Eighty-seven-and-a-half percent had normal spontaneous vaginal births, most of which occurred in a birth room without electronic fetal monitoring. Cesarean sections were performed 7.9 percent of the time, as against 25 percent in the region in this age category, and forceps were used for 4.6 percent. Pitocin was used to augment labor only when indicated in 16.6 percent of the cases. There were no stillborns.

The conclusion of your survey, that we must be extremely skeptical of advice that limits women's options, is very timely. With increasing numbers of

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Notes & Comment

Some Thoughts On Quality

"Quality of care" is suddenly in the news. It has become a touchstone of resistance to the rapid reorganization of the health care system currently taking place in the U.S.

It has brought such varied issues to the fore as: How do we determine what care is "necessary"? What constitutes an essential package of services? How can quality of care be measured? Does the growing for-profit sector deliver lower quality care than other sectors? What information do patients need to make truly informed and independent medical choices, free of provider pressure? Health policies and institutional practices which might compromise quality of care are generating a demand to demonstrate that, at the very least, no harm is being done.

In the early 1980s, access issues provided the focal point of concern within the health care system. Changes in the economy and a bitter recession revealed large pockets of uninsured and underinsured people, many of whom were previously covered. A financial squeeze on certain providers, along with a growing tendency to shun patients who threatened providers' bottom lines, led to a further reduction in access. Reagan-era program cuts deepened the problem. In many states, the continuing access crisis has generated a legislative response. Numerous state commissions urged—and legislatures passed—laws expanding access. Congressional legislation, effective last July 1, extended access to health insurance for laid-off employees, and provided momentum both for Senator Kennedy's bill, which would further expand health care for these employees, and a bill requiring states to set up insurance pools for high-risk, uninsured individuals. The access crisis has also sparked renewed policy interest in a comprehensive national measure to ensure access adequately in a way that departs from the current piecemeal, gap-filling approach.

The quality-of-care issue, and the related issue of the efficacy of medical practice, promises to have an even more profound effect, cutting as it does to the heart of the medical enterprise: the nature and content of the transaction between practitioners and patients. Systems of paying for and reviewing medical care, emphasizing "doing less," have brought a flood of anecdotal horror stories and some legal action alleging that the "less" in these cases was grossly harmful to patients. But proponents of changed fiscal incentives point to the wide variations in medical practice in different communities and institutions, the lack of apparent harm in the low-cost styles, and the enormous amount of fat in the system due to previous incentives to "do more." On the other hand, many privately insured patients now, for the first time, feel organizational and financial constraints pressing on the quality of health care they receive and on the quality of their lives.

The quality issue has emerged as the edge of both the popular response and the resistance to the major public policy restructuring initiative of the mid-1980s, the Medicare DRG (Diagnosis Related Group) system. As Ronda Kotelchuck shows in this issue of the Bulletin, the attempt to alter medical practices through DRGs has elicited an outcry from elderly people, leading to a belated governmental concern with measuring and monitoring the quality of their care. People felt they were being hurt by this sweeping cost-control program, while the government had no credible way of monitoring the care. Medicare patients and their family members claimed they were bearing more of the home care burden. They also began to feel they were being accorded second-class treatment, as the government placed severe restrictions on their inpatient care based on the desirability of their diagnosis from the hospital's and the government's point of view.

Although hospitals were under no obligation to release patients after their DRG days had been "used up," a widespread belief developed among patients and their families that they were being sent home "quicker and sicker" after this time had elapsed. In response, the Federal Government, for the first time, has been forced to develop a credible system of monitoring the quality of hospital care; although, by the time such a system is in place, years from now, much of the damage will have been done. The immediate result of resistance has been an expansion of patients' rights and increased caution among politicians fearful of the political consequences of elderly people perceiving the DRG program as one causing them needless anguish.

Can quality of care be measured?

Issues of quality of care and efficacy have moved to the fore in other health care arenas as well. Malpractice juries in their verdicts and damage awards continue to provide harsh judgment on medical practice. Variations among hospitals in mortality rates for certain operations—medical batting averages, in effect—have alerted the public to wide institutional disparities in risks—disparities that may conflict with received notions of quality. Growing interest in holistic approaches can be attributed in part to skepticism, fear, and even revulsion toward mainstream medical practices. No longer attached to a physician whom they blindly trust, patients are trying more and more to assess for themselves the risks and benefits of care, steering their own paths through the welter of competing providers and treatments.

With the content of medical practice increasingly being shaped by new incentives and direct review, those responsible for leading the reorganization of the health care system are grappling with the quality-of-care issue at center stage, in view of all. Efforts to reorganize health care have helped call into question the content of that care and the form of incentives and institutional arrangements ensuring its proper delivery.

For activists the issue is not simply ensuring access to care but assessing the form and quality of that care. No longer confined to areas on the periphery of medical practice, such as prenatal care, the issue of access to quality medical care is now being contested much nearer to the core of medical practice. The next round of health care reform responding to broad, popular demands—already visible in the response to this fall's successful national health program referendum in Massachusetts—will doubtless be informed by both trends of the 1980s to develop proposals for full access to a form of medicine conducive to people's needs, provided in a setting which reinforces the desired style of practice.

Tony Bale is a sociologist and a member of the Health/PAC Board.
Now They Tell Us

The Environmental Protection Agency has issued an "emergency" order banning the use of a pesticide that has been a mainstay of American agriculture for almost 40 years. Dinoseb, a powerful defoliant used to kill weeds, poses "a very serious risk" to field workers and farmers exposed to the chemical, according to an agency administrator.

Dinoseb is one of hundreds of pesticides developed and marketed before stringent safety tests were required. The EPA has found that many of the older studies approving pesticides for market were scientifically invalid or, in some cases, fraudulent.

Under the Federal pesticide law passed in 1972, the EPA has been moving—at a snail's pace—to have companies retest the primary ingredients for their products. Several major research centers, including the National Cancer Institute, have subsequently linked some of the largest selling herbicides and insecticides to increased incidences of leukemia, lymphatic cancer and other diseases among farm workers.

These findings, coupled with the discovery of pesticide contamination in drinking water in more than half the states, have recently prompted both houses of Congress to approve legislation speeding up safety reviews of about 600 active ingredients in nearly 50,000 products now widely used. Like Dinoseb, many of these products have been disseminated throughout the environment for decades. That's a long time to live with an emergency.

Congress's Starvation Tactics

What may look like a little fancy footwork and politicking on the Hill more resembles a dance of death from the viewpoint of famine-stricken Africa.

This fall, the U.S. Congress took $225 million from special reserve funds earmarked for African famine relief and put them in an "economic aid" package for four Central American countries supportive of U.S. anti-Sandinista policy. The purpose of this little-noted rip-off was to win the necessary Congressional votes to pass President Reagan's $100 million military aid bill for the Nicaraguan rebels.

Representatives apparently felt that $300 million in aid to El Salvador, Guatemala, Honduras and Costa Rica would clear their consciences for the vote on military aid to the CIA-led contras. The Congressional contrabanders grabbed $225 million from the mouths of starving Africans to entice their giddy colleagues to vote for the measure.

Nearly 18 million Africans still depend on food aid for their survival, according to the United Nations Office of Emergency Relief. In the Southern Sudan, famine equal to that of Ethiopia in 1984 is threatening the lives of 2 million people.

But, thanks to Congressional spinelessness in the face of the Reagan war machine, food relief to these masses will be sharply curtailed as the money is rerouted to the four Central American countries. Incidentally, these four indigent allies receive 16 times more U.S. aid per capita than do the African nations.

Nuked Food Dumped in Sri Lanka

A reader from Sri Lanka writes that in July of this year, chicken imported from Europe were also much too cheap. European-style biscuits appeared in local packaging, and frightened consumers started destroying them on their own initiative.

The next month, the nation's Atomic Energy Authority (AEA) confirmed what many already knew: Contaminated food from the nuclear disaster at Chernobyl was being dumped—into Sri Lankans' bodies. Chairman Grenville Dharmawardena of the AEA, an outspoken proponent of nuclear power in hydroelectric-rich Sri Lanka, has "consistently failed to divulge what the actual levels of contamination are," our friend writes, but it is known that certain contaminated shipments are being accepted for sale even if they exceed somewhat the recently raised limits of 13.5 bequerels per kilogram. Of particular concern to Sri Lankans is cesium, which has a half-life of three million years. It is easily concentrated in dairy products, which are a major import in the island nation.

France, Switzerland and Holland are leading the contaminated food-dumping, but several other nations are involved.

Campaigning for Medical Ethics in South Africa

For many black township residents injured in clashes with South African security forces, the state hospitals—often the nearest or most appropriate facility—have become extensions of the police net. The public was made aware of this during the mid-1985 unrest in the Eastern Cape. Following a massacre outside the black township of Langa, the police maintained a large presence at the emergency room of Livingston Hospital, the local state hospital for blacks. Injured patients were subjected to scrutiny and in some cases placed under police guard. Local general practitioners say they were intimidated by police to keep them from providing alternative care. Another publicized example occurred earlier this year at the Alexandra Clinic in Johannesburg. Following clashes in Alexandra township, police demanded access to patient files at the clinic. The doctor on call refused, claiming confidentiality of patient information. The police subsequently gained access via a court subpoena.

