

HEALTH CARE CONSUMER

NEWSLETTER of the Champaign County Health Care Consumers



Fall 1983

Midwifery Hearing Generates Local Interest

An October 27th public hearing entitled "Birthing Options in Champaign County" generated mixed responses from the county Medical Society, the local health planning board and State Representative Helen Satterthwaite. The hearing, sponsored by CCHCC's Midwifery Task Force, was attended by over 80 persons, 18 of whom testified. The testimony was presented to Rep. Satterthwaite; Sherry Steigman, Vice President of the local health planning board; and Dr. Lewis Trupin, President of the Champaign County Medical Society. All three were invited by the Task Force to listen to the comments and concerns of community residents.

All of the speakers favored greater birthing options for local women and several emphasized the inadequacy of birthing and prenatal services available to low-income women. Testimony also covered a range of other topics including the need for birthing options that allow for minimal medical intervention; the growing demand for nurse midwifery services not available in Champaign County; the advantage of a birthing center; and even the growing trend of home births. Following the testimony, each of the three panelists were asked to sign a pledge to seek support from the organizations they represented.

As a result of the issues raised at the hearing, the local board of the East Central Illinois Health Systems Agency (HSA) voted to form its own task force on the recommendation of Ms Steigman. The Task Force would explore nurse-midwifery and the issue of low-income access to prenatal and birthing services. It is the hope of CCHCC that the HSA will consider incorporating concerns about low-income access and nurse midwifery services into their Health Systems Plan for our area.

By far, the most receptive response to the pledge was from Representative Satterthwaite. Stating that she had "no problem signing," Rep. Satterthwaite put her name on the pledge which stated: "I pledge to support legislation that will aid: the



Over 75 local residents attended a public hearing where panelists Lewis Trupin, M.D., Helen Satterthwaite, and Sherri Steigmann listened to their testimony concerning Midwifery services.

development of the nurse-midwifery profession; the development of alternative birthing centers; and access of low-income persons to birthing and prenatal services."

The response of Dr. Trupin and the Champaign County Medical Society was less enthusiastic. Although Dr. Trupin eventually signed the pledge, he cited several reasons why he felt the Medical Society would not support the Task Force efforts. In his pledge, Dr. Trupin agreed to introduce two resolutions to the Medical Society. The first stated that the Champaign County Medical Society endorses the profession of nurse-midwifery, while the second encouraged physicians to offer reduced-cost prenatal and birthing services to low-income women. Unfortunately, at their November meeting, the Medical Society refused to support the resolution stating their support for nurse-midwives and challenged claims that low-income persons lack access to prenatal and birthing services.

CCHCC Midwifery Task Force will be meeting in early 1984 to develop a strategy for following up on each of the responses. "We weren't really surprised with any of the responses," explained CCHCC Director Cynthia Ward. "We have our work cut out for us but we look forward to working with the HSA task force. It should provide an excellent forum for continued work on this important issue."

IN THIS ISSUE

STATE AND NATIONAL HEALTH CARE CAMPAIGNS

Illinois Public Action Council and the People's Medical Society join the battle p 4

AIDS—WHOSE PROBLEM IS IT?

Medical facts, political implications, and some suggestions concerning the dreaded disease p 7

THE BUSINESS OF HEALTH CARE, PART II

A consumer perspective on the growth of for-profit corporations in the health care field p 3

TALK TO YOUR DOCTOR

As discussed in the previous Health Advocate Reports, malpractice suits are one means of handling a complaint about a physician's practice. Another means—often more appropriate—is simply talking to your doctor. Although they shouldn't be, doctors are usually unaware of the cost of their services and of the billing procedure. By approaching your doctor or dentist directly to talk about price—both before and after receiving services—consumers are often able to avoid the headache of dealing with the business office or a secretary. If a bill is over-due, consumers can avoid being harassed by collection agencies by arranging to make regular payments. Even very small payments are adequate if they are all that the consumer can afford and if they are made regularly.

Likewise, many cases involving a complaint about the quality of services can be resolved by discussing it with the medical provider first. For example, a woman had been suffering with poorly fitted dentures for the past two years. For fear of being charged again, she had not returned to the dentist who did the original work. Knowing that she could not afford to go to another dentist, she was considering suing the original dentist for repayment. Yet, with the help of a Hotline Advocate, she was able to resolve the situation to her satisfaction after a face-to-face meeting with her dentist. This direct communication between the consumer and the provider of health services can be as effective as other means which both would prefer to avoid. For assistance in setting up such a meeting with your doctor or dentist—a process which can be intimidating, at first—call the CCHCC Consumer Health Hotline at 352-6533.

"SPEND DOWN" CONFUSION AND FRUSTRATION

A single woman with a disability applies for Medical Assistance through the Illinois Department of Public Aid. Her assets are within the eligibility guidelines but her income of \$400 per month is too high for her to receive a grant. However, she is enrolled in the Medical Assistance No Grant (MANG) program under Aid to the Aged, Blind and Disabled (AABD) with a "spend down" amount of \$822. For her, and for many other Public Aid recipients, this is a source of confusion and frustration. Just what is this "spend down"?

