# SCIENCEFOR PEOPLE

# Cracking the Medical Establishment

\$2.00 Vol. 14 No. 6



Radical Therapy DES Feminist Health Clinic Racism in Medical School

## about this issue

"...the medical profession and social responsibility seem to be anathema to one another . . . medicine is more about status and prestige . . . " by Rod Toneye

Why another *SftP* issue on health care? We've maintained in the past that health care services and medical practices in the U.S. tend to be more sickening than health-promoting. We've argued that the underlying reason is that in our society goods and services are produced for profit rather than human needs, thus the struggle for a different economic system is fundamental to the protection of our health.

In this issue we proceed from this economic basis to focus on 1) the problems of elitism and the monopolization of health care by the U.S. medical system, and 2) the solutions—political activism and the creation of people's alternatives. We discovered that the articles illustrate the need to come to grips with the connection between the personal and the political, and with the complex interaction of external and internalized oppression. Understanding these relationships will not only help us to secure better health care in the near future but is essential to our overall struggle for a new society.

Alan Berkman's letters about the use of torture and health services to attack revolutionaries and the role of grand juries in the process speaks for itself (just read it).

Patricia Sipe's account of the DES tragedy demonstrates the hegemony of the medical establishment and the collusion of drug companies and the FDA. She makes a compelling case for our participation in medical research and the formulation of health policy.

Like Patricia Sipe's article, Patricia Parsons' discussion of radical therapy stresses the relationship between the personal and the political. Radical therapy is not merely an alternative to present mental health care. It questions the very definition of normalcy and the causes of "mental disorders." By illuminating the interactions among the personal, the political, internalized oppression, and external oppression, radical therapy gives us additional tools for political struggle.

Rod Toneye draws from his experience as a black medical student to detail the multiple ways in which institutionalized racism operates in the training of health professionals. He shows how elitist and racist attitudes within medical schools and the medical profession limit the opportunities and choices of many black health professionals. Toneye's analysis reminds us that as long as medical care is left in the hands of white professionals, it will serve only the privileged few.

Bonnie Kay and Carol Regan present a case study of successful feminist health activism in Chicago. Through collective action and political organizing, women were able to revamp elective abortion services to meet consumers' needs—needs that were not being properly met under the values and practices of the medical mainstream. Although the activism centered around the unique issue of abortion, it has practical implications for gaining access to health care services in general.

The stress on women-related issues, though not intentional, is probably not accidental either. Health care services to women epitomize the paternalism and elitism of present medical practices. Furthermore, using the organization and group processes of the feminist movement, so crucial to the left as a whole, women have been particularly effective in creating alternatives to the present health care system.

#### **UPCOMING ISSUES OF SFTP**

The SftP Editorial Committees are now finishing the articles for the Jan/Feb 1983 special issues on "Towards a Science for the People." This thematic issue will celebrate volume 15 of the magazine and will articulate our vision of a people's science.

The East Bay Editorial Committee is now soliciting articles for the March/April 1983 issue on "Technology and Repression."

Please send all articles, outlines, graphics, and other material to: Science for the People, 897 Main St., Cambridge, MA 02139. To contact the East Bay Committee write Science for the People, Box 4161, Berkeley, CA 94704.

## SCIENCE FOR PEOPLE

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## letters

#### U.S. JUSTICE— A CASE OF MALPRACTICE

In late May, Alan Berkman contacted us about writing an article for this issue. As he says in his letter, he was unable to obtain all the information he needed to complete the article in time for our deadline. However, we felt that the issues he raised were pressing, so we are publishing his letters now. An article by Berkman about the use of torture on political prisoners, the complicity of doctors with such practices, and the role of the grand jury is planned for a later issue.

#### Dear SftP:

I've been a practicing physician for the past ten years in communities such as the Lower East Side and South Bronx in New York City and in Lowndes County, Alabama; I've been a political activist for considerably longer.

Stemming from both my medical and political commitments, I have seen a number of political prisoners over the past ten years. This includes people from Attica: Lolita Lebron, Andres Figueroa Cordero, William Morales, Dacajawea. I was at Wounded Knee as a doctor in 1973.

Recently, I saw two of the people arrested after an attempted expropriation of a Brinks truck on October 20, 1981 in Nyack, New York...I was asked to see them by their respective lawyers. [One] was captured on October 20th and had his neck broken by Rockland County Sheriff's officers during interrogation sessions sometime between October 21-26. Officials, including prison doctors, steadfastly maintained he was fine although his lawyers and family could clearly see he was both in great pain and was experiencing loss of strength in his lower extremities and paraesthesias. Even after Xrays definitively demonstrated a broken cervical vertebra, the local District Attorney and prison officials (including the doctor) refused to hospitalize him. Only intense outside pressures forced his transfer to a hospital where he underwent an emergency spinal fusion. I was involved in seeing him, exposing in court what had occurred, and in getting him adequate care.

I also saw [the other], who was tortured in a very classic fashion by the FBI. He was burned by cigarettes, his toenails were pulled out, and he was beaten to the point where his pancreas was partially destroyed and he was hospitalized for 14 weeks. Through his lawyer...he immediately made this public; the FBI denied it. His hospital records, which I had the opportunity to see, totally verified [his] story. I wrote an affidavit to that effect that was used in court to win guarantees of decent health care.

I think these events in and of themselves warrant attention from progressive people. In particular doctors' complicity is an issue in the entire world medical community (Chile, Steven Biko's death, Nazi Germany). Clearly it needs to be an issue here.

The other development in this case, though, involves me directly. On May 11, two agents from the FBI/New York Police Department Joint Terrorist Taskforce visited my office at Lincoln Hospital. They wanted "any information I might have" and variously threatened to revoke my license, destroy my career, and imprison me if I refused to cooperate, or they would give me "all the money I wanted" and change my identity if I would cooperate. When I refused to talk to them, they subpoenaed me to a sitting grand jury.

I refused to collaborate with the grand jury, a position I believe all progressive people should take in the face of increasing use of the grand jury against progressive movments. As a result, I am now imprisoned at the Metropolitan Correctional Center for 18 months.

I would propose writing an article about the various issues raised by this case for progressive health workers for your November/December issue. I believe it could be both interesting and important.