No one knows the full extent to...
which health service personnel are collaborating—actively or by default—with the police. There is, however, a strong widespread belief among township civic activists that state hospitals are unsafe. Consequences have included delays in seeking treatment, and even self-treatment.

The anti-apartheid National Medical and Dental Association (NAMDA), among others, has launched a campaign to make hospitals and other health care facilities safe for those injured by the police. The campaign reminds doctors and nurses of their primary ethical responsibility to their patients, particularly that of confidentiality. Campaigners, for example, have sought to overcome the widespread misimpression that there is a law obliging health personnel to report bullet wounds to the police.

The state argues that its police are entitled to any information they want if they suspect a crime has been committed. By using the catch-all charge of “public violence,” however, anyone injured in a clash with the police is presumed to be guilty of a crime.

Whether hospitals can offer sanctuary will depend, to a great extent, on the degree to which the state uses its extensive powers to brush aside pleas of a special relationship between doctors and patients. It will also depend on the willingness of health care personnel—many of whom are politically conservative doctors—to fight for their patients’ rights.

(For more information about NAMDA, write to Box 17160, Congella 4031, South Africa.)

Empowering the Homeless

“When I was hospitalized, I didn’t want no nurse, no health care. I wanted a job and some space to stand on my own,” said Chris Sprowal, president of the National Union for the Homeless (NUH) at an Oct. 22 forum on the health care problems of the homeless, co-sponsored by Health/PAC.

Sprowal, who said he was ill and without a job or home before helping found the union a year ago, has since been actively organizing the homeless in Philadelphia, New Orleans, Washington, D.C., Boston, Baltimore, Chicago, Los Angeles and, most recently, New York City. Speaking before an audience of health care professionals at the Cardozo School of Law, Sprowal warned that enhancing health care and other human services in shelters only serves to perpetuate these substandard facilities as unhealthy traps for the homeless. The task for concerned people, he said, is to attack the structural problems, not provide superficial palliatives.

“There should be no more crazy-ass programs in those shelters,” Sprowal contended. “Let’s close the shelters and declare a housing emergency. Let’s rebuild homes and give people care in those homes.” Piecemeal approaches to the health care problems of the homeless, he added, promise to prolong their anguish and condemn them to chronic dependency. Sprowal admonished providers that the homeless—not experts—must set the terms on which their health care is to be provided, ostensibly a goal which the union has set for itself. “How much good is your health program at the Holland Hotel, where the dangers are pimps, drug dealers and loan sharks?” he asked.

Sprowal called for support in helping the growing number of uprooted, economically disconnected people in our cities find training, jobs and a political voice. “We got to get political,” Sprowal said. “We have to start to create the atmosphere for homeless leadership to grow.”

Former director of the New York City Department of Health’s Health Program for the Homeless, Karen Benker, MD, voiced strong support for Sprowal’s points. “We shouldn’t squabble over policy but discuss issues of power for the homeless,” she said. “The best way we can defend public health interests is by standing shoulder to shoulder with organizations fighting to empower the homeless.” (For more information about NUH, write: National Union for the Homeless, 330 West 42 St., New York, N.Y. 10036.)

Docs and Seniors Do Battle Over Double Billing

Massachusetts seniors and the state’s medical society have locked horns in court for a second time in a battle whose outcome may revolutionize doctor-payment practices across the nation.

State lawmakers have unanimously ruled that doctors may not charge their Medicare patients more than the federally approved rate. Practitioners who attempt to bill patients for additional amounts (a federally allowed practice known as “double-billing”) can lose their licenses.

Soon after the legislature passed the measure in November 1985, the American Medical Association and the Massachusetts Medical Society filed suit to block implementation of the law. The medical groups lost the case and are currently appealing the ruling in the First Circuit Court of Appeals in Boston.

Physicians, so far, have remained relatively immune to the cost-cutting fever that has swept the land. But if Massachusetts seniors and their representatives win this and probable subsequent appeals, lawmakers and consumer groups nationwide may take the cue.

Three more states are considering similar action. In neighboring Rhode Island, doctors defeated a measure last year that would have forced them to
accept Medicare assignment (i.e., approved-rate payment) as a condition of licensure. But the state medical society is expecting to battle similar legislative actions next year. A Washington state initiative, making Medicare double-billing a violation of state consumer protection laws, should come before the legislature in January. And in California, a state senator held hearings last year on a proposal to discipline physicians turning away Medicare patients or charging more than the approved rate. No bills resulted, but the issue is expected to rise again, especially if the Massachusetts law is upheld.

Medical groups argue that physicians will turn away Medicare patients rather than accept assignment against their will. But in Massachusetts, where the law has been in effect since passage, no such complaints have been heard.

The American Association of Retired Persons (AARP), which supports the Massachusetts law, warns, however, that forcing Medicare assignment in areas with a physician shortage may backfire on the patients if doctors refuse to accept Medicare patients at all.

Daniel Manning of the Greater Boston Legal Services, which spearheads the legal defense of the measure, says statewide senior citizens groups have alerted their members to the possibility of physician resistance through their refusal to treat. These groups, Manning says, “have found no evidence of problems with access to care.”

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**Bulletin Board**

**Seeking Marxist Perspectives on Social Science and Medicine**

A special issue of Social Science and Medicine will appear during 1988 featuring Marxist perspectives in these fields. The limit for submissions is 30 pages of double-spaced text. For more information, contact Professor Howard Waitzkin, UC Irvine, N. Orange County Community Clinic, 300 W. Romneya Dr., Anaheim, CA 92801.

Readers of Dr. Waitzkin will be happy to know that his book, *The Second Sickness: Contradictions of Capitalist Health Care*, is now available in paperback. In her review of the hardcover edition in the Bulletin (Vol. 15, No. 3), Georgeanne Chapin writes, “Waitzkin’s goal is to describe, in a systematic and readable fashion, the ‘social crimes’ that account for the special configurations of health, illness and medical care in our society.” This challenging book concludes with fundamental suggestions for activists ready to work hard for social change. Published by The Free Press; $11.95.

**Mass. Activists’ Newsletter**

*Staying Alive!* is the newsletter published by CommonHealth, which describes itself as “an organization of health care advocates who believe that access to quality health care is a right, not a privilege.” They’ve done especially good work on HMOs, among other subjects of national interest. The current issue quotes a Brookline cardiologist: “Recently an HMO would not allow me to admit a patient for monitoring and tests until after the weekend. My patient died of a heart attack that weekend.”

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**March Conference on Lesbian and Gay Health**

The 1987 National Lesbian and Gay Health Conference and the Fifth National AIDS Forum will be held March 26-29, 1987, at the Sheraton Universal Hotel in Los Angeles. Sponsored by the National Lesbian and Gay Health Foundation, George Washington University Medical Center and the Los Angeles Gay and Lesbian Community Services Center, over 1,000 people are expected to register for this year’s conference. Contact Greg Thomas at GWU Medical Center, 2300 K St., NW, Washington, DC 20037, or call 202-676-4285.

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**Pregnancy is Not an Illness**

*Childbirth Alternatives Quarterly* promotes midwifery, cesarian prevention, the spirituality of the birth experience and activism. Subscriptions, for $15 per year, are available from Janet Isaacs Ashford, Editor, 14230 Elva Ave., Saratoga, CA 95070.
F
d five years after scientists at the Centers for Disease Con-
deral first identified the Acquired Immune Deficiency
Syndrome, the full dimensions of the AIDS tragedy re-
main unknown. But one somber point is clear: Failure and in-
difference characterized the initial federal response to the killer
disease, crippling early research and public health education
efforts that might have slowed the epidemic's growth.

From the beginning, two formidable barriers impeded the
public health community's ability to respond appropriately to
AIDS—the structural defects deeply embedded in the Amer-
ican health care system and the ideological blinders worn by
the Reagan Administration. This article examines how Wash-
ington responded to AIDS and what its blunders reveal about
the nation's health policies.

Today, the lethal epidemic has earned a prominent place on
the nation's health agenda. Federal AIDS spending increased
dramatically from $5.5 million in 1982 to $233.7 million in
1986. Declaring it the number one health priority, President
Reagan still proposed only $213.2 million for AIDS in 1987.
Congress wants higher funding levels—a recent House-Senate
Conference agreed upon $410.7 million for 1987. And Admin-
istration officials have termed the progress of AIDS research
to date "spectacular."

Perhaps so, but with 15,000 people already dead, more than
1.5 million others infected by the AIDS virus and the Centers
for Disease Control (CDC) projecting that 270,000 people will
be diagnosed with the disease by 1991, there is no room for
complacency. Questions about the government's failure to
safeguard the health of its citizens linger to haunt not only its
victims and their families, but all those committed to equitable,
effective health care.

Slow Action From The Start

Ideological, bureaucratic and fiscal constraints jammed the
federal response during the first two years of the AIDS
epidemic. Those were critical times. Had coherent planning
replaced the blend of neglect and hysteria that surfaced, sci-
entists might have checked exposure to the AIDS virus by the
time 10-15 percent of the gay population was infected, accord-
ing to epidemiologic studies in New York and San Francisco;
instead, half of all gay men may now harbor the virus. If the
government had quickly recognized AIDS as a major health
disaster and launched a well-coordinated, adequately funded
plan of attack, if money had been allocated for basic research
and public education immediately, if the disease's early vic-
tims had not been stigmatized homosexuals or black and
Hispanic drug users—then the course of one of the most
devastating epidemics of the 20th century might have been
different.