The "spend down" figure is the amount of medical expenses which a Public Aid recipient must incur over a specific period of time *before* they are able to receive a Medical Card ("Green Card") for that time period. Contrary to popular belief (even among some Public Aid case workers) these expenses do *not* have to be *paid* by the recipient before he or she can receive a green card—it is only required that the bills are *incurred*. Medical expenses which can be included in the "spend down" amount are not only the direct hospital and doctors' charges, but also health insurance premiums, Medicare premiums taken out of Social Security checks, mileage expenses to the hospital or doctors' offices (up to 19¢/mile), and medically necessary medication.

The "spend down" figure is derived from a formula which uses a person's gross income and family size. The Illinois Department of Public Aid sets a minimum income amount for a given family size. With an income below this amount, the Public Aid recipient has no "spend down" and can receive a green card immediately. But, using the example of the single

woman with an income of \$400 per month, the "spend down" is determined in the following way: first, \$25 is automatically deducted from her income ($\$400 - \$25 = \$375$). Then, the minimum income level set by Public Aid is subtracted from the \$375. Under AABD with a family size of one, this amount is \$238. So, $\$375 - \$238 = \$137$. Lastly, this amount is multiplied by six for the six month time period ($\$137 \times 6 =$). Thus, \$822 is her "spend down" amount.

If you feel that your Spend Down amount is too high, an appeal can be made to the Public Aid office. They are required to give you a "Statement of Facts" sheet which explains what they did. Then, you are entitled to an informal conference followed by a hearing. For questions or help in setting up an appeal, call CCHCC at 352-6533.

CCHCC Sixth Year Celebration

On November 11th, a simple storefront proved to be a splendid setting for a highly-charged and well-deserved CCHCC Sixth Year Celebration. Approximately 100 people turned out to eat, drink, dance and socialize, all of which were tied together by the warm surreal sounds of a Caribbean rhythm band. Specifically, the Clemente High School Steel Drum Band, from Chicago. Playing with a high degree of professional competence and personal charm, the ten-member band gave a combination lecture-demonstration and concert which captivated the audience for the better part of three hours. Short of a mid-winter trip to Trinidad, a better display of traditional Caribbean musical styles could not be found.

The other highlight of the evening was the volunteer recognition ceremony. This year's Volunteer-of-the-Year Award went to Susan McGrath for her outstanding commitment to CCHCC. The Leadership Award of appreciation was shared by Mike Doyle and Cynthia Ward. Awards were given to two distinguished Task Force members: Lillian Cotter of the Medicare Task Force; and Loretta Morales, of the Health Hotline and Midwifery Task Force. In addition, Laury Mantel was recognized for her participation in CCHCC's summer fundraising canvass, while Ann Robin was presented with an award for being the volunteer to sell the most number of Sixth Year Celebration raffle tickets. And, for showing the board the "lighter side of things", Louise White and Ray Murphy were both recognized.

After the recognition ceremony, the band invited members of the audience to get a quick lesson in steel drum playing. Within a few minutes, the new recruits were playing what sounded like "Oye Como Va," and were rewarded for their efforts with a hearty round of applause from the audience. The band then took over for the remainder of the evening.

As the band packed up in high style (members dropped out one by one, until the final solo player was carried from the stage), a moment of suspense developed as the raffle drawing was held. Kathi Bowden was announced as the lucky winner of the prize.

Now that the Celebration is over, and that close to \$1,500 was netted for CCHCC, a big Thank-you goes out to the many people who helped make this event possible.

Medicare Task Force Update

"We have a sense of moving ahead, of changing things for the better," beams Lillian Cotter, newly elected Chairperson of the Medicare Task Force. "The problems with Medicare are obvious. It's the solutions that take a lot of time—but, luckily, the task force is seeing some interest and cooperation from the medical profession," she continues.

The problems are obvious enough to anyone on Medicare. A list of price increases due to go into effect on January 1, 1984 shows this dramatically. Part A (Hospital Insurance) deductible for days 1-60 will be \$356 as compared to the current \$304. For days 61-90, it will go up to \$89 per day from the current \$76 per day. Beyond 90 days ("lifetime reserve days"), the new deductible will be \$178 per day, up from the current \$152 per day. The monthly premium taken straight out of the Social Security checks for Part B (Medical Insurance) is going up from \$12.20 to \$14.60. And finally, the deductible for days 21-100 in a nursing home will go up from \$38 per day to \$44.50 per day. The overall average is a 17% increase in cost to the Medicare beneficiary. Worse yet, this follows an identical increase from last year. Added to this is the spiralling inflation in health care costs across the board.