#### Dear SftP:

I'm very sorry for not getting back to you earlier. I got involved in preparing my own appeal (a waste of time) and let my other resonsibilities slip. I apologize for any problems it has caused in planning the November/December issue.

I did take a fling at a fairly detailed outline of an article based on the sketchy outline I had developed. I found that I lacked the information necessary to go from my personal experiences to a more general argument. I've since sent away to Amnesty International for information from the Torture Research Group. If it is possible, I would definitely take a raincheck on the article and will continue to work on it.

I found the issues of *SftP* very interesting. I used to read the magazine regularly a number of years ago but had seen it only sporadically over the past few years. It stimulated some long-latent thoughts I've had about my own experiences...in poor Third World commmunities, and perhaps now I'll have a chance to develop them. If it's possible I would definitely like to continue to receive issues of the magazine.

Through some effort and some luck, I've managed to transfer to a new unit. While it's actually a little "hotter"—more fights, etc.—than my previous unit, it has the distinct advantage of having two other comrades who are here for contempt of political grand juries....a Puerto Rican indepentista and trade union leader found Fred Landis' article on CIA Psychological Warfare very helpful and immediately related it to his own experience in Santo Domingo in 1965.

Being with two friends has been very important for me in developing a constructive pattern to my days. We exercise for at least an hour every day, run on the roof (there's no yard) a few times a week, and do formal study together twice a week. While it's clearly not the way I would choose to spend my time, I do hope to make it a positive period—including doing the writing I want to...

I sincerely appreciate your concern, and I will try to follow through now that the legal rituals are done with, and it's definite I'll be here until November 1983. If you have any books that you're sent by publishers that you would not normally keep and would like to send them to me, I would like that.

I would like to maintain some contact. I'll work on my article and will send it to you as soon as possible.

Alan Berkman, M.D. #04582-054 Metropolitan Correctional Center; 7N 150 Park Row New York, NY 10007

#### **BIOLOGICAL WARFARE**

Dear SftP:

The recent article by Alexander Hiam on biological warfare (SftP, vol. 14 no. 3, pp. 32-35) gives the impression that, with the help of recent advances in biotechnology, scores of remarkable new biological weapons are within the grasp of the military. His approach, "biological warfare agents could be almost anywhere attacking anything," is certainly scary and gets attention. One reader seriously asked me what SftP meant by giving such great ideas to the Pentagon! But most of Hiam's scenarios for new biological warfare agents have only the flimsiest scientific basis.

The idea of a bug to destroy enemy oil supplies is genuinely ludicrous. The bacterium that was designed, publicized, and even patented for degrading oil slicks has never been practically useful. Its invention popularized the notion that the world's oil supplies could be gobbled up by a bug gone out of control. In fact, there are an enormous variety of naturally-occurring microbes that digest oil. They can proliferate only in water, but feed where oil is floating above. Many precautions have been developed by the oil industry to retard their growth, especially in large oil tanks which contain water.1 The bacteria do not swim in the oil. digesting it as they please, and not even a genetic engineer could overcome this physical impossibility. New bugs of military value to attack rubber, or plastic, or the bottom of ships, are equally unrealistic. By ignoring practicalities, Hiam makes the future of BW research sound like science fiction.

What about designing new diseasecausing microbes? The new organism must not only be deadly, it must also be transmitted effectively to other victims. For example, Escherichia coli, the intestinal bacterium, already kills thousands of malnourished infants by diarrhea and dehydration. In fact, by causing diarrhea it spreads more widely. The E. coli could also be engineered to carry a gene for some insect, plant, or microbial toxin, but then would be very unlikely to survive and spread as well or better than the unencumbered original strain. This is probably the biggest problem in BW research.

There are probably some very practical reasons for the U.S. military interest in BW research which Hiam docu-

ments. One might be to classify strains of a particular disease organism by aspects of its genetic structure in order to know which corresponds to the most ineffective or deadly. Strains of bacteria can change their properties if grown at length in the laboratory, and there is no guarantee that ones isolated years ago have not changed. This is undoubtedly a big headache for biological weapons specialists.

The military claims that its research is for defensive purposes, only. This dubious statement must be exposed along with the foul history of U.S. work in this area: for example, the U.S. gave amnesty to Japanese military personnel who carried out human BW experimentation in prison camps during World War II, in return for exclusive access to their data. With more hard information and less speculation, we can start to build public and scientific opposition to the growing military research on biological weapons.

Scott Thacher Cambridge, MA

#### REFERENCES

1. J.B. Davis, Petroleum Microbiology. New York: Elsevier Publishing Co., 1967. 2. R. Gomer, J.W. Powell, and B. Roling, "Japan's biological weapons: 1930-1945." Bulletin of the Atomic Scientists, vol. 37, no. 8, 1981.

#### ANIMAL USE IN RESEARCH

Dear SftP:

Tests need animals—or do they? Humanity, acting on this first premise has condoned the yearly suffering and death of millions of nonhuman animals in the name of scientific progress. What AMRAE (Advocates for the Moral Reevaluation of Animal Experimentation) is objecting to is not the occasional, legitimate use of some animals for research purposes where substantial gains to animal health (human and nonhuman) could be immediately realized; but rather the finality and immutability of the researchers' mindset which precludes them from even envisioning a day when nonanimal substitutes may replace many of the current animalusing tests. As evidenced by U.S. House Subcommittee Hearings this past October, the public is beginning to question the necessity of much scientific experimentation as well as the role

alternatives could play in reducing animal suffering if only actively encouraged.

Of the 100 million animals subjected to research in the U.S. annually, it is estimated that as much as two-thirds of this is nonmedical. Even if we were to consider only the best experimentation, i.e. that involving medical research, there is still much which remains open to question.

Cancer research exemplifies this misdirection of priorities. Since the "War on Cancer" was declared, we have expended \$7 billion and millions of animal lives in exchange for a prognosis which today (for the most common forms of cancer—those affecting 85% of the individuals with this diagnosis) is no better than it was 25 years ago. The incidence of cancer has increased from 1 in 20 at the turn of the century to one in three, according to statistics by the National Academy of Sciences. As for the direction of funding, despite estimates that as much as 85% of cancer is environmentally related, less than 3% of the \$100 million budget spent annually for research is directed towards this area.