Contrast the federal response to AIDS with the actions taken
in 1975 after swine flu was identified among army recruits at
Fort Dix, New Jersey. Fearful that the outbreak could signal
the return of the calamitous pandemic of 1918, $135 million was
appropriated within two months to develop a national swine
flu program. Although swine flu has been described as "the
epidemic that never was," and questions emerged as to the vac-
cine's safety, funds were nevertheless allocated with dispatch,
a public health campaign was implemented almost instantly
and 40 million Americans were immunized within months.

Racism and Homophobia

Why was the response to AIDS so lethargic by comparison?
Racism and hostility to the gay community certainly provide
part of the explanation. Racial minorities and intravenous drug
users, whose access to care has always been marginal, account
for almost 40 percent and 17 percent, respectively, of all
reported AIDS cases. Although gays have substantially more
political clout, gay lifestyles and sexual practices so offended
influential right-wing ideologues in the Reagan Administration
that a trickle of AIDS cases became a flood before any action
was taken.

Very little federal money has gone
directly to treat AIDS patients.

The AIDS epidemic occurred at a time when policymaking
was dominated by efforts to cut federal social welfare pro-
grams, a coincidence with tragic consequences for public
health. By treating AIDS as a series of state and local problems
rather than a national public health disaster, the Reagan Admin-
istration ensured a fragmented and inadequate response to one
of the most mysterious diseases in recent history. Two years
were allowed to pass before it acknowledged the need to
allocate money specifically to AIDS. Then the Administration
compounded a deadly mistake by withholding information

Peter S. Arno, PhD. teaches in the Dept. of Health Care
Administration at Baruch College-Mount Sinai Medical
School. Karyn Feiden, a freelance writer and editor, is a
member of the National Writers Union.
from Congressional committees seeking to determine the resource needs of Public Health Service (PHS) researchers. Congress eventually earmarked $5.5 million in 1982, over a Presidential veto, but by then early surveillance, epidemiologic and laboratory research efforts had already been compromised.

At the 1983 House Committee on Government Operations hearings on the federal response to AIDS, witness after witness blasted the fragmented and poorly coordinated approach taken by the Department of Health and Human Services (HHS). In response to those criticisms, former Assistant Secretary of Health, Dr. Edward Brandt, Jr., told the committee that the Public Health Service had a focused “plan of attack” adequate to meet the needs of the epidemic. Committee members asked for a copy of that plan, along with related budget figures.

Two months later, HHS submitted a six-page document, created specifically for the Congressional committee, that only highlighted the department’s inadequacies. The document, an abbreviated fact sheet about past activities, provided no information on future research plans; no overall strategy, timetable, or evaluation procedure; and no cost projections. The Committee on Government Operations concluded: “PHS has developed neither a mechanism for generating plans that delineated specific areas of research, surveillance, treatment and public education, nor for ensuring that the full range of activities occurs.”

Congressional Controversy Over Funding

Three years later, debate over funding levels remains scarred by political in-fighting and an obsession with the budget deficit. Every year, individual Public Health Service agencies, including the Centers for Disease Control, the Food and Drug Administration, and the National Institutes of Health, tell the Department of Health and Human Services what they need from Congress for AIDS research. Consistently ignoring the advice of its own experts, the Department slashes PHS requests by one-third or more before submitting them to Congress. In a bluntly worded letter to former HHS Secretary Margaret Heckler last year, Congressman Henry Waxman (D-Ca.) complained that the Administration had substituted “rationalization and equivocation” for well-informed funding and personnel requests. HHS submitted figures for ’86 budget hearings only after Waxman’s subcommittee threatened to subpoena relevant documents.
Government officials fear explicit discussion of homosexual behavior and IV drug practices.

The AIDS epidemic highlights structural flaws in our national health policies.
Federal AIDS Efforts Called "Dangerously Inadequate"

The nation’s most prestigious scientific body has sharply criticized the Reagan Administration’s response to the AIDS crisis, calling federal efforts “dangerously inadequate.” The charge by the National Academy of Sciences in late October has heightened public debate on federal responsibility in such vital areas as the development of vaccines, therapeutic drugs, and public health education. The Academy warned of an impending “medical catastrophe”—as if one doesn’t already exist—and called for a $2-billion-per-year investment by the government in research and public education. The report, “Confronting AIDS,” also called for greater Presidential leadership and a national commission to generate and coordinate efforts by the Feds to do battle with the lethal epidemic.

shifted from Washington to state and local governments, and on to afflicted individuals and their families and friends. Very little federal money has gone directly to treat AIDS patients. Except for those cared for at the clinics of the National Institutes of Health, almost no PHS funds (exclusive of the Federal Government’s portion of the Medicaid program) have been spent on treatment.

Like the victims of other catastrophic illnesses, AIDS patients lose their health insurance when they become unable to work unless they can afford to pay the costly premiums themselves. Pauperized at their most vulnerable moments, they are forced to sell virtually all their assets before turning for assistance to Medicaid or charity. In the increasingly competitive health care environment, insurance premiums from covered patients are no longer sufficient to subsidize poor populations, thus heightening their barriers to medical care even further. In no other industrialized nation except South Africa does private sector dominance of health care place the sick and dying in such a precarious state.

Punitive, victim-blaming measures—such as quarantine, job dismissal and even tattooing—continue to be proposed.

Cruel Delays in Social Security

In April 1983, the Social Security Administration (SSA) ordered that disability benefits be paid to all applicants with AIDS-related infections who were unable to work but had contributed enough in payroll taxes to qualify. Several months passed between applying for and receiving funds; many victims died before their benefit payments ever arrived. It was two years before the SSA corrected this structural flaw and declared people with AIDS eligible for presumptive disability, reducing the waiting period for receiving benefits to just a few weeks. There are, however, no national standards for determining disability that encompass all AIDS-related disabilities, including severe AIDS Related Complex (ARC).

New York City Hall demonstration against proposed 1985 legislation to ban teachers and students with AIDS from public schools.
The fact that the SSA has ruled that AIDS patients are eligible for presumptive disability illustrates the gay community's ability to influence public health policy. In cities with large gay populations, such as New York and San Francisco, the supportive care received by many AIDS patients is actually superior to that received by the victims of other severe chronic illnesses. The Federal Government, however, cannot take credit for this. The development and growth of community-based AIDS service organizations, largely through massive gay-organized volunteer efforts, is helping to create a high-quality integrated care delivery system. Whether the current level of voluntarism can continue to match the pace of the epidemic or serve the growing segment of IV drug users; whether volunteer care is viable outside major metropolitan areas and can serve victims of other diseases; and whether voluntarism allows the government to abdicate its obligations to its people, remains to be seen.

The AIDS epidemic, then, highlights structural flaws in our national health policies. While federal health programs increasingly focus on strengthening the private sector's role in health care, publicly provided care is underfunded and inadequate, and a national health plan remains years away. The decentralized approach to health care forces municipalities affected by the epidemic to shoulder the burdens of national problems. Research becomes entangled in the federal budget process, blocking a decisive response to public health emergencies. An obsession with technological solutions to illness allows lifesaving health education to be undervalued and underfunded.

The picture that emerges from the analysis of the timing and adequacy of the federal response to AIDS is of a nation still ill-prepared to respond to a crisis, an Administration too blinded by its own ideology to know when to reorder its priorities and a fragmented health care system unable to distribute the financial burden of catastrophic illness equitably.
Boston Meetings on Ethical Issues

Public Responsibility in Medicine and Research (PRIM&R) is sponsoring two meetings this spring on the subjects of animal care and use committees, and research with special populations.

The first will be held March 16-17, 1987, at the Copley Plaza Hotel in Boston, and is entitled, "Making Your Animal Care Committee Work: Current Issues and Practical Problems." The meeting will focus on issues affecting the operation of Institutional Animal Care and Use Committees (IACUCs), which were mandated at every research facility by the 1985 Animal Welfare Act. IACUCs are charged with both ensuring that animal care and research meet federal standards and with reviewing all research projects involving the use of animals.

The second meeting will be held April 27-28, and is called "Research With Special Populations: The Terminally Ill, Infants and Children, the Elderly, and the Mentally Disabled." This gathering, at the Boston Park Plaza Hotel, will focus on such issues as the use of clinical trials and placebos in terminally ill persons, the right to die and recent related legal developments, the use of comatose persons in research, genetic testing research and doing research on persons with AIDS. For further information, contact Joan Rachlin or Nadine Dolby at PRIM&R, 132 Boylston St., Boston, MA 02116, or call 617-423-4112 or 1099.

Teaching Hospitals with High Death Rates Get Listing

Teaching hospitals are widely regarded as the best places to go for quality medical care, yet many are on the government's list of hospitals with high death rates. The names of all U.S. hospitals on the list have been released by the Center for Medical Consumers, a New York City-based public interest organization. This is the first time the government's list has been published for the nine diagnostic categories that include congestive heart failure, transurethral prostatectomy, major joint procedures, gallbladder surgery, coronary bypass, heart attack, pneumonia, gastrointestinal hemorrhage, and pacemaker implants. Copies may be obtained by sending $3.00 to the Center at 237 Thompson St., NY, NY 10012.