So why the optimism from the Medicare Task Force? "For senior citizens, our huge medical expenses are also our buying power," explains Task Force member, Doris Arnold. "As the single largest group of health care consumers, we can bargain with the providers for a services package." Over the past several weeks, she and several members of the Medicare Task Force have been meeting with representatives of Burnham City Hospital for just this purpose. The meetings are a result of the large public forum organized by the Medicare Task Force last August. The negotiating process between consumers and providers promises to be lengthy but rewarding. Marjory McGrath, CCHCC Board Representative from the Medicare Task Force, cautions that "Burnham has made no promises yet, but we do feel that they are willing to work with us to find a local solution."

Negotiating sessions are taking place at the Champaign and Urbana libraries. Burnham City Hospital is being represented by three of their top administrators while the Medicare Task Force has a negotiating team of fifteen members. The discussions have been professional and cordial. By all indications, the two sides will continue meeting for a few more months until an agreement is reached.

"We are not asking for another charity program," points out Clara Clark, another newly elected CCHCC Board Representative from the Medicare Task Force. "We are bargaining with Burnham as equal partners. They need us as much as we need them." She refers to the financial plight in which Burnham and the other local hospitals are finding themselves due to empty beds. Recent news articles have reported that occupancy rates are low—in the 60 to 70% range—for all three local hospitals. Burnham has projected a \$700,000 revenue shortfall for themselves this year. The Medicare Task Force has developed a proposal based on the dire financial situation of Medicare patients and of hospitals who would like to attract more patients. The proposal being discussed now is designed to be beneficial to both parties.

Other recently elected officers of the Medicare Task Force are Mary Evans who will serve as Vice-Chairperson and Mr. Carrol Davis who will serve as Secretary. Anyone on Medicare or soon to be on Medicare is encouraged to participate in the Task Force. For information on the next meeting, call CCHCC at 352-6533.



Last August, members of CCHCC's Medicare Task Force convinced Burnham City Hospital to negotiate local solutions to Medicare problems.

Business of Health Care—A Consumer Perspective—Part Two

A quick glance through the local paper will show that health providers no longer consider it unethical to advertise their services. Health care providers, most notably hospitals and clinics, now spend large amounts of money advertising. This new propensity for advertising is but one symptom of the new-found "competition" that exists in the U.S. Health Care System. In the last issue of Health Care Consumer, we explored the emergence of for-profit health care corporations. In this, the second article in a series on the Business of Health Care, we will examine this new trend of competition and what it means to consumers of health services.

At the turn of the century, proponents of "scientific medicine" were battling for a leading role in defining the shape and course of U.S. medicine. One factor impeding the progress of scientific medicine was its relative cost for education. Schools of scientific medicine required more support staff and more developed courses: They could not, like the schools of the rival sects, be supported by student fees alone. In order to compete, the scientific medicine

community turned to private funding sources for support—and they received it. From 1910 through the 1930's, foundations contributed over \$300 million to schools, facilities and research in scientific medicine. Thus had begun the subsidization of medicine.

Beginning with the passage of the Hill-Burton Act in 1946, the U.S. government took over the leading role in financing medicine from the foundations. The Hill-Burton Act provided over \$5 billion to hospitals across the country for expansion. Other legislation was passed providing funding for medical research and subsidies to medical schools. However, the biggest subsidy for American medicine came with the passage of the Medicare and Medicaid bills in 1965. Interestingly enough, the AMA bitterly fought against passage of these bills, fearing government intrusion into their profession. However, the benefits of these programs to the medical community soon became apparent and eventually won their overwhelming support.

State and National

Health Care Campaigns

Within the last year, the issue of health care has markedly risen in prominence in the agendas of state and national citizen action organizations. Momentum for this movement in the progressive organization network is growing in response to the escalating crisis in health care. Once an issue of importance to only a few constituencies, health care is rapidly becoming an issue that touches the lives of most Americans. The newly unemployed are for the first time without health benefits; the employed are facing the crisis as they are forced to make concessions in contract talks to cover the escalating cost of health benefits; senior citizens, for whom Medicare is no longer adequate, can no longer afford the cost of supplemental insurance; and those who once received government assistance with medical bills now find themselves no longer eligible for all or some services. Coalitions representing these groups are forming at the state and national level to ensure that their voices will be heard and their interests will be represented in debates on health policy.

For the Champaign County Health Care Consumers, this boom of activity on the state and national level not only adds support for our existing activities, but will open the door to our participation in a new range of consumer health activities. The development of state and national progressive health campaigns will facilitate the sharing of information and resources on local health care organizing efforts. In addition, CCHCC will now be able to effectively participate in campaigns aimed at impacting state and national health policy.

In our last issue of Health Care Consumer, we reported on the emerging health campaign of National Peoples Action (NPA), a national citizen action organization. In this issue, we've included articles on Illinois Public Action Council's (IPAC) health campaign and the People's Medical Society. We are hopeful that reports on national and state health action campaigns will continue to be regular features in U.S. health care policy and in the Health Care Consumer.