Employing the standard animal model, it is estimated that it would take 25 years to test the chemicals currently on the market; and yet nearly 1000 new chemicals are introduced yearly. If one considers synergism (the combined effect of chemicals, e.g. nitrates from hot dogs, ham, bacon, etc. when combined with substances containing amines—tea, wine, beer, cigarettes, cereal, Librium, from nitrosamines—one of the most potent carcinogens known) the problem is further compounded. In addition, the Reagan administration under the guise of deregulation is opening the doors to increased pollution of air, land and water in exchange for short-term commercial profit for a few. With hazardous chemicals vying for the distinction of becoming the number one health problem of the 1980s, it seems clear that decreasing the incredible proliferation of new chemicals will do far more for reducing morbidity and mortality from cancer (by decreasing its incidence) than all animal testing.

Asking for analysis and evaluation of the current health care system is not tantamount to standing in the way of progress or endangering the lives of humans. We are spending an incredible sum for medical care. Has this been a good investment?

As in many fields, prevention (and health maintenance) is far more cost effective than (disease) treatment; and yet, preventative medicine remains the Cinderella of the medical specialties. It is time we asked ourselves whether the major killers in this country—coronary artery disease, strokes, cancer, accidents, cirrhosis, etc.—could be more effectively addressed through prevention.

And yet our approach to health care remains characterized by doing too much too late. For the most part, research is oriented towards searching for a commodity—a drug or treatment—which can then be sold to a gullible public. Rather than informing the public that through proper weight, vegetarian diet, exercise, reduction of stress and refrainment from cigarettes, alcohol and other hazardous chemicals, they could play a crucial role in preventing disease in themselves and the subsequent dependence on the medical establishment which it entails.

The medical community has done an incredible job in the diagnosis and treatment of selected disease states; let us now see how effectively these energies can be channeled into the maintenance of health.

We have learned a great deal through past animal research about many environmental and lifestylerelated sources of illness; now it is time for us to pass from the phase of data collection into the phase of decisionmaking, integrating what we know into a positive approach to life and health, cleaning up our environment and transforming our society along more sensible lines. As we see it, the animal rights movements, by refocusing attention on the value of life and all living things, can only be of positive benefit to the health of humankind as well as the rest of the animal kingdom.

Holly Jensen
AMRAE (Advocates for Moral
Reevaluation of Animal
Experimentation)
10830 SW 86 Ct.
Gainesville, FL 32601

#### SFTP-A REAL GEM

Dear SftP:

When someone first showed me SftP magazine when I was a physics student at the University of California at Berkeley, I thought "whoa, this is just a bit much for me." Now I embrace

SftP as my own. I dropped out of school because science, as I saw it, and politics were incompatible. Now I look forward to returning some day to science work with a full awareness that politics are part of science and science can be part of politics, part of "revolutionary" (excuse the use of that overused, heavy connoted word) politics. Thanks for helping me in my political development.

The last issue I received on, "Women Challenging Science Challenging Women" was a gem. Every single article, including the introduction, was useful. I've shown it around and "hyped" it to lots of people including my mom. She took that and the book

Science and Liberation and devoured them both, cover to cover.

Right now my commitments are mostly in draft resistance. In the future, they may be with SftP-type work. Until then, keep up the good work; I'll keep reading SftP.

Paul Trudeau Berkeley, CA

We welcome letters in response to *SftP* articles or on topics of current concern. All letters should be typed and include a name and address. Send them to Science for the People, 897 Main St., Cambridge, MA 02139.

### A Thoughtful Gift

# Give your friends a Science for the People book!

#### Science and Liberation

by Rita Arditti, Pat Brennan and Steve Cavrak, 1980.

A collection of 20 essays on the role of science and scientists in the modern world.

\$6.50 plus 75¢ postage.

#### Feed, Need, Greed

by the SftP Food and Nutrition Group, 1980.

An alternative curriculum on food, resources and population. A classroom-tested tool full of facts, graphics and exercises. \$5.00 plus 50¢ postage.

#### Biology as a Social Weapon

by the Ann Arbor Science for the People Editorial Collective, 1977. A compilation of critical pieces on the theories of biological determinism (sex roles, IQ, and aggression). \$7.95 plus 75¢ postage.

#### The Sociobiology Packet

by the Boston Sociobiology Group. Newly revised 1980.

A packet of eight articles which puts together the analyses of sociobiology's most critical opponents. This is a must for anyone interested in this contemporary debate. \$4.00 plus 60¢ postage.

Order your books today in time for the holidays!

SftP members are entitled to a \$1.00 discount on any book listed above, and a 50¢ discount on the sociobiology packet.

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# news notes

## RECOMBINANT DNA AND BIOLOGICAL WEAPONS

Two members of the National Recombinant DNA Advisory Committee to the National Institutes of Health and former activists with Science for the People, Richard Goldstein and Richard Novick, urged their colleagues on the committee to pass a resolution prohibiting the use of recombinant DNA technology for developing biological weapons. The two scientists suggested that such a use is "the most serious biohazard imaginable for this technology." (See A. Hiam, Science for the People, vol. 14 no. 3, p. 32.) However, apparently other members of the committee did not take this issue too seriously as the resolution was overwhelmingly defeated. David Baltimore of MIT, formerly an outspoken opponent of chemical and biological weapons, offered the lame excuse that passing the resolution might have implied that existing international conventions did not prohibit such developments already.

Unfortunately, this refusal by the Committee to take a stand comes at a time when there is increasing evidence that the U.S. government is planning a substantial expansion in its biological warfare research with particular interest in recombinant DNA (Nature, June 24, 1982). The Army requested the National Academy of Sciences to carry out studies on chemical and biological warfare including possible offensive uses of recombinant DNA technology. The Academy rejected that portion of the request relating to biological weapons. There are also reports that the Army has requested hundreds of millions of dollars for such research.

One of the areas most likely to be pursued by research supported by the Army will be the use of the new technology to develop vaccines against biological weapons already prepared by other approaches. In this way an invading U.S. Army could be made immune to various disease agents which have been spread among an enemy army or population. This was con-

firmed in a recent interview with Colonel Richard Barquist, head of the Army Medical Institute of Infectious Disease (New York Times, September 7, 1982, p. A12). Barquist commented, "We're involved in medical defensive research," and pointed to the advantages to be taken of the "technological wave sweeping through bio-medical research."