A Far Out Reader

The Utne Reader digests, reviews and reprints "the best of the alternative press." Founded and published by Eric Utne, who helped found New Age in 1974, each thick, bimonthly issue is an eclectic blend of scholar-
And What About the Patients?
Prospective Payment's Impact on Quality of Care
by Ronda Kotelchuck

Three years after implementation of Medicare's Prospective Payment System, no one really knows what PPS has done to the quality of care for some 29 million older Americans. Are the quality-of-care problems now coming to light the tip of an iceberg, or just a floating ice cube? as one Rand Corporation researcher posed the question.

Considerable obstacles stand in the way of answering the question. That's because, unlike widely available hospital cost and utilization data, there is neither a universal definition of quality of care nor a data collection system to allow its monitoring. Are the problems encountered under PPS actually greater or fewer than those which occurred before its inception? At the moment no one can say. Until quite recently, the Federal Government, which administers the system, has utterly failed to take responsibility for answering these critical questions.

Quality Concerns

PPS raises three major concerns regarding the quality of American health care. The first is the danger that the enormous pressure to achieve cost savings under the new system may lead to undertreating patients. The second is the inadequacy of the system's key instrument, Diagnosis Related Groups (DRGs), to account for the severity of a patient's illness, prompting hospitals to avoid or dump these patients. The third is whether certain types of care formerly provided in the hospital will be available to patients in alternate care settings such as nursing homes.

By paying a flat price per case instead of hospital cost, PPS is the first hospital payment system to force hospitals to reduce costs if they are to survive or prosper. These economies include reductions in length of stay (LOS) and the decreased use of ancillary testing, pharmaceuticals, medical supplies, and therapies—usually leveraged through the hospital's physicians. The system has prompted some dramatic reductions in these areas. In 1984, the first full year of PPS, Medicare length of stay fell by 9 percent—three times the decrease of any previous year. In 1985 it dropped an additional 8 percent. Simply put, quality of care may be threatened for the first time by PPS's incentive to provide too few, as opposed to too many, services.

The new system has also prompted hospitals to cut their workforce, which currently accounts for over 60 percent of their total costs. In fact, in the year following PPS's implementation, the hospital workforce fell 3.5 percent. It was the first such drop in post-war history. In 1985 there was a 5 percent reduction. Nursing staffs, which comprise the vast majority of all hospital personnel, are particularly vulnerable. The California Hospital Association reported a 9 percent cut in full-time nurses and a 37 percent drop in part-time nurses in 1983. As one examines these numbers it is important to keep in mind that, aside from physician competence, nursing care is the single most important determinant of the quality of inpatient care.

"I feel like all of this is what killed my mother. It is just like murder to me."

DRGs, the 471 categories of illness used as the basis for reimbursing hospitals for patient care, are seriously deficient in a number of ways which may compromise the quality of that care. Most seriously, they do not reflect severity of illness. Because DRGs limit themselves to only five pieces of data to categorize a patient and establish the rate at which the hospital will be reimbursed, they fail to account for the additional costs of treating patients with multiple conditions or very advanced disease. Patients with these conditions pose serious financial liabilities, often prompting hospitals to transfer or avoid them altogether. DRGs do not recognize the use of different treatment modalities, some of which may be costlier, but more beneficial. In addition, DRGs will not reimburse hospitals for treating more than a single condition, even though this may be best or, in certain cases, crucial for the patient's recovery.

Finally, PPS incentives to shorten a patient's length of stay and reduce treatment costs are forcing a major shift of subacute care services from hospitals to nursing facilities and patients' homes. Medicare discharges to skilled nursing facilities increased 40 percent and discharges to home health care rose 30 percent in the year following PPS's inception. As these shifts occur, patients are in danger of falling into a "no care zone" as the demand for aftercare services outstrips supply. Not only are aftercare providers unequipped to deal with these more intensely ill patients, but Medicare coverage for these services is extremely limited. As a result, many patients simply cannot obtain the care that was previously provided and paid for in the hospital.

Ronda Kotelchuck is a member of the Health/PAC Board. This is the second of her three-part series on PPS.
The types of quality problems that may arise from these cost-cutting incentives include: inappropriately refusing to admit patients; inappropriately transferring patients to other hospitals; understating the necessary services; substituting quality materials, devices and supplies with inferior ones; and prematurely discharging patients. These problems are compounded by public confusion about Medicare coverage and patients' rights and appeal options under PPS, a confusion which leaves patients helpless to challenge decisions affecting their care.

The Primitive Art of Assessing Quality
As noted previously, the extent of these problems cannot be measured because we lack not only a widely accepted definition of quality, but also the relevant data and a system for measuring it. HCFA (the agency that administers Medicare) should take responsibility for overcoming this deficiency. Instead, the Health Care Financing Administration exploits the absence of information to dismiss reported quality-of-care problems as few, isolated and anecdotal.

In addition to showing no embarrassment over its irresponsibility, HCFA has been seriously negligent in complying with Congressionally mandated reporting on the impact of PPS. At least eight such reports and studies required over the last two-and-a-half years are overdue. The first report, due in December 1984, was released in draft form a year later, but only in response to a subpoena from the Senate Special Committee on Aging chaired by Senator John Heinz (R-Pa.). HCFA's report addressed hospital cost and utilization issues, but not quality concerns. Its second report is now a year late.

HCFA also failed to issue an impact report due two years ago on skilled nursing facilities. Although the agency had completed an impact report on home health care, it opted for an oral briefing rather than to publish its findings. In the briefing, HCFA officials denied that a significant increase in discharges to home health care had taken place, blatantly contradicting their own internal data. Their failure to report on the impact of PPS has spawned considerable speculation that they are incompetent, hiding something, deliberately snubbing the impact of PPS has spawned considerable speculation that they are incompetent, hiding something, deliberately snubbing Congress, or all of the above.

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Meanwhile, a host of outside studies conducted by such groups as the Commission on Professional and Hospital Activities and the Rand Corporation are underway and expected to provide some answers.

What obstacles prevent the government from assessing PPS's impact on the delivery of care? The most vital quality-of-care information cannot be measured in the hospital, but is reflected in a patient's health status outcome following discharge from the hospital to the home or long-term care setting. Unfortunately, current data collection and review systems stop at the hospital door, and studies which attempt to overcome these limitations tend to be laborious, costly and one-shot at best.

If it really wanted to, HCFA could help solve this problem. Data systems exist which can help assess patients' health status outside the hospital. For example, physician and outpatient claims, paid under Medicare Part B (which reimburses physician services), constitute a potentially important data source. Claims data, available from skilled nursing facilities and home health agencies, and post-discharge death data, which is available from Social Security files, could also be used. Clearly, all of these data sources could be merged to yield ongoing, easily usable information on the most important measure of quality: health status outcome. It should be underscored that the obstacle is neither technical expertise nor resources, but political will.

What the Professionals Say
Lack of scientific data has forced those concerned with the system's impact on quality to seek out other sources of information, including professional opinion polls and Congressional hearings. Both have been pivotal in shaping current public perceptions that PPS has caused the quality of American health care to falter.

According to many professional association polls, physicians strongly believe that the quality of care has deteriorated under PPS. Sixty-six percent of hospital medical directors responding to a 1986 AMA survey indicated that the quality of care had suffered and 43 percent noted pressure under PPS to discharge patients early. Forty percent acknowledged that they were in fact discharging Medicare patients earlier under PPS. The terrible irony is that nearly all of these respondents indicated that earlier discharges worsened patients' health.

Among hospital administrators, 54 percent said they expected quality of care to diminish as a result of PPS (in contrast to only 20 percent of consumers polled), according to a survey by the National Research Corporation. While fears were greatest among administrators of small hospitals, 65 percent of these respondents also said they expected their hospitals to profit under PPS.

Many of these surveys are admittedly unscientific. They have low response rates and respondents are likely to be among the most dissatisfied, especially physicians who are traditionally hostile to regulatory forces that restrict their independence. The poll results are nonetheless important because they voice concerns from those people with front-line responsibility for quality of care.

The Heinz Committee
More than any other group, the Senate Special Committee on Aging, known as the Heinz Committee, has raised the quality-of-care issue under PPS to the level of a grave public concern. At Senator Heinz's request, the General Accounting Office (GAO) conducted the first study of premature discharges. Surveying six communities, the GAO found
patients being discharged “sicker and quicker,” home health agencies facing heavier caseloads of more intensely ill patients, and an inadequate supply of nursing home beds to meet the burgeoning need. As expected, PPS’s defenders, in particular HCFA, once again dismissed these findings as unscientific.

The Committee’s three well publicized hearings on the quality impact of the PPS system were held in late 1985. One after another, patients, physicians, relatives, hospital and nursing home administrators and advocacy groups testified to the worst imaginable abuses under the PPS system, with special ire reserved for HCFA. One 65-year-old woman (see box) told of her mother’s death 14 hours after being prematurely discharged to a nursing home. “I feel like all of this is what killed my mother. It is just like murder to me,” she said, referring to the system which thrust her frail, dying parent out of the hospital. For lack of any other, these hearings became the sole public forum where patients, advocates for the elderly, providers of all types and researchers could bring their experiences, findings and concerns.

Patients’ Rights Gone Wrong

Among the many concerns raised by the Heinz hearings was the great frustration over PPS’s baffling and virtually dysfunctional system of patient appeal rights, rights intended to safeguard the quality of patients’ care. Thanks largely to these hearings, gains have been made in the patient appeal process. But until recently, patients seeking to appeal abuses under PPS would have had to be both healthy and clever enough to outwit a system that was nearly the perfect Catch-22.