IPAC Launches Health Campaign at Annual Conference

The responses ranged from disbelief to surprise as the workshop participants listened to Cynthia Ward's description of CCHCC's Hill-Burton campaign. Some were startled to learn that their community probably contained hospitals that were legally obligated to provide free care and to inform every patient that they might be eligible for this free care. Others who knew of the Hill-Burton program were amazed that a community organization had gained commitments from local hospitals to set up their own free care programs once their federal Hill-Burton obligation expired.

CCHCC's Executive Director gave the presentation on local health care organizing at the 8th Annual Conference of the Illinois Public Action Council (IPAC). IPAC, a coalition of over 140 citizen action organizations around the state, drew close to 400 people to their conference, which was held November 19th and 20th in Champaign-Urbana. The conference provides an annual event for coalition participants to share information on issues and to ratify IPAC's issue agenda for the coming year.

In addition to hearing about the local organizing efforts of the Health Care Consumers, participants at the health workshop heard about health campaigns that are in progress at the state and national level. David Patt of Illinois Citizens for Better Care (ICBC) outlined ICBC's agenda for addressing quality of care in nursing homes. The goal of their campaign will be to increase nursing home compliance with the Illinois Nursing Home Reform Act and to push for increased reimbursement levels for nursing home care through the Medicaid program. ICBC plans to hold accountability sessions around the state in the coming year on these issues.

Eric Schulman, legislative director for the National Council of Senior Citizens, addressed health care issues from a national perspective. He stressed the need for effective health care cost controls as the only real solution to the

Medicare funding crisis and urged all those present to work to make quality, affordable care a high priority issue in the next year's elections at all levels. Schulman argued that consumer pressure must be brought to bear in order to counteract the enormous influence of the AMA and its lobbyists.

Following presentations by the health workshop panelists, workshop participants ratified five resolutions that will form the basis of IPAC's health campaign. They are as follows:

1) **Effective cost control**—The fight for effective cost control must be a high priority. Structural changes in a health care delivery system which presently encourages waste, inefficiency, and inflation should include:

- *Across the board replacement of the "fee for service" mode of payment for hospital costs with a system of prospective payment which applies to all third-party payers and which provides for service to the uninsured.
- *The encouragement of more cost-effective alternative delivery systems, such as nurse-midwives, birthing centers, and denturists (specialized dental technicians who provide dentures without relying on dentists as middlemen), where such systems are able to maintain acceptable levels of quality.

2) **Save and Strengthen Medicare**—Any campaign designed to save and strengthen Medicare must address the real cause of the funding crisis. We must demand that any solution to the program's problems should recognize runaway health care inflation (and not "over generous" benefits and eligibility) as the root of the crisis. Narrow fiscal solutions (such as cost shifting onto the backs of beneficiaries) are not acceptable alternatives to system-wide structural change. Medicare assignment as payment in full for physician services should be made mandatory.

3) **Citizen Participation in Health Policy Decision at all Levels** is necessary to temper the bureaucratic orientation of the giant institutions of health care. The trend toward economic concentration in the health care industry should be closely monitored and regulated. Community and citizen control of health care resources should be made a high state and national priority.

4) **Universal Quality Health** should be placed high on the national agenda. We should oppose resolutely any further cuts in health care programs and continue to fight to restore access to those deprived of it by cuts already made. A national floor for Medicaid eligibility should be established. A mechanism should be developed by which the public could intervene in policy decisions which, if left to profit-motivated providers, could deprive segments of the population (the poor, people in rural areas, etc.) of access to needed care.

5) **Quality Control** should continue to be a high campaign priority. Reform of Illinois' nursing home regulation, and

vigorous enforcement of those regulations is a particularly urgent need in the area of quality. Full public disclosure of all information relating to the cost and quality of care should be required.

Quality health care is a fundamental human right. As with any other such right, citizens must be willing to organize and fight to achieve and protect it. The coming year will be a pivotal one in that fight. Citizens should gear up to place efficient, affordable, accessible, and higher quality health care on the Illinois and national agendas for 1984.

As a constituency that utilizes the greatest portion of health care services, and is therefore most impacted by health care policies, IPAC has formed a senior citizen Task Force to lead the IPAC health care campaign. At the IPAC conference nominations were taken for the Senior Task Force Board. Among those elected, were CCHCC Board Members, Mamie Smith and Louise White. Congratulations, Mamie and Louise!

Health Yes, Doctors No: People's Medical Society

How to achieve maximum health with a minimum of doctors and drugs? This question is being addressed by a new national organization called The People's Medical Society. Started earlier this year after a series of editorials in *Prevention* magazine, the group is designed to give people more control over and resources about their own health care and to improve the overall U.S. health care system. By doing so, the People's Medical Society is a rare blend of self-care and consumer advocacy in the health field.