#### **FERTILITY STUDY FIZZLES**

The publicity generated by a study on female fertility in the February 18 issue of the New England Journal of Medicine has led to considerable panic among women planning to put off child-bearing until their thirties. This panic was fueled by newspaper headlines such as, "Study Finds Female Fertility Drops After the Age of 31' and "Women Reconsider Childbearing after 30." French researchers showed, using artificial insemination on normally fertile women with sterile husbands, that the success rate for pregnancy was 74% in the women under 30 years of age, 61% for those 31 to 35 and 54% for those over 35. Because artificial insemination was used, the authors themselves were very cautious in extending their conclusions to natural intercourse.

However, in an editorial in the same journal, the conclusions were taken much further. It was pointed out that "the changing roles of women" had led to an increase in the delay of 'child-bearing until their thirties in exchange for career development." It was then suggested that the results of this study indicate that "individual and societal goals may have to be reevaluated." In other words women should return to having children in their twenties and put off their careers. It was the wording of the editorial which led to the subsequent press and media interest.

In response to the publicity, numerous letters pointing out the unwarranted nature of the conclusions were published in the New York Times (Mar. 14, 1982) and The New England Journal of Medicine (August 5, 1982). According to letters written by two members of Science for the People, "artificial insemination is known to give lower pregnancy rates." The authors described how studies have shown that the lower success rate seen

in the French study may simply be due to the longer time, on the average (about 2 months!), that it takes women in their thirties to conceive. They suggested that the attitude in the editorial and the subsequent publicity "may derive more from concerns with the changes the women's movement has brought than from any new insight into problems of fertility."

Another letter described a Wellesley College study which showed that couples, who became parents early in life, later on wished they had delayed in order to develop as individuals and couples. A Princeton researcher stated that the editorial did a "substantial disservice by misinterpreting the results" and a registered nurse from New York wrote that the reports struck her as a "rather insidious variation on keep 'em barefoot and pregnant."

The rapid response to this latest attack on the women's movement led to numerous articles in the press and to radio interviews correcting the original unwarranted conclusions. Writing letters to the press sometimes helps!

#### SCIENTISTS AND PENTAGON CLASH

Scientists and military authorities clashed this August at an optical instrumentation conference held in San Diego, CA. Only days before the conference began, the Pentagon sent warnings to all participating Department of Defense (DOD) contractors that defense related papers must be cleared by the DOD. Although the warning was consistent with official regulations it caused chaos during the conference—including the withdrawal of over 100 scheduled papers—and anger in the scientific community. An editorial in Science called the DOD's action a "raid" and a "humiliation," and suggested that it might indicate an "emergent tilt [of the DOD] toward reliance upon preemptive powers.'

—Information from Science, September 24, 1982, vol. 217 no. 4566, pp. 1232-1233

#### **GENES ON THE JOB**

Approximately 59 major companies indicated that they may start genetic screening of workers within five years. This information was revealed as a result of a survey by the Congressional Office of Technology Assessment. The

survey showed that 17 companies have admitted to already using genetic testing in the past five years. Unions did not respond to the questionnaire because, according to James English of the United Steel Workers, "they didn't know what genetic screening is all about."

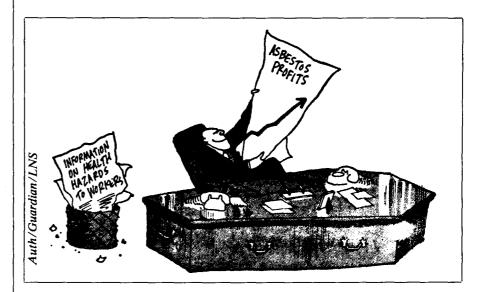
The screening programs are supposed to detect workers who are more susceptible to occupational diseases caused by workplace pollutants. (See J. Beckwith, "Industrial Genetic Screening." Science for the People, vol. 12, no. 2, p. 20.) However, according to Science, scientists in general believe that the screening tests are "arbitrary... and...not very predictive." Furthermore, union activists such as Anthony Mazzochi of the Oil, Chemical, and Atomic Workers' Union fear that the testing has the "potential for discriminating against certain workers." He is also concerned that the screening "approach can be used to shift occupational health concerns away from the workplace and place the blame for illness on the worker's faulty genes.'

—Information from The New York Times, June 23, 1982 and Science, July 23, 1982.

#### JOHNS-MANVILLE TRAGEDY WAS AVOIDABLE

In late August, the Johns-Manville Corporation, the major producer of asbestos in the U.S., filed for Chapter 11 bankruptcy as a way of avoiding a growing number of workers' injury claims. In full-page ads featured in newspapers across the country, the Manville Corp. claimed it was innocent in what has become "...an unexpected occupational health catastrophe..." Yet, evidence that asbestos is dangerous has been available for years.

Since the early 1900s it has been known that exposure to asbestos causes lung diseases, and the industry can hardly claim to have been unaware of this. An industry-sponsored study conducted by the Metropolitan Life Insurance Company in 1929 found evidence that more than half of a group of exposed workers, many employed by Manville, had some degree of asbestosis, a debilitating and often fatal respiratory disease. In fact the first death due to asbestos exposure was reported by 1900, and by 1918 some insurance companies would no longer sell life insurance to asbestos workers.



The first scientific article linking asbestos to lung cancer appeared in 1935 in a journal published by the American Association for Cancer Research. By 1960, more than 60 papers had been published relating asbestos exposure to asbestosis, lung cancer, and other diseases. Hundreds of papers have followed since.

Reminiscent of the Watergate scandal, the issue of who in the industry knew exactly what and when has been a major subject of contention. If the companies involved had been able to show that they could not have foreseen the health risks of asbestos, they would be in much less trouble—both financially and legally—than they now appear to be.

Some of the suits against Manville, citing corporate papers from the 1930s (the so-called Sumner-Simpson documents), allege that major firms in the industry actively conspired to suppress information about asbestos hazards from both workers and the public. Commercial Union Insurance of Boston has used this contention as a basis for rejecting insurance liability for Manville workers.

Furthermore, even as late as the 1960s, companies refused to cooperate when scientists researching asbestos-related diseases sought company medical and employment records. At that time Dr. Irving Selikoff, the now renowned asbestos researcher, was denied access to the worker health records of several asbestos companies. He eventually used union records to assemble the final proof of the massive cancer hazard posed by exposure to asbestos.