Under this Byzantine system, patients could challenge a premature discharge only if they were notified in writing of the hospital’s intention to release them, or to charge them if they refused to go. This “notice of noncoverage” was the only source of information about appeal rights and procedures that hospitals were required to provide. Worse yet, they were not required to issue these notices unless they intended to bill the patient. This allowed hospitals to inform patients of their discharge verbally, preventing them from ever seeing the notice of their appeal rights.
Premature Discharge, Premature Death

Citizen Betty Kraut’s testimony before the Senate’s Special Committee on Aging, Sept. 26, 1985, was one of many statements by bereaved family members which called attention to the tragic pitfalls of the Prospective Payment System. Her words, which follow, offer a glimpse at a system that has victimized patients when they are least able to defend themselves.

“My mother was 85 years old when she died early this year. She had been ill with kidney failure, high blood pressure, heart condition, blindness, and a loss of hearing. I entered her in the hospital January 9, 1985, with a heart attack and kidney failure. The hospital took good care of her except for her meals. She was so weak and unable to feed herself. She was on oxygen 24 hours a day and her heart was so bad that her skin color had turned blue. During her hospital stay, my mother required around-the-clock oxygen, she had a catheter, IV tubes, and a feeding tube.

Then, on January 29, 1985, I received a call from the hospital stating that my mother would have to go to a nursing home because she no longer needed their acute level of care. On January 31, they sent for an ambulance and transferred her to the nursing home. This was done against Dr. Kellawan’s orders and while he was out of town. I was not told anything at all at the time that I could appeal to the hospital to not send her out. I did everything I could to prevent them from moving her, but they told me that Medicare would not let her stay any longer and they were losing money on her. To make matters worse, the hospital informed the nursing home that she was able to feed and bathe herself and also had bathroom privileges. This was absolutely not true. She could not move at all.

My mother passed away on February 1, 1985, just 14 hours after entering the nursing home. A day or so after her death, I received a letter at my home from the hospital saying that if I did not agree with my mother’s discharge, I could send in a written appeal.”

It was a gap that invited misinformation and abuse. Most patients simply accepted what they were told and left the hospital, too intimidated to challenge such statements as, “Your DRG is up,” “Your Medicare days are up,” or “Your benefits are expiring.” Patients simply didn’t know that their Medicare eligibility and benefits remain unchanged under PPS, or that only physicians—not hospitals—can discharge them, and then only when deemed medically appropriate.

Also unavailable to patients was clear information about Medicare’s coverage of different levels of aftercare and their impact on patients’ discharge rights. For instance, a patient, when no longer acutely ill, may not be discharged if he or she is in need of skilled nursing care and none is available outside the hospital. Until placement can be found, Medicare will continue to pay the hospital as if that patient were acutely ill. This is not the case, however, for patients requiring lower levels of care, such as intermediate care, home health care, or home support services. By Medicare standards, discharging patients who require home or intermediate care is acceptable, regardless of whether such care is available. Thus, gaps in Medicare coverage itself seriously weaken the quality and coordination of care and compound the confusion over when it is appropriate to discharge the patient.

Finally, patients who successfully cleared these hurdles to challenge their discharge encountered yet another contradiction: They were given two calendar days notification before being charged. If they appealed, a determination was required within three working days. Thus, in order to exercise appeal rights, a patient had to risk paying for at least one day of care—or several days—if the process spanned a weekend. If the patient was dissatisfied with the review determination, he or she could seek administrative and then judicial appeal. However, the risk of personal financial liability ruled out doing this while remaining in the hospital.

Stung by criticism, HCFA moved to address this major flaw in the appeal system. Effective March 24, 1986, hospitals must distribute to every Medicare patient upon admission a notice entitled, “An Important Message from Medicare.” In language agreed upon by five major provider and patient advocacy groups, the document spells out the circumstances under which a patient may be discharged, along with the appeal rights and procedures available.

In addition, Congress has recently removed the financial risk of patient appeals by postponing the time when hospitals can charge patients until after the appeals have actually been deter-
mined. While hardly adequate to protect the quality of patient care, these reforms offer significant improvements.

In the next installment of this series, we will conclude our analysis of quality of care under PPS by examining critically the role Professional Review Organizations (PROs) play in policing the Medicare System. We will also explore how public concerns about quality issues have triggered legislative responses to the problems of the Prospective Payment System.

Understanding the DRG Appeals Process

1. **Patient Disagrees**
   - **Notice of Noncoverage**
   - **Hospital & MD**
   - **Appeal within 2 days**
   - **Pro Review 3 Working Days**

2. **Determinations**
   - **Approval**
     - Medicare will cover continued care
   - **Denial**
     - File for Pro Reconsideration

3. **Further Considerations**
   - **Appeal**
     - Medicare will cover continued care
     - Patient pays for continued hospital stay; may file with Social Security Administration if controversy is at least $200

4. **Administrative Law Judge**
   - Will rule on legality and due process

5. **Decision Outcomes**
   - **Approval**
     - Pro Decision Overturned; Medicare will pay for continued care
   - **Denial**
     - Pro Decision Correct; Patient will pay for continued care; file for judicial review if controversy is $2000; seek legal counsel

6. **Judicial Review**
   - **Approval**
     - Earlier decisions overturned; Medicare will pay for continued care
   - **Denial**
     - Earlier decisions correct; patient will pay for continued care in hospital beginning with third day after receiving notice
Women in this age grouping who are bearing children, I would also add to your recommendations that healthy women be attended by nurse-midwives and physicians who believe that birth is a normal process and that nutrition education and parent preparation are essential to the process of empowering parents to make decisions regarding the birth process.

Anne Stein, C.N.M., M.S.  
Assistant Professor  
Nurse-Midwifery Educational Program  
University of Medicine and Dentistry of New Jersey

While I concur with Phyllis Kernoff Mansfield ”[Like A Boxer Over the Hill? Assessing the Prejudice Against Mid-Life Childbearing,” Bulletin, Vol. 16, No. 6] that the medical literature should be critically and skeptically examined, I reach different conclusions on the questions of maternal age and reproductive outcome. Dr. Kernoff Mansfield claims the eight outcomes she selected for scrutiny were those most consistently reported to be adverse with advancing maternal age. In fact, she left out those for which the data are most persuasive: infertility, spontaneous abortion and chromosomally anomalous conceptions, particularly Down’s syndrome. A 10-year study of women experiencing spontaneous abortions (cases) and women obtaining prenatal care (controls) at three Columbia University-affiliated hospitals demonstrated a consistent association between advancing maternal age and conception delay, with the gradient becoming steep when maternal age reaches the late 30s, and a rise in spontaneous abortion of both chromosomally normal and abnormal conceptions (although the slopes of these curves are dissimilar, both become steep after age 35).

Analyses of New York City births shed a different light on some of the outcomes Dr. Kernoff Mansfield does examine. John Kiely’s research showed women 35 and over to have increased risks for low birthweight offspring, stillbirths and neonatal mortality. The excessive rate of stillbirths is due entirely to fetal demise prior to labor and not to loss during labor and delivery. Our own preliminary analyses at the Health Department of pregnancy-associated deaths to New York City residents, indicate a significant increase of risk associated with advancing maternal age, after controlling for sociodemographic risk factors.

I certainly agree that more careful work needs to be done. I do not, however, think that exposing the methodological flaws of certain studies is equipping the opposite findings. Nor do I think that we expand women’s options by denying biological truths. There has been a trend within feminism that has consistently felt that revelation of any female biological “vulnerability” (particularly if associated with reproduction) would undercut progress toward women’s liberation. I feel differently. I think a true feminist perspective will lead us to demand that social policy accommodate biologic and social needs—be it through parental leave and day-care policies for women to work and be parents simultaneously, or through pushing medical research to address the realities of reproducing after age 35.

Wendy Chavkin, M.D., M.P.H.  
Director, Bureau of Maternity Services and Family Planning  
New York City Dept. of Health

Editor’s note: The titles and authorship of the studies Dr. Chavkin cites may be obtained by writing to the Health/PAC office.

Phyllis Kernoff Mansfield replies:

What is striking to me is the degree of inconsistency of the results among studies in this area. I can cite recent studies that come to opposite conclusions from those Wendy Chavkin mentions. My emphasis on inconsistent results and methodological flaws is not to “prove” that older women have no special risks, but to alert women and their health care providers that the notion of a biological boundary at age 35 is not written in stone.

Why is this important? Let us look at the disadvantages to first-time mothers over 35 in automatically being labelled “high-risk” patients by the medical profession. First, these women may be at increased risk for iatrogenic complications resulting from physician-elected interventions (such as increased reliance on obstetric drugs, more c-sections) deemed necessary solely because of age. The literature supports this occurrence. Second, such women are at risk for stress-induced complications of pregnancy and birth, related to the fears of being a “high-risk” patient. Third, these women may be denied the opportunity of nurse-midwifery services, since these professionals are being pressured not to accept “high-risk” patients. And, fourth, I know of many women in their early 30s who are being leaned on heavily by their physicians to hurry with their childbearing before 35, somehow picturing a woman’s reproductive capability suddenly going sour on her 35th birthday.