"I am biased," states Robert Rodale, editor of *Prevention* magazine and chairman of People's Medical Society, "but I feel that health comes before medicine and the attempt to correct disease." Citing sedentary life-styles, poor eating habits, stress and iatrogenic ("doctor-caused") diseases as correctable sources of ill-health, Rodale says that prevention is the place to start. The People's Medical Society extends the concept of medical self-management from the individual to society at large. Rodale says that in order to save the medical system, "we need to create an umbrella of 'civilian' control. Doctors are not trained as managers, yet they play the dominant directing role now. The result is a kind of manage-

ment anarchy, without much direction and with almost no tie-in to the economic condition of society as a whole."

As Rodale indicates, the People's Medical Society has not given up on the medical profession; PMS simply wants doctors and medical administrators to subscribe to and practice consumer-oriented health care. Charles B. Inlander, Executive Director of PMS, has declared that "we are no longer going to tolerate being kept in the dark about our own health nor are we going to accept inconsiderate treatment. We expect the relationship between the doctors and ourselves to be an equal partnership." To that end, People's Medical Society has drawn up a 10-point Code of Practice that it believes should be the basis of the doctor/patient relationship. Inlander asks consumers to bring it with them to their next doctor's visit and discuss it with the doctor. If the doctor agrees with it, send the name to PMS and they will send the physician more information. In time they hope to publish a directory containing the names of those doctors who subscribe to the Code. The Code of Practice is printed below; for additional information or more copies of the Code, write to People's Medical Society, 14 E. Minor Street, Emmaus, PA.

CODE OF PRACTICE

As a PMS Code of Practice practitioner I will assist you in finding information resources, support groups and health care providers to help you maintain and improve your health. When you seek my care for specific problems, I will abide by the following Code of Practice:

Office Procedures

1. I will post or provide a printed schedule of my fees for office visits, procedures, testing and surgery, and provide itemized bills.
2. I will provide certain hours each week when I will be available for non-emergency telephone consultation.
3. I will schedule appointments to allow the necessary time to see you with minimal waiting. I will promptly report test results to you and return phone calls.
4. I will allow and encourage you to bring a friend or relative into the examining room with you.
5. I will facilitate your getting your medical and hospital records, and will provide you with copies of your test results.

Choice in Diagnosis and Treatment

6. I will let you know your prognosis, including whether your condition is terminal or will cause disability or pain, and will explain why I believe further diagnostic activity or treatment is necessary.
7. I will discuss diagnostic, treatment and medication options for your particular problem with you (including the option of no treatment) and describe in understandable terms the risk of each alternative, the chances of success, the possibility of pain, the effect on your functioning, the number of visits each would entail, and the cost of each alternative.
8. I will describe my qualifications to perform the proposed diagnostic measures or treatments.
9. I will let you know of organizations, support groups, and medical and lay publications that can assist you in understanding, monitoring and treating your problem.
10. I will not proceed until you are satisfied that you understand the benefits and risks of each alternative and I have your agreement on a particular course of action.

Business of Health Care

con't from pg. 3.

When introduced, Medicare reimbursed providers on a cost-plus basis. The government reimbursed whatever the hospitals and doctors charged for services without examining the justifications for these charges. Providers could, and did, include expenses for new building, new staff, new equipment, and even fees for union busting consultants in their bill to the government. Together with similar reimbursement systems utilized by private insurance companies, Medicare and Medicaid fueled what became known as the "spiraling cost of health care." As Richard E. Brown details in his book, *Rockefeller Medicine Men*, "Following the introduction of Medicare and Medicaid, hospital and physician fees rose each year at twice their previous rates of increase, and the cost of medical care in general rose twice as fast as inflation in the rest of the economy." Since 1965, inflation in health care has far exceeded most other commodities. In 1981, it was nearly triple the overall rate of inflation. In addition to raising costs of existing services, expenditures of federal dollars led to the rapid expansion of medical facilities and technological support services. "Hospitals felt assured that everything from automated blood-chemistry analysis machines (costing upwards of \$100,000) to computerized axial tomography (CAT) scanners (costing \$300,000 to \$750,000) could be paid for Capital investment per hospital bed rose three times as fast in the five years after Medicare and Medicaid began as it did in the five years before, reaching \$56,000 per bed on 1976 Expansion has resulted in as many as 100,000 excess hospital beds in the country, averaging about \$20,000 per bed in annual operating costs," reports Brown.