During this period workers were often unaware of the risks, and even misled. One asbestos worker in an infamous plant in Tyler, Texas, said, "...I can remember some of our supervisors saying it not only wouldn't hurt you but was good for you! They even used to tell us you could eat it!"

The acrimony over asbestos and other hazards has arisen not only because of the magnitude of the human health disaster that has occurred (estimated by Dr. Selikoff to be 10,000 deaths per year), but also because those in positions of authority and knowledge misused those positions. Workers had the right to expect protection from avoidable risks and an honest disclosure of the risks that were considered unavoidable. Had Manville heeded the early evidence of the health hazards and adequately protected its workers, perhaps it wouldn't be in its current legal entanglements, and, more important, perhaps countless lives could have been saved.

Representatives of the Manville Corporation could claim that its current predicament is an unexpected economic catastrophe, but it cannot claim that the outcome for the unfortunate workers exposed to this insidious material was "an unexpected occupational health catastrophe."

—Edward L. Leochler
Toxicology Program, MIT
Jonathan Beckwith
Harvard Medical School
Jonathan King
Dept. of Biology, MIT
—Adapted from a letter to the editor
which appeared in The Boston Globe
September 17, 1982.

# THE WONDER DRUG WE SHOULD WONDER ABOUT

#### by Patricia Sipe

DES—"The wonder drug you should wonder about." We began to hear about DES in those terms after 1971, when a rare form of vaginal cancer occurring in young women was linked to the drug DES (diethylstilbestrol, or simply stilbestrol) their mothers took while pregnant. We should wonder, and there is more to wonder about than this link with cancer.

We should wonder what side effects it causes in the mothers who took it and in their offspring (sons as well as daughters) and what effects remain to be discovered. We need to raise questions about the drug companies that marketed an inadequately tested drug, using millions of women as guinea pigs. We need to raise questions about the Food and Drug Administration (FDA) that approved the drug, relying on the drug companies themselves to provide evidence of the drug's safety. We need to raise questions about a health care system in which the drug was widely prescribed despite evidence that in preventing miscarriage (the major purpose of its use in pregnant women) it was no better than a placebo\*. (See the accompanying glossary for definitions of terms marked with an asterisk.) We need to find answers to these questions, to act to ensure care for the exposed, and to learn the lessons of this important medical fiasco.

There are literally millions of DES-exposed people who are starting to ask these questions, and finding answers—piecing together the complicated DES story. Although estimates vary, the women who took the drug while pregnant, the DES mothers, are thought to number as many as three million. There are about 2 million sons and 2 million daughters who were exposed in utero\*. We now struggle with the various aspects of our exposure—sometimes individually, at other times collectively; sometimes focusing on our own medical problems and emotional reactions, sometimes denying our

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experiences, and at other times focusing on political analysis and action. Sometimes we act with exposed and nonexposed friends and family, and sympathetic health professionals; at other times, we act alone.

I am a 29-year-old DES daughter, and this article is part of my own effort to fit the pieces together.<sup>2</sup> As an exposed person, I know the need for reliable, accurate, up-to-date information on which to base decisions about health care. The medical establishment does not provide us with this information, and the popular press tends to print anecdotal and often sensationalistic accounts. The more we learn, the better we understand why it has taken us so long to fit the pieces together. The history of DES is an incredible series of blunders, collusions, and cover-ups on the part of the drug companies, researchers, health professionals and the FDA.

I have only recently (and with difficulty) begun to integrate the DES issue into my political activities. My understanding and analysis of DES exposure is necessarily rooted in my own experience. The last portion of the article is devoted to a discussion of the insights I have gained from my own background and an attempt to draw out more general political implications. This article is itself part of a process which has already involved many people. Although the friends who have contributed to it are too numerous to mention individually, I especially want to thank the women I worked with in DES Action, and the members of the Science for the People Editorial Collective (Ann Arbor) who supported the project from beginning to end. It will be a welcome continuation of this process if the article stimulates discussion and responses from people involved in various political activities, and not only those with a particular interest in DES.

#### History

In 1938, two Harvard doctors, Dr. Olive Watkins Smith and Dr. George van Sichlen Smith, began to administer natural estrogens to pregnant women. This approach was based on an earlier discovery that estrogen and progesterone levels decrease prior to complications in pregnancy and prior to miscarriages.

DES is a synthetic compound which in many ways acts like the natural hormone estrogen, but DES began to be used to prevent miscarriages and complications of pregnancy because it behaved differently than natural estrogen, in that it could,

allegedly upset and bypass the balancing effect of the pituitary...it appeared to stimulate the body's own production of progesterone, which is necessary to sustain pregnancy.

Sir E. Charles Dodd, whose work was funded by the British government, first synthesized DES in 1938. It was soon manufactured and marketed on a broad scale. It was inexpensive and could be administered in oral form, because unlike natural estrogen it is not destroyed by gastric secretions. For these reasons, DES was enthusiastically received by the medical community.

As early as 1938, the same year it was synthesized, the safety of DES began to be questioned. In that year, it was shown that animals exposed to DES develop breast cancer. 4.5 Results of other toxicity tests were published the same year, and throughout the 1940s.

In 1948, Dr. Olive Smith published a report<sup>6</sup> based on the observations of 117 physicians who had administered DES to a total of 632 pregnant women. She recommended DES therapy for pregnant women who had previously had miscarriages, women with high blood pressure, and as a preventative measure to protect against complications of pregnancy.

These recommendations initiated the extensive use of DES to prevent miscarriages; many women were given the drug at the first sign of spotting, if they had previously miscarried, or if they had trouble conceiving. Meanwhile, others were raising questions about the efficacy as well as the safety of the drug. The studies that formed the basis of the 1948 recommendations were carried on without controls, (that is, there was not a similiar group of pregnant women who were not given DES but who received similiar care in other respects). Some began to wonder whether the Smiths' favorable results could be due to the extra care and attention their patients received.