I regret that my work may be construed as “denying biological truths.” I call it as I see it. The Down’s syndrome literature, for example, though surprisingly fragmented, shows consistent evidence for a rise with age; in fact, the steep rise begins even before age 35. In terms of the other outcomes, I would suggest a strategy that gives attention to the individual woman wishing to make childbearing decisions, assessing her current health, past reproductive history, stresses and fears and various other important predictors, in addition to age.  

Peer Review  
continued from page 2
I didn’t intend to get arrested when I signed up to take part in the American Public Health Association (APHA) – sponsored protest against U.S. underground testing of nuclear weapons at the Nevada nuclear test site Sept. 30. During the bus ride to the Camp Desert Park test site in the desert I changed my mind.

Between 500 and 600 doctors, nurses and other public health professionals who were in Nevada to attend the APHA annual meeting were joined by a smaller number of Las Vegas residents. We traveled to the test site 65 miles northeast of the city in nine chartered buses and 40 cars. Leading the group were astronomer and anti-nuclear activist Carl Sagan; Bernard Lown, co-president of International Physicians for the Prevention of Nuclear War, which won the 1985 Nobel Peace Prize; H. Jack Geiger, President of Physicians for Social Responsibility; and key APHA leaders, including the past, current and elected presidents.

We were advised by a lawyer traveling with us on the bus that if we chose to engage in a nonviolent act of civil disobedience by crossing a white boundary line on the highway leading to the test site we would be charged with criminal trespass, a misdemeanor. Those convicted were likely to have to pay fines of $150 to $260 and would then have a criminal record. Following the legal briefing, the discussion between the bus passengers on the merits of civil disobedience as a means for making a public statement convinced many of us that it was the right thing to do.

We had been told that the U.S. Department of Energy had set off its tenth underground test of the year nearby at around 9 a.m. Angered by this, I, like most of the others, felt determined to make a strong statement against our government’s decision to continue testing despite the Soviet Union’s unilateral moratorium on all nuclear testing. The Soviet moratorium, which commenced on August 6, 1985, has been extended three times and is now set to expire unless our government reciprocates.

We were asked to sit on makeshift wooden benches where we awaited nonviolent training exercises. The brief series of speeches which followed was interrupted by past APHA president Victor Sidel’s announcement that the test scheduled for the morning had been delayed and was in fact scheduled to be detonated in about fifteen minutes. He advised us of the small risk of radioactive venting at the site and said those who wished to leave should board the lead bus which would soon depart for Las Vegas. No one moved toward the buses. Then Sagan held a radio scanner to the microphone which enabled us to hear the countdown. Neighbors joined hands. Some wept until the countdown was finished and the scanner went silent. The cry of a protestor’s baby and Sagan announcing, “Unlike a real nuclear war, this one passed us by,” broke the stillness. He continued: “I’m going to cross the line. I invite you to join me.”

Soon after, 139 of us did. Familiar songs from the civil rights movement and the struggle to end the Vietnam War rang out as we marched about a third of a mile down the highway. Those who planned to engage in civil disobedience were flanked on each side by a demonstrator who chose not to be arrested. As we marched, buses of bemused and hostile looking workers passed us, many of them giving us “the finger.” At the line the local police warned us that if we continued we would be trespassing on Federal land and would be arrested. We kept going and were handcuffed and escorted to buses, where we awaited processing.

A woman seated next to me on the police bus remarked that this was her first demonstration. She was a blackjack dealer in one of the Las Vegas casinos who learned about the planned demonstration on local television and felt compelled to join the protest, as did four of her friends from town. Their boss had given them the day off so that they could participate. She said the test blasts were growing more and more frequent, shaking her house and making her increasingly angry. She told me that she had never contemplated getting arrested, but after experiencing the events of the afternoon she also felt that she had no choice.

Most of us entered pleas of not guilty and now await a joint trial.

Sally Guttmacher is Assistant Professor in the Graduate Department of Public Administration at Rutgers University and a member of the Health/PAC Board.
New “Coke”: Not All It’s Cracked Up To Be
by Nick Freudenberg

For at least the past 30 years, we have seen one drug “epidemic” after another—marijuana, the psychedelics, heroin, amphetamines, angel dust and now crack. Each has appealed to some significant proportion of young people while raising a corresponding frenzy among adults to wipe out its use. Taken together, these episodes of drug abuse have had a devastating impact on this country’s youth. Unfortunately, there is no evidence that the interventions now being proposed will be any more effective than earlier ones.

From a public health perspective, the shrill response to crack is out of proportion to the threat. While no one doubts that crack is a dangerous drug that more people are now using, there are no firm estimates of mortality or morbidity from cocaine addiction. Compared to the 350,000 annual deaths attributed to tobacco and the similar number of alcohol-related deaths each year, the toll from cocaine is miniscule. As yet, however, no one has urged calling in the U.S. Army to defoliate tobacco fields in Virginia and North Carolina, nor has the death penalty been proposed for advertising executives who develop multimillion-dollar media campaigns aimed at persuading young people to drink wine coolers and beer.

As crack hysteria sweeps the nation, it might be useful to step back and analyze the political response to this drug that seems to intoxicate both its users and its opponents.

This summer, President Reagan called for a $100-million drug education program and the U.S. House of Representatives responded with a $1-billion plan. Whatever the final expenditure, it will far exceed the budget for health education for heart disease, cancer, or AIDS.

Actually lowering cocaine abuse will be far more difficult than voting the funds. One traditional response—now favored by many crack opponents—is an “educational” program designed to scare young people into abstinence. Too often, such efforts turn into disinformation campaigns in which more sophisticated young people dismiss “lessons” which contradict their own observations, and then dismiss the educator as well.

Another common tactic is the moralistic approach, which also often serves only to diminish the credibility of the communicator. While Ronald and Nancy Reagan’s plea to “just say no” may have made good prime time television, it is unlikely to have any positive effect. In fact, Catherine Bell-Bolek, the chief of the prevention research branch of the National Institute on Drug Abuse, warned that “those programs that used scare tactics, moralizing and information alone may actually have put children at increased risk” of drug use.

Rather than focusing on the particular harmful effects of the currently fashionable substance, it would make more sense to ask why young people in this country have regularly turned to drugs in such large numbers. Answers to this question might help to develop responses which are both appropriate and effective.

Planners of more sophisticated educational programs have argued that what young people lack are self-esteem, coping skills for dealing with stress and anxiety, and the ability to resist peer pressure. Evaluations of a few programs attempting to remedy these deficits have shown some success in reducing young people’s use of legal drugs such as alcohol and tobacco.

But the premise that a brief intervention can change a young person’s self-esteem or coping skills ignores the context in which many young people live. In New York City, for example, nearly half of public school students drop out or are pushed out of school before graduation. Unemployment rates among minority youth exceed 50 percent. More than 150,000 young New Yorkers aged 16 to 21 are out of work and out of school. It is estimated that 25 to 45 percent of U.S. urban males have been arrested by age 18. These broader social forces are the roots of drug problems for one sector of youth. For other social classes, alienation, boredom, and the thrill of risk-taking shape drug habits. Any real attempt to solve America’s drug problem must address these realities. Urging young people to say no to drugs is a policy that blames the victims of injustice rather than its perpetrators.

But while most of the current debate totally ignores the social roots of drug addiction, it is equally insufficient to attribute all drug use to poverty and injustice. To do so ignores the pervasiveness of drug use in all social classes and offers no useful guidelines for intervention short of social revolution.

In reality, drugs are as American as cherry pie. Any serious efforts to change the nation’s drug habits will necessitate interventions at many levels, including comprehensive health education that helps people see the connections between health, behavior and social structures. It would also require creating institutions which offer young people viable pathways to adulthood, as well as new, more effective forms of treatment, supported by funding sufficient to make these services available to those who need them when they need them. The sad truth is that the United States now lacks both the scientific knowledge and the political will to develop comprehensive, effective and humane methods to prevent and treat drug addiction.

The shrill response to crack is out of proportion to the threat.

Public health workers can combat this situation by encouraging people to reject superficial and simplistic solutions. Only when all elements of society are willing to engage in a serious effort to understand and control drug addiction will progress be made.

Nick Freudenberg is Director of the Program in Community Health Education at the Hunter College School of Health Sciences, City University of New York.
Body English

More Is Not Always Better by Arthur A. Levin

Does doing less necessarily cause harm? The people scurrying around trying to contain the $400 billion spent annually on health care should be asking this question. Practitioners, joined by consumers, loudly protest that attempts to reduce costs—by cutting services—must also reduce quality. They haven’t asked the question either. It’s time to ask it now.

The obvious question is, does it do more harm than good?

Progressive concerns about health care during the 1960s and 1970s principally focused on achieving equitable access for all citizens. Activists struggling toward the goal of expanding access continue to proclaim that health care is a “right,” not a privilege—and indeed it is. But advocates for equity appear to assume that medical services have intrinsic value and that better access, almost by definition, produces better health. Many also assume that a known standard of care exists and that practitioners always agree on what constitutes optimal treatment. Unfortunately, none of these assumptions is true.

The pages of medical journals have always been ruffled by questions and controversies about the safety, efficacy and utility of various medical practices. And it’s no secret that practice decisions and treatment modalities are influenced at least as much by education, specialty training and a practitioner’s environment as by scientific rationale. Moreover, diagnostic and therapeutic practices sometimes continue to be used long after their efficacy or safety has been disproven.