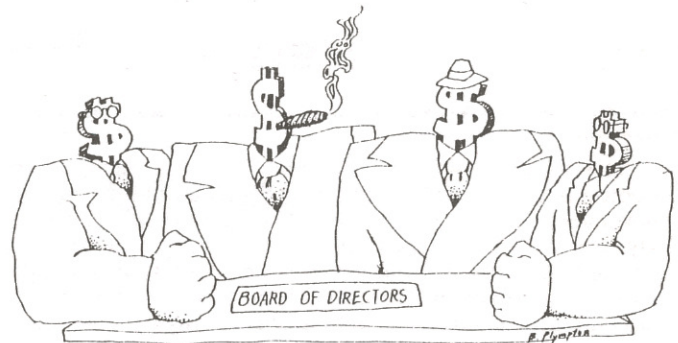
Supported first by philanthropists and then by the federal government and insurance companies, the U.S. Medical System has developed in the absence of cost constraints. The result has been capital-intensive services that are over abundant in some areas and non-existent in others. By the early 1970's, the federal government began to realize it had bought into a system which it could no longer afford. Initial efforts by the government to halt the rising cost and the maldistribution of services proved to be too little, too late. Federal regulatory agencies such as Health Systems Agencies (HSA's) and PSRO's were dominated by the professionals they were designed to regulate and given little or no power.

With cutbacks in federal and state funding and no one to turn to to support their excessive costs, medical providers find themselves with huge and unnecessary facilities and not enough patients to fill them or money to pay for them. As a result, the medical profession is facing competition. For them, it is a new phenomenon. A phenomenon that has left some in the medical profession worried, and others ecstatic. Unable to support the system as it is presently structured, the medical system in the U.S. is expected to go through a tremendous transformation in the coming years. Unfortunately, unless something is done, the pattern will probably mirror other aspects of the economy where the larger institutions buy up or push out the smaller, resulting in a tremendous consolidation of economic and political clout in the hands of a few. Institutions with the resources to weather

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a few. Institutions with the resources to weather the storm are ecstatic about the trend. For them, there is not only the certainty that they will survive—but that they will prosper. Institutions with limited service areas and resources are worried, and with good reason. Being smaller, these institutions will be more immediately affected by competition. Many will not have the financial cushion, nor the flexibility, to survive.

And where is the consumer in this scenario? In the short run, there will be benefits for some. For those with the money to pay for services, the competitive phase will allow them to have more input in the services they receive. Until recently, it was primarily physicians who dictated health care choices for consumers. Consequently, it was the physicians that were sought out in marketing studies and advertising for medical services. Now, with consumers selecting more of their own health care services and with competition for patients more keen, the medical profession is turning to consumers. The cover story in *Business Week* reports, "As hospitals diversify, they will have to learn management, planning and marketing techniques from the industrial world.... When the 722 bed Miami Valley Hospital in Dayton was recognized last year ... it used Madison Avenue style market research, involving in-depth consumer investigations to find out what its patients wanted."



PROFITS IN HEALTH CARE

As the medical profession turns to consumers in this phase of competition, so can consumers turn to the medical profession. With providers looking for ways to increase service utilization, it is the perfect opportunity for organized consumer groups to negotiate with providers. By recognizing the competition among providers for more patients, organized consumers can barter for expanded services, reduced costs, and other "needs" identified by consumers.

In Milwaukee, Wisconsin and several other cities around the country, senior citizens have negotiated expanded coverage under Medicare with local hospitals in return for utilizing their facility. Here in Champaign County, CCHCC has convinced local hospitals to provide "free and low cost care" to persons unable to pay, even after their federal Hill-Burton obligation has expired. In other communities that have organized health care consumer constituencies, groups have found providers more receptive than in the past.

There are some major drawbacks to the trends developing in the health care system. For example, most communities do not have organized health consumer coalitions. This minimizes the likelihood that local providers will help address community needs in an effort to bolster their own institution.

More ominous is the type of health care system that lies ahead if current consolidation trends continue. Whereas, competition is the catch word in the short run, it promises to be only a short term phenomenon.

In the long run, larger institutions will expand their service area, buying out or closing down smaller community-based health providers. This trend is already apparent in central Illinois, where rural hospitals have been shut down while institutions in the larger cities expand at an incredible rate. In time, consumers will have fewer choices available. Those health providers that do survive the consolidation process will be large, insensitive bureaucracies that are less accountable to local needs and concerns. When the competition is gone, these institutions will have little or no incentive to offer competitive prices or services.

AIDS—Whose Problem Is It?

7

Less than three years ago, no one had ever heard of AIDS. Today it is a household word, a disease feared by many Americans and considered a threat to public health. Because AIDS is such a new disease, it is not yet well understood by the general populace, or even by the medical profession. Gays, whose numbers include more AIDS victims than any other segment of the U.S. population, are particularly worried about the disease. They believe that AIDS research has progressed slowly precisely because most of its victims have been gay. But as AIDS strikes more people from outside the gay community, concern has begun to spread across the entire nation—and gays increasingly fear a backlash of repression that may cause them to lose many of the civil rights they have gained over the past decade. Just what do we really know about AIDS, and whose problem is it?