Controlled studies were undertaken by J.H. Ferguson<sup>7</sup> and W.J. Dieckmann<sup>8</sup>, working at Tulane University and the University of Chicago Lying-In Hospital, respectively. Ferguson, in the fall of 1952, gave DES to 200 pregnant women, and compared them to 200 pregnant women receiving placebos. His results were that the DES group had a slightly *higher* rate of miscarriage. Soon Dieckman published the results of his Chicago double-blind study. (Double-blind means that neither the doctor nor the patient knows who is receiving the drug and who is receiving the placebo.) The patients participating in the study were told that the tablet

might help prevent pregnancy complications, and that they would not hurt the woman or her baby. His results also showed that DES was no better than a placebo in preventing miscarriage, and that DES may even be conducive to premature labor.

The Smiths' reaction to the Dieckmann report was to reaffirm their conviction that DES had "saved many babies." In another (1954) paper, they recommended commencement of DES treatment in high-risk cases as soon as the woman became aware of her pregnancy. Their contention was that DES would even "make a normal pregnancy more normal." The Smiths refused to attribute any significance or validity to the Dieckmann study.

Many women continued to receive DES therapy during the 1950s. In the 1960s, as the studies showing that DES was not effective gradually seemed to have an impact, and other drugs became available for the same purposes, the use of DES declined greatly. However, DES continued to be used for this purpose until and even *after* it was contraindicated by the FDA in 1971, when the link with cancer was established.

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#### Link To Cancer In Humans

From 1966 to 1969, eight young women in Boston, between the ages of 15 and 22, were treated for a rare form of vaginal cancer known as clear-cell adenocarcinoma. Until this time, only three cases of this cancer had ever been reported in such young women in all of the world's medical literature. Drs. Arthur Herbst, Howard Ulfelder, and David Poskanzer' undertook a study to find the cause of this cancer. They ruled out factors such as douches, tampons, contraceptive pills, and sexual activity. "Finally," they reported, "one of the mothers made an intuitive guess that the cause might be the DES she was given during pregnancy."10 The researchers were soon able to confirm that seven of the eight mothers of these girls who had developed this cancer had taken DES during their pregnancies. Soon other cases of the disease began to appear, and nearly all of the young women had been exposed to DES in utero.

Estimates were made of the extent of the drug's use; since it was so widespread, more cases of this can-

cer could well be expected to appear. By the end of 1971, Dr. Herbst and Dr. Robert Scully had established a registry to gather as much information as possible on all known cases of this cancer in women born after 1940.11 Within two years there were 170 cases included in the registry; there are now over 420.

By reviewing these cases, researchers have observed that the incidence of cancer rises sharply after age 14, peaks at 19, then falls thereafter. The generally accepted estimate is that the risk (through age 24) of DES related adenocarcinoma is between 0.14 per 1000 exposed and 1.4 per 1000 exposed. Since it is not mandatory to report cases of adenocarcinoma to the registry, this estimate is subject to undercounting. However, the rate is much lower than originally feared<sup>12</sup> and this knowledge is quite reassuring to the many exposed women. Still, since the oldest DES daughters are now in their late thirties, many questions about the later effects of DES remain unanswered.

Study of the registry cases also provided the information that this risk is greater for DES daughters whose mothers took the drug earlier in pregnancy. (In humans, the vagina begins to develop in the second month of pregnancy and is completed by the twentieth week.) In 1980, there were 400 patients in the registry whose follow-up records could be obtained. Of these, 79 (about one in five) have died. As with many types of cancer, survival rates are higher among those whose cancers are detected in the early stages.13

#### More Side Effects Of DES

Although adenocarcinoma has received the most attention, there are many other side effects of DES. Only an outline of the range of side effects on DESexposed daughters, sons and mothers is possible here; those interested in detailed information may wish to consult other sources. The DES Task Force Report<sup>14</sup> summarizes the information that was available in 1978. Cynthia Orenberg's book<sup>15</sup> is written for the layperson, while that edited by Herbst and Bern<sup>16</sup> is a more technical reference. The national organization DES Action is a good source of information, particularly for the exposed person. (See box.)

The most dramatic effect of DES exposure, adenocarcinoma, fortunately strikes a very small proportion of DES daughters. However, as many as 97% have vaginal and cervical abnormalities related to their DES exposure. Adenosis\*, the most common of these changes, is variously estimated to occur in 34% to 95% of DES daughters; about 4% of nonexposed women have adenosis. There are also other noncancerous tissue abnormalities.

DES Action—conducts educational and public

YOUR

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information campaigns aimed at identification of exposed people; compiles physician referral lists; organizes in-service training programs at clinics for nurses and family planning practitioners; functions as a support group;

advocates legislation for care of exposed people;

publishes a quarterly newsletter, the DES Action Voice.

To subscribe to the Voice, or to obtain more information and a list of local DES Action groups, contact either national office:

East Coast Office: Long Island Jewish-Hillside Medical Center New Hyde Park, New York, 10040 (516) 775-3450

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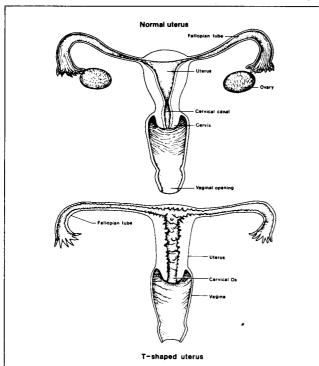
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DES daughters often have gross anatomical changes in vagina or cervix, including hooded\*, collared, or cockscomb cervix. Many of these benign conditions, including adenosis, cockscombs and ridges, regress and sometimes disappear by age 30. Many DES daughters have abnormalities of the uterus and fallopian tubes that are DES-related. The most common of these is a T-shaped uterus with a small uterine cavity.



The uterus at the bottom shows three abnormal conditions found in many DES daughters. The abnormal uterus is T-shaped instead of the normal triangular, is smaller in volume than normal (hypoplastic), and has a shaggy, bumpy lining in contrast to the normal smooth uterine lining. These abnormalities are suspected as causes of the higher incidence of pregnancy difficulties among DES daughters.

This diagram is reprinted with permission from C. Orenberg, DES: The Complete Story. New York: St. Martin's Press, 1981, p. 62. It is copyright 1981, St. Martin's Press.