Medicine likes to wrap itself in a cloak woven of scientific fact, but it often unravels to reveal that the profession’s knowledge of the causes and cures of illness is far from complete. In addition, many health policy analysts exempt themselves from analyzing the benefits and risks of the varied and complex activities comprising medical care services. (Curative medical care services are the focus of our health care system.)

Too often they also fail to ask the obvious and instead assume, in the American tradition, that more and bigger is, by definition, better.

During the 1980s another question is being asked with increased frequency: Can the U.S. afford to spend 11 percent of its gross national product on health care? Many critics say no, emphasizing that the U.S. spends a larger share of its GNP on health than any other industrialized country. (In true conservative fashion, they fail to mention that the U.S., unlike every other industrialized nation but South Africa, lacks a program of national health care entitlement.)

Others argue that we can and should commit to spending these dollars to assure adequate health services and cite a bloated defense budget as a more appropriate area for cost containment. While the argument continues, a frenzy of concern about continuing inflation of costs has resulted in new reimbursement schemes in the public sector and a restructuring of benefits in private health insurance plans. Some changes, like DRGs, threaten to change the way treatment decisions are made, because they exert financial constraints on the content of service. Such changes demand that analysts reconsider old assumptions about the content of care and force the issue of quality to the foreground.

If it is assumed, for instance, that doing more is better, does it follow that doing less is worse? Consumer groups and others argue that Medicare’s DRG reimbursement scheme has harmed the health of older Americans, but are they guilty of the “less is bad” assumption? In addition, practitioners warn that any restriction on their ability to do whatever is “needed” for a given patient violates their oath and is likely to result in harm. Have they also fallen victim to the “more is better” assumption? I think so.

In medicine, as in other human services, the possibility exists that doing less may sometimes produce a better result. History repeatedly tells us that the more technical and invasive human activity becomes, the greater the risks of harm instead of benefit. The past promise of nuclear energy, for example, has emerged as a threat to our present wellbeing. Much of medical practice has not been shown to be efficacious and/or safe when scientific standards of proof are applied. To assume that limiting such practices will necessarily be harmful ignores that reality. It also fails to recognize how little we know about the causal relationship between practice and outcome.

Now an endangered species, retrospective reimbursement was often accused of encouraging unnecessary medical services—tests, surgical procedures and hospital stays—all of which put people at risk and were often economically wasteful. The goal of “first do no harm,” an important standard to apply when assessing medical practices, should also be applied in monitoring our new, more stringent cost containment program.

Everyone must keep in mind the obvious question as the content of medical practice changes: Does it do more good than harm? Most of all, we need to stop assuming that doing more necessarily improves the quality of our lives or that doing less necessarily diminishes it.

Arthur Aaron Levin is President of the Health/PAC Board and Director of the Center for Medical Consumers, publisher of the newsletter HealthFacts.
The Beauty of the Disabled


by Grace Gibbons and Jane Thierfeld

The idea for With the Power of Each Breath: A Disabled Woman's Anthology was an outgrowth of a support group of which its editors were members. That root is apparent as we read the anthology.

Made popular by the women's movement, support groups have brought women of common experiences together and have served as sources of personal and collective strength. They have provided receptive and empathetic environments for the exchange of personal stories, feelings, and practical information; they are settings in which it is acceptable to let go and laugh or to cry; to give voice to rage or pride. There are great risks taken by a woman who may, in a support group, articulate for the first time experiences and emotions she has held deep inside, but so are there rewards. Perhaps, also for the first time, she is truly heard, or perhaps other women hear in her words something of their own lives.

With the Power of Each Breath attempts to accomplish something akin to the support group experience, for we sense the risk many women have taken with their writing, and we see the attempt, through the diverse voices of 54 individuals, to call other disabled women from their isolation and connect with them. When disabled women begin to bridge the gaps between themselves, it will be easier to bridge the gaps with nondisabled women, and such an attempt is long overdue. Disabled women have stood somewhere in between the feminist and disability rights movements, their unique position addressed by neither, and their needs as well as their strengths virtually ignored by the rest of society.

With the Power of Each Breath is a book by, for and about disabled women. The support group that inspired its creation was brought together by the common experience of chronic illness. That fact, though, does not prevent it from succeeding as art; to the contrary, it may be because it succeeds as art that it is so worthy a contribution to forwarding the interests of disabled women. Most of the women whose work appears in the volume are accomplished writers. The writing overall is therefore quite good, and the volume encompasses many forms: short story, essay, poetry, personal letter, and so on. Subject matter, attitudes and emotions run a gamut as well: from memories of family life to surviving an auto accident; from fear to determination; from abuse of disabled women to reproductive rights.

Ann Finger, a writer, teacher, feminist and proponent of disability rights, has contributed a superb short story that is told with humor and truth. "Like the Hully-Gully but not so Slow," is written in the first person about an intellectually precocious 11-year-old girl who uses leg braces and who has been diagnosed by a doctor as experiencing “precocious puberty.” "Easy for him to say: He wasn't five feet tall at the age of eight, sprouting breasts, and hair in strange places. Bleeding."

The girl's disability is realistically handled in the story: it is not given a place of prominence; nor is it treated incidentally. The braces are a fact of her life that she hates, but the disability is a part of her; so are a cruel 14-year-old sister, career goals, questions about sex, and a father who is hospitalized for "manic-depressive psychosis."

We see another type of contribution in two of the several informative prose pieces. In "Infusing Blues," Susan E. Browne, a diabetic, writes in detail about a problem she experienced with an insulin pump, and Tzipporah Benavoraham, who is blind, tells of her system for keeping herself economically supplied with readers in a short essay, "Read Into a System: and Thrive."

In her sensuous "This Body I Love," Deborah Abbott writes easily of parts of her body until she comes to the smaller of her legs: "I have never known how to name it. To make reference without causing further harm. The Small One? The Weak One? The one which bows like a sapling in a climate of winds? I am a doctor as experiencing "precocious puberty."

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Though, as the editors point out, about half of the women will die as a result of their disabilities, most writers say little
about death. Robyn Miller is one who does, confronting the fact of death as she watches a friend who is dying of the same disease she has. In "Taking Leave," Robyn recognizes that she is powerless to help and compares one's own death, as something that can be fought, with watching someone else die, as "a passive thing to do." She sees her 11-year-old friend taking her leave, drawing away from the world, while Robyn wants to draw her nearer. Speaking to her friend through her essay, Robyn says: "It is not just, this gradual leave-taking of a child. If it were fair, it would not be fought by so many doctors, working with science to accomplish what you and I need so much. If I wait for the day I see a medical miracle with eagerness, you must understand I have wished it would have come in time to save you." A 20-year-old junior at Barnard College when this book was published, Robyn died of cystic fibrosis three months later.

*With the Power of Each Breath* has much to say to all of us. We can do a great service to our clients or patients, who may be living in the isolation the editors and contributors seek to combat by sharing with them this volume that has been written for them. And we can all share the experience of the editors who tell of their own reading of the material: "We were moved to tears and laughter, given strength, and prompted to face deeper issues."

In 1980, Bernard F. Stehle, an English teacher at the Community College of Philadelphia, taught a composition course at the Philadelphia Home for Incurables (The name has since been changed, at the residents' behest, to Inglis House.) The 12 students he taught, all in wheelchairs, and the other 400 residents, were severely disabled by conditions such as cerebral palsy, muscular dystrophy, multiple sclerosis, quadriplegia. During one class, a general discussion arose about forming good sentences and paragraphs. When Stehle used human relationships as an analogy, the discussion turned to the students' own relationships and loves. After many such personal stories, Stehle blurted out, "So that's why they call this place the Home for Incurables—you're incurably romantic!" Stehle returned to Inglis House often during the next three years, camera and tape recorder in hand, to hear the residents talk about their relationships and to share their feelings about love and commitment. The result is an unusual book of photos and words, *Incurably Romantic.*

The book is, as Stehle has said, a collaborative effort between the photographer and his subjects. The people he photographed chose the locations that held special meaning for them, giving the reader a more personal glimpse inside their world. Though we are not told about the locations or their significance, we are aware, as we look at the photos, that something very personal is being shared, and we are affected by it. In his introduction to the book, Stehle tells of one couple who, "very protective of their privacy, chose to have me photograph their intimate space—but without them in it." "This is like our shrine," she said of her room, "the place where we spend our best time together."

Stehle did not pose his subjects, either. Instead, he asked them to "be together in whatever way they liked." Some couples embrace, others hold hands, some are seen side-by-side. One woman, who cannot use her hands, was photographed feeding her boyfriend, who also cannot use his hands, with a fork held between her teeth.

The words that accompany the photos were taken from interviews with the subjects and are straightforward remarks each has made about the relationship. Included as an afterword to the book is an insightful and intelligent piece by Joseph W. Schneider, a sociologist who has done research on people's experience of illness and disability. Beyond dealing with the sexuality and the relationships of the persons photographed, Schneider quite rightly wonders about those residents of Inglis House who do not appear in the photos: those who did not wish to be photographed, and those who were not involved in relationships such as the ones we see and read about in Stehle's work. Schneider asks, "Who are their friends? Who cares for them? Talks? Listens? Touches?"