AIDS (Acquired Immunodeficiency Syndrome) is a serious medical condition in which the body's natural immunity to disease is severely impaired. People who suffer from AIDS are susceptible to a variety of illnesses that rarely strike people with healthy immune systems. Kaposi's sarcoma, a cancer of the blood vessel walls, and a particular type of pneumonia known as *Pneumocystis carinii* pneumonia, are two relatively rare diseases which are nonetheless common among AIDS victims. No one who has contracted AIDS has ever regained proper immune function, and the survival rate of those with the disease for two years is less than 10%. However, some scientists speculate that since we have no clear way to test for AIDS, those labeled as having the disease may only be those with the most severe cases, while others may have milder cases from which they may recover. No one knows for certain.

According to the Public Health Service, 1,922 cases of AIDS were reported in the U.S. between June 1981 and August 1983, resulting in 743 deaths. They state that although members of all races have been stricken, 95% of AIDS victims are male; about three-fourths of all reported cases have been of homosexual and bisexual males with multiple sexual partners, 17% of all cases involve intravenous drug abusers, 5% involve Haitian entrants into the U.S., and .8% involve persons with hemophilia. Most victims are between 25 and 44 years of age, although there have been instances of infants and older people contracting the disease.

Until recently, AIDS seemed to be a problem confined for the most part to the United States and Haiti. However, as of this November, people in 33 countries and all continents have fallen prey to it. Although the number of those stricken with AIDS abroad remains small, it is growing at an alarming rate. The number of AIDS victims in Europe has doubled in one year, just as it did in the U.S. after it was first discovered here. In the U.S., the number of cases has been doubling every six months, although some scientists think there is a possibility that the numbers may be levelling off. No one knows for certain if this is so—and if it is, no one really knows what it means.

One of the difficulties in understanding exactly how AIDS is transmitted is that the incubation period for the disease is quite long—from a few months to two years. The early symptoms of AIDS are much like those of a cold or flu: fever, night sweats, swollen glands, unexplained weight loss, diarrhea, persistent coughs, fatigue, loss of appetite. Anyone who has these symptoms persist over a long period of time should consult a doctor. As yet, there is no test to detect AIDS in blood, although researchers are working on satisfactory ways of screening AIDS victims.

Medical researchers have wavered in their opinions about the possibility of nitrite inhalants as causative agents, and cytomegalovirus, once a likely suspect, is now thought to be an opportunistic infection and not the cause of AIDS. Because it appears that the disease may be transmitted through sexual contact, blood transfusions, or contaminated needles, many scientists believe AIDS may be caused by a

virus in the blood and/or body fluids (such as semen). However, some of those who have contracted the disease do not appear to be in the so-called "high-risk" groups. In Haiti, 20-30% of AIDS victims are female, and in Africa the disease strikes men and women in equal numbers. Some researchers believe that this is so because of poor sterilization of needles in these areas but, again, no one knows for sure.

All of this uncertainty in cause and transmission has left the Public Health Service trying to find ways to contain the disease. This has put them at odds with the gay community, who fear that PHS's recommendations are an attempt at social rather than medical control of the disease, and that these may lead to gross violations of their civil rights. The Public Health Service's recommendations to avoid contracting AIDS are:

- 1—Avoid sexual contact with people known to have or suspected of having AIDS.
- 2—Avoid having multiple sexual partners and avoid sexual contact with those who do.
- 3—Members of high-risk groups should not donate blood.
- 4—Physicians should order blood transfusions only when medically necessary. Extreme care should be used when handling hypodermic needles.
- 5—Condoms should be used during passive anal intercourse, as this seems especially dangerous for contracting AIDS.

This issue of social control of AIDS is not a simple one. There is not at present any medical control possible, and a change of lifestyle is the only answer currently available for people in high-risk groups. But categorizing gays—and others—as members of "high-risk" groups has caused much turmoil. Members of the moral majority have declared AIDS to be God's just punishment for homosexual immorality, and Haitians have been stunned by an appalling economic blow as tourism, once their second largest industry, has suffered a severe decline. Scientists at the Center for Disease Control, who have been criticized both for bad science and bad social policy in their use of risk groups, have just recently quit using these categories in discussing AIDS. Besides the enormous problems such categorization created for those in the high risk groups, it also may have lured everyone else into a false sense of security about the possibility of their contracting the disease.

But even though these categories have been officially dropped, many gays believe that the damage has been done and will have unpleasant, long-term consequences. Richard Goldstein eloquently presented the gay community's fears in a recent article in the *Village Voice*:

It's only been about a decade since [homosexuals] were commonly subjected to arrest... We have every reason to fear a recurrence of that nightmare if America authorizes sexual repression in the name of public health. For gay people, the consequences of that repression are bound to extend far beyond the bars and baths. Since sexuality is seen as the basis of our identity, our freedom to work, live, and love as we please would be affected. The AIDS crisis for us is twofold, involving the threat of death and the loss of civil liberties.

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Information and Resources

The Public Health Service has a toll-free AIDS hotline open from 8:30 a.m. to 5:30 p.m. EDT daily. The number is 1-800-342-AIDS.