The reproductive difficulties of DES daughters are only recently beginning to be evaluated. About one-half are having problems including primary infertility (difficulty becoming pregnant), premature births, still-births, cervical incompetence\* and ectopic\* pregnancy. One study showed that nearly one-half of all pregnancies among DES daughters ended in miscarriage or premature delivery and death of the fetus. Ectopic pregnancy is estimated to occur at least five times more often among DES daughters than among the nonexposed, and may even represent as many as one in seven pregnancies. 16

Researchers generally agree that about 80% of DES daughters who want children will, if they "keep trying", eventually bear at least one live child.<sup>17</sup> There is presently no evidence to indicate that the children borne by DES daughters have a higher rate of birth defects or any other abnormalities than the general population.

Much less is known about the medical problems of DES-exposed sons. Roughly one-third of DES sons have one or more genital abnormalities, including epidydimal cysts\*, microphallus\*, and undescended testicles\*. Sperm and semen abnormalities, such as decreases in sperm count and density, and in sperm motility have been observed, and can be expected to cause fertility problems in these men.<sup>19</sup>

DES mothers seem to get breast cancer more often and earlier than their nonexposed counterparts. 20,21 Some researchers have found that these differences were not "statistically significant" (that is, they found at least a 5% probability that these increases could be due to chance alone). Other researchers have disputed these findings.

It is very clear that we do not yet have complete information about the side effects of DES. Although the risk of adenocarcinoma before age 24 has been estimated, no one knows what to expect as DES daughters reach menopause. Adenocarcinoma was unheard of in young women before the use of DES, but it does occur in women over 50, and the incidence of cancer in the reproductive organs in general is higher in that age bracket. The medical community acknowledges the possibility of a "second peak" of adenocarcinoma.

A recent book summarizing the medical knowledge of DES exposure underscores this point. It concludes,

In view of our current lack of knowledge, DES exposed individuals should be followed on a regular basis in the future in order to maintain appropriate medical surveillance.<sup>22</sup>

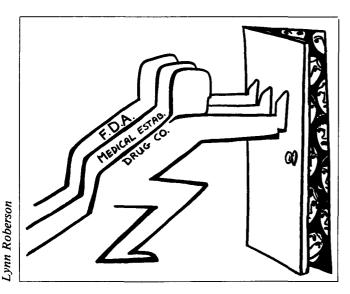
#### The Drug Companies And FDA Approval

The fact that DES was inadequately tested is so widely acknowledged that as late as August 1982—41 years after its appearance as a drug—two authors, one of whom is employed by the FDA, made this remarkable statement in a paper in *The American Statistician*, "against the background of the various regulatory requirements for information, it must be noted that there has been no systematic study of the toxicity of DES." In view of the questions raised about the safety of DES in the late 1930s and early 1940s, how is it that the drug was approved and marketed so widely?

Under the 1938 Federal Food, Drug, and Cosmetic Act, drugs could be distributed "for research purposes" without FDA approval.<sup>24</sup> Beginning in 1939, the year after it was synthesized, the drug companies distributed free samples of DES to physicians—thereby creating a market for the drug. In order to put the drug on the market for general prescription use, the FDA, which does little or no research of its own, required proof or safety from the drug companies. Several drug companies filed New Drug Applications during 1939, but withdrew them upon learning that evidence of safety was insufficient for FDA approval.

By the end of 1940, the drug companies saw that they were battling each other. They formed a "small committee" headed by Dr. Hines of Eli Lilly and Co., a major producer of DES. The transcript of Dr. Hines' testimony in a 1979 liability suit showed that "Hines had been aware that DES had a cancer potential, but, as Hines said, since the rates of cancer were not 'significant' they continued to work to get approval anyway."<sup>25</sup>

They were coached by some FDA officials about how to obtain approval of the drug; the only way was to pool their research data and file a joint Master Application. Twelve companies filed jointly in May 1941, and in September of the same year, the FDA approved the drug for prescription use in the treatment of menopause, vaginitis, and as a lactation suppressant. In 1947, the FDA approved the drug for use in pregnancy. At that time, no studies had been done on pregnant mice or other animals.



The FDA was slow to respond to the discovery of the link with cancer in 1971. In March of that year, the editor of the *New England Journal of Medicine* sent the FDA a preprint of the article by Herbst *et al.* (to appear

in April) which linked DES exposure in mothers to adenocarcinoma in their daughters. <sup>26</sup> On April 14, Herbst sent copies of his raw data. Meanwhile, Peter Greenwald, the director of New York's Cancer Control Bureau, surveyed state records and found five cases of cancers in women aged 15 to 19, confirming Herbst's findings. On June 22, 1971, New York's Commissioner of Health sent a memo to every physician in that state, urging them to halt the prescription of DES for pregnant women, and to report cases of vaginal adenocarcinoma promptly. The FDA was informed of this action by the Commissioner.

At that time, the FDA had the power to ban the drug based on the knowledge that it was ineffective. No proof of the link with cancer was necessary. Yet the "FDA took no steps to restrict DES use in pregnancy until November 10, 1971, the day before Congressman Fountain opened hearings to investigate the delay."<sup>27</sup>

This was 23 years after DES was first shown to cause cancer in mice, 18 years after it was shown that it was ineffective for its intended purpose, and seven months after the FDA was directly notified that this use caused cancer in humans! In the Congressional hearings, the only explanation that the FDA could give for the delay was that time was needed to for careful evaluation of the data. Yet in March of 1972, they finally admitted that they were unable to locate any memoranda indicating studies or review of the data. The Seamans<sup>28</sup> estimate that 20,000 DES daughters (and presumably as many sons) were exposed after the link with cancer had been established, while the FDA dragged its feet.

In the nine-month period after DES was banned for use in pregnancy, DES sales actually rose by 4%.<sup>29</sup> One explanation is that the FDA cannot enforce a ban on a drug for a particular use. As long as the drug is legally on the market, a practicing physician has the right to use it as she or he sees fit. Dr. Robert Pantell, a pediatrician in a rural clinic in Idaho, testified before a Senate Committee that in 1974 DES was still being prescribed to pregnant women.<sup>30</sup>

Another explanation for the rise in DES sales is its use as a postcoital contraceptive, or "morning-after pill", which began in the early 1970s. In 1973, the FDA mailed a Bulletin to physicians which stated in part:

FDA has approved, under restricted conditions, postcoital (contraceptive) use of diethylstilbestrol (DES), a synthetic estrogen... The Agency considers the use of DES for this purpose to be safe only as an emergency measure (in situations such as rape, incest, or where, in the physician's judgement, the patient's physical or mental well-being is in jeopardy).<sup>31</sup>

Yet in the 1975 hearings, FDA officials denied that the

drug had ever been approved for this purpose. Also testifying in the hearings were two doctors, employees of the FDA, who would normally sign the approval papers, but who had refused to do so and had been relieved of this responsibility by their unnamed superiors. From their testimony, it is clear that the usual procedures had not been followed. The use of DES as a postcoital contraceptive has been widespread, particularly on college campuses, and has gone far beyond use in emergency situations.