*Incurably Romantic* is an unusual artistic endeavor that opens our eyes to an aspect of the institutionalized disabled that our society has failed to acknowledge—sexuality. Disability and institutional life do not affect one's need and right to be a sexual being, capable and deserving of love, companionship and intimacy, and Stehle's work makes that point with beauty and sensitivity.

It is necessary, though, to enter a word of caution. Stehle has made no attempt to produce a work representative of disability and sexuality in general, and it would be a mistake to view it as such. In working with clients or patients who are disabled, we are always seeking resources, especially resources that deal with such a misunderstood and general-
Felons In Lab Coats


by Hal Strelnick

Pick up any recent issue of the Wall Street Journal or Business Week and the evidence is compelling: We are in the middle of an epidemic of corporate crime.

E.F. Hutton was caught check-kiting billions in overnight overdrafts. The Bank of Boston and Crocker National Bank were nabbed accepting billions in large cash deposits without reporting them, the first step in laundering money from drug deals and organized crime. General Electric, GTE and General Dynamics have all been caught defrauding the Federal Government on defense contracts. The Manville Corporation and the A.H. Robins Company have declared bankruptcy to protect themselves from the flood of product liability suits arising out of the death, disease, and disability their asbestos and Dalkon Shield IUDs have caused. In December 1984, the SmithKline Beckman Corporation pleaded guilty to criminal charges for failing to report the lethal side effects of their blood pressure-lowering drug Selacryn to the Food and Drug Administration. In August 1985, Eli Lilly & Company pleaded guilty and its former chief medical officer pleaded no contest to similar charges arising from its arthritis drug Oraflex. They were also charged with failing to alert consumers, through appropriate labels, to the drug's potential side effects of liver and kidney failure. And the list goes on.

John Braithwaite's book comes at a time when the business press and business schools have tacitly acknowledged the systemic nature of this problem by devoting more attention to corporate ethics, but his perspective is very different. The New York Times and Business Week appear to be most interested in the impact of a scandal on the morale and productivity of a corporation's employees. Braithwaite's major concern is preventing the crimes and protecting the health and pocketbooks of consumers. To this task he brings an impressive—and appropriate—list of credentials, including Director of the Australian Federation of Consumer Organizations and research criminologist at the Australian Institute of Criminology. Braithwaite is a kind of Aussie Ralph Nader.

While on a Fulbright Fellowship to the United States, Braithwaite conducted more than 130 interviews with executives of multinational pharmaceutical corporations and an equal number of regulators, health activists, former executives who have left the industry and officers of the pharmaceutical manufacturers associations in the United States, Australia, Mexico, Guatemala and Great Britain. What he found is far more complicated, more human, and more interesting than what many Marxists and consumer activists would assert logically and inevitably follows from the pharmaceutical industry's unmitigated pursuit of profits.

Braithwaite begins with a thorough review of the industry's lengthy criminal record—bribery, fraud and negligence in drug testing and research; unsafe manufacturing practices; price fixing and antitrust violations; corporate drug pushing (i.e., "advertising"); dumping of banned or harmful drugs in Third World markets; a variety of international tax evasion schemes managed through intra-company transfer pricing; and other more direct rip-offs.

Some of the case studies will be familiar to Bulletin readers (see Vol. 14, No. 2, 1983). Hollywood could not invent such shady "success stories" as the con man who posed as a physician, became the chief executive of and built up the McKesson and Robbins Pharmaceutical Company (known today as Foremost, McKesson, the giant medical supply manufacturer and distributor) by selling the company's high alcohol products (mainly hair tonic) to underworld bootleggers during Prohibition; or the Swiss manufacturer Hoffman-LaRoche, which
built up its massive profits between the two world wars by selling heroin and morphine to the underworld.

As the recent convictions of Lilly and SmithKline Beckman indicate, this sordid history is only a prelude to the present. Braithwaite cites a comprehensive study of corporate crime in American business published in 1979 that found that pharmaceutical companies have more than three times as many serious or moderately serious crimes per firm as other corporations and have a worse record of international bribery and corruption than any other industry. In their own reports to the Securities and Exchange Commission almost every American pharmaceutical company among the top 25 has admitted to between $100,000 and $6 million in questionable payments. Without shame, many of them went to considerable lengths in these reports to prove that these bribes were tax deductible.

Braithwaite, however, challenges the idea that more regulation and more vigorous enforcement and prosecution of existing laws will improve the industry's record and protect the consumer's health. He argues thoughtfully and persuasively for developing quality control and self-regulation within the corporation, including encouragement of internal whistleblowing to levels of corporate hierarchy and authority that can put an end to illegal and questionable activities, as well as for laws that genuinely promote whistleblowing to outside regulators. He argues that regulators should negotiate softly with the industry but carry the big sticks of publicity sanctions and innovative equity fines ("capital punishment"; corporations would have to pay stocks or securities to a victim compensation fund). Such fines would hurt the corporation and its senior management where it counts without bankrupting the corporate treasury. Another innovative fine would give the money to public interest groups that investigate and monitor the industry.

While Braithwaite believes that some showcase prosecutions of corporations and their executives are valuable deterrents, his interviews uncovered the uncharted title of "vice-president who'll go to jail"—the designated corporate scapegoat, even though no corporate executive has ever been jailed under the Food and Drug Act. (In fact, in the Thalidomide case no individual or corporation was ever convicted of a crime anywhere in the world.)

The threat of imprisonment, Braithwaite argues, has a perverse effect. It stiffens the procedural safeguards of due process originally designed to protect powerless individuals against a despotic government; because the legal resources of a major pharmaceutical company equal or surpass those of the FDA, these safeguards protect the powerful. Braithwaite asserts that removing imprisonment as a potential punishment would ultimately lead to more convictions.

This argument cuts across our usual left-right polarities. While the right calls for law and order for the poor, it complains that attacks on white collar crime represent "over-regulation." When the left calls for law and order (including prison sentences) for corporations and their executives, it often fails to recognize the tremendous complexity and infinite delays in these cases and the vast public resources consumed with little certainty of convictions. Braithwaite offers some new approaches to fitting the punishment to the crime and attempting to insure that some justice will be done.

Some of Braithwaite's recommendations, such as corporate "sunshine" laws that would open up more proprietary information to public view, and reductions in the longevity of protective drug patents, seem naive pipedreams given the industry's current political and economic clout. Others, such as a law that would ban the use of trade names and insist that all drugs be marketed and advertised using their generic formulas, might be original enough to catch the industry off guard. Unlike most of the industry's critics, Braithwaite recognizes the social contribution of pharmaceuticals and the potential multinational's have for upgrading production and quality standards in the Third World.

This book is not one which "rounds up the usual suspects." It offers a broad array of original, challenging and even workable ideas to protect the public's health from abuses, negligence and mistakes of the industry. It serves as a model for the empirically based analysis that is needed in many sectors of the health system to deal with the rapidly growing—and changing—power and complexity of corporations and the concurrent epidemic of corporate crime.

In 1937, the Republican Party approached McKesson's con man chief executivte to run for president against FDR; he declined and was exposed the following year. In 1986, a corporate con man of a different sort is in the White House. Crime is now rampant in the suites, and the Reagan Administration has moved to decriminalize it in the guise of "regulatory relief." The Administration has also moved to legalize bribery and the dumping of hazardous and banned drugs in the Third World, relaxed anti-trust enforcement altogether, and proposed socializing product liability costs onto the rest of us. A few corporations have been caught moving faster than the Reagan Revolution's decriminalization of white collar crime. One can only speculate how big the iceberg is under this exposed tip.

Hal Strelnick is a physician teaching in the Department of Family Medicine at Montefiore Hospital in the Bronx and a member of the Health/PAC Board.
Sexual Politics As Science
No Magic Bullet by Allan M. Brandt.

by Robert Cohen

Doctors are more comfortable with acronyms than they are with reality; terms such as VD, STD, and RPR simplify and purify problems whose complexity physicians would prefer to avoid. Among its many qualities, Allan Brandt’s book, subtitled A Social History of Veneral Disease in the United States Since 1880, offers a fascinating demonstration of how this process operates.

The phrase “venereal disease” itself is an example of manipulation through terminology. Diseases which are sexually transmitted are no longer thought of as infections, but instead are placed in a proscriptive and victim-blaming discourse. Brandt attempts to describe how sexual attitudes, independent of the state of scientific knowledge, have played a major role in the treatment of these diseases. He effectively shows, for example, how women have been blamed for spreading syphilis and gonorrhea, even though the scientific evidence suggests that men do so much more efficiently. At the same time, men with syphilis or gonorrhea are chastened; their medical problem is regarded as just punishment for their uncontrolled sexuality.

In an illuminating narrative, Brandt relates how the public health and military establishments orchestrated a national venereal disease hysteria during preparations for World War I; he vividly describes the harassment and attempted elimination of semi-official prostitution from cities across the United States. The parallels with current Department of Defense and Health and Human Services policies of blaming prostitutes for the spread of AIDS within the military, and banning recruits with positive HTLV-III antibody tests, are haunting.

This book has informed my own assessments of current policies for screening and treating sexually transmitted diseases. Brandt successfully demonstrates that sexual politics can be more powerful than science and that, in fact, sexual politics becomes science when either the reality or the perception of a “venereal” disease epidemic reaches a critical threshold.

Robert Cohen is a physician and a member of the Health/PAC Board.
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