The Public Health Service also publishes a leaflet, updated as new information becomes available, called "Facts on AIDS." This is available free of charge by writing: Public Health Service, Office of Public Affairs, Room 721-H, 200 Independence Ave. S.W., Washington, DC 20201.

The National Gay Task Force has a crisis line in New York, (212) 807-6016.

The problem of social control is tied to gays' beliefs that the Public Health Service is not putting enough money or effort into finding a medical cure. The budget of the Public Health Service includes \$5-1/2 million for AIDS research in FY 1982, \$14-1/2 million for FY 1983, and over \$17-1/2 million for FY 1984, with an additional \$12 million already approved. This money is being used at Public Health research agencies, such as the National Institutes of Health and the Drug Abuse and Mental Health Administration in Washington, and by research centers around the country. Some public health officials believe that the current funding is all that can be used at present without encouraging a great deal of mediocre research, but other members of the Public Health Service believe that large numbers of scientists could be mobilized into AIDS research almost immediately, and without compromising the high quality of research.

Although there have been rumors to the contrary, no one in Champaign County has to date contracted AIDS. The local gay community is greatly concerned over this issue, and the Gay Illini are sponsoring a week of AIDS-related activities February 20-24. Dr. David Oster, a nationally recognized expert on AIDS from Howard Brown Clinic in Chicago, will be speaking the night of February 24. For more information, call the Gay Illini at 333-1187.

AIDS is not and should not be a problem confronting the gay community alone. AIDS is a menace to the physical well being of us all, just as it is a threat to our social well being if we allow it to be used to trample over the civil liberties of any American. As an issue that impacts all health care consumers, CCHCC will be working with other community groups, including the local chapter of Americans for Democratic Action, on AIDS in the coming months. We are tentatively planning a forum on the topic for late winter. Anyone interested in working with us on this project should contact CCHCC at 352-6533.

WHO WE ARE

Champaign County Health Care Consumers is an organization of local citizens concerned with improving health care delivery to all residents of our area. We are community-based and include representatives of women and minority groups, religious bodies and local elected officials, local businesses, labor unions and progressive provider organizations. We believe that health care is too important a matter of public concern to be left solely to those who provide it, and that major improvements will come only with the real involvement of consumers. Champaign County Health Care Consumers is funded largely through tax-deductible contributions of members and other local community residents. It is a not-for-profit, tax-exempt organization. For more information on becoming a member write CCHCC, 124 N. Neil, Champaign, IL 61820 or call (217) 352-6533.

WHAT WE DO

We focus on consumer participation, education, and action. Our public forums educate the general public on consumer health issues. Our leadership training workshops provide consumer leaders with knowledge and skills to carry out their responsibilities. Our newsletter helps keep consumers abreast of health care problems and emerging solutions. We work for responsible health planning and administration in accordance with federal regulations. We form Consumer Task Forces to address community health problems, currently emphasizing the problems facing low-income consumers and women. We have established a Consumer Health Hotline for residents who have questions, concerns or complaints about the local health care system. Finally, we publish The Doctors Directory for Champaign County.

Volunteers Needed

Since CCHCC began in 1977, most of the work accomplished by the organization has been done through volunteer efforts. In addition to our task forces, CCHCC has a number of other projects that are dependent upon volunteer input. A sample of our volunteer projects are listed below. If you're interested in one of these or would like to discuss other ways you can work with CCHCC, call us at 352-6533.

• Education and Media Program Volunteers

Volunteers are needed to work with CCHCC's Education and Media Committee. Working with the committee, volunteers will coordinate CCHCC's on-going series of community forums and plan publicity campaigns for the organization. If you've had any experience working with the media, or are interested in health education, you'd be an asset to the committee. Position will require monthly meetings and a few additional hours of work a month.

• Dr's Directory Editorial Assistant

CCHCC is beginning work on our third edition of the *Dr's Directory for Champaign County*. The Dr's Directory includes information on local physicians' fees, practices and philosophy as well as features on consumer health topics. In the third edition we hope to expand the types of providers listed and the topics of consumer health covered. Volunteers are needed to assist with: developing questionnaire; gathering lists of physicians by specialty; researching and writing consumer health sections; and collating, mailing and following up on surveys. Requirements for volunteers—none, except a commitment to volunteer at least four hours per month.

• Health Hotline Advocates

Help! We are being swamped with calls and our Health Hotline has a backlog of cases. Attend our upcoming Health Hotline Training Session on Sat., Feb. 11 from 10:30-3:30 and Mon., Feb. 13 from 7 to 9 pm. Once a trained advocate, you can help local consumers resolve complaints with physicians, insurance companies and clinic billing offices. In the process, you'll learn a lot about the local and national health care system. Advocates need to have a home phone and be good at working with people. Time required is about 2 to 4 hours a week.

CHAMPAIGN COUNTY
HEALTH CARE CONSUMERS
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