Over the years, DES has been prescribed for many different purposes. In addition to prevention of miscarriage, it has been used as a lactation suppressant, to relieve the symptoms of menopause, to induce miscarriage, to treat acne, to treat certain types of breast and prostate cancer, and as a "morning-after pill" (actually a five-day treatment). In addition to its many applications as a prescription drug, DES was also used as a feed additive for cattle for several decades.

The use of DES as a postcoital contraceptive continues today. Its side effects, which include nausea in 81% of patients and vomiting in 34%, contribute to its ineffectiveness. In the cases when it fails (or if the woman was already pregnant) rejection of the alternative of abortion means the birth of more DES-exposed babies. The risk of pregnancy from a single instance of unprotected intercourse is estimated to be about 1 in 20, so many of those who receive the treatment would not have become pregnant without it.

Another current use of DES is as a lactation suppressant in new mothers who choose not to breast-feed their infants. (DES has been marketed under at least 65 names—the most commonly prescribed drug for this purpose is *Tace*.) The FDA Committee on Obstetrics and Gynecology recommended withdrawal of approval for this use in 1978, due to evidence that the drug is unsafe, ineffective, and unnecessary. Yet now, four years later, no such official action has been taken, and DES is still routinely administered in many hospitals. Even known DES daughters, who should avoid further exposure to estrogens when possible, have been offered Tace and the "morning-after pill." <sup>33</sup>

#### Who Assumes Responsibility For DES?

In the 1975 Senate hearings, Dr. Pantell remarked, "the sad thing seems to be the unwillingness of anybody to assume the reponsibility in protecting the consumer in these instances." In fact, the drug companies, medical establishment, and government are much more concerned with protecting themselves from responsibility.

Public and Congressional pressure resulted in the initiation of the DESAD project (short for DES Adenosis) by the National Cancer Institute in 1974. The

study involves more than 3,300 DES exposed daughters, and at least 750 controls. Originally, it was designed to study exposed sons as well, but it was limited by "insufficient funds." Funding for the project, which was set to expire in 1982, has been extended for one year, and the project is currently seeking additional support. Studies such as these are very important since they are the only mechanism to pick up future health problems among exposed people.

The DES Task Force was formed in 1978 by the Department of Health, Education, and Welfare, in response to pressure from consumer groups. Its function was to evaluate the medical information available regarding the side effects on and care of the exposed. The summary report <sup>36</sup> urged that physicians and other health professionals be informed of the Task Force's findings, suggesting short courses at professional meetings, compilation of referral lists of DES specialists, and development of educational materials for other health professionals such as nurses and social workers. Further studies of the effects of exposure were recommended.

The report emphasized, "it is imperative that all involved persons know of their exposure." It recommended that all prescribing physicians notify the women to whom they prescribed the drug, and that public information programs be instituted informing exposed people of the need for follow-up care. The Task Force recommended that the major insurance carriers be urged to extend their coverage to include physicians' fees for regular checkups required by DES daughters. However, as Orenberg<sup>37</sup> comments,

many of the task force's recommendations—to wit, those requiring any sacrifice of time and/or money from physicians and insurance companies—have yet to be implemented.

For example, I have yet to meet a single DES mother whose DES-prescribing physician notified her of her exposure. Worse yet, many of these physicians refuse to cooperate when the women contact *them*.

All too often, the members of the medical profession were slow to recognize their mistakes. Dr. Little, the director of obstetrics and gynecology at Case Western Reserve School of Medicine, was questioned in the lawsuit filed in 1979 by a DES daughter (Joyce Bichler) against Eli Lilly:

Finz [Bichler's attorney] asked Dr. Little if, even in the light of what we know about DES today, he would still give DES to pregnant women. Dr. Little looked straight at Finz, and said, 'Yes.'

'I would like to point out to the court,' he [Finz] said, 'that since 1971 DES has been banned by the

FDA for use in pregnancy...despite this, Dr. Little says he would still give the drug to pregnant women.'38

Nor have medical schools responded with adequate educational programs. The need for such training is crucial, particularly for family planning practitioners, who play a very important role in the identification of exposed people. Yet many medical and nursing students do not routinely learn anything about DES exposure.

If the government and medical establishment have been slow to assume responsibility, the resistance of the pharmaceutical industry has been more active. DES daughters are beginning to sue, and lawyers for Eli Lilly are coordinating the defense nationwide. The Smiths for example, have turned over all their records to Lilly.<sup>39</sup>

Joyce Bichler, who has written a book telling the very personal story of her illness and legal action, successfully sued Eli Lilly and Co. Even though she could not prove that Eli Lilly manufactured the actual pills her mother took, she was entitled to collect because Eli Lilly was the largest single manufacturer of the drug and the drug companies had all acted similarly (enterprise liability). According to another recent decision (in the Sindell case), even if a plaintiff cannot identify the manufacturer, if she wins her case, the companies must share the cost according to their percentages of the DES market (market share liability).

One thing is certain—the drug companies are learning from the DES experience and are taking measures to protect themselves from accountability should they be involved in similar cases in the future.

The drug companies pooled their resources to get the drug approved; now they are pooling their resources to defend themselves against suits which would hold them jointly responsible for the effects of their actions. More recently, they, among others, are lobbying for the passage of a new product liability law.

That bill (S. 2631) was introduced in the Senate in June 1982, by Robert Kasten (Wisconsin). It would preempt existing state laws, which in at least some cases are more favorable to consumers. It provides for a ten year limit of liability, unless the harm did not manifest itself within ten years. In that case, the limitation would be two years from the time the injured person discovered

(or should have discovered) the harm. Kasten says the bill would "pinpoint responsibility" and that it would "bring uniformity into the process."

The bill requires that an injured person who does not know the manufacturer of the product that injured her or him be able to show that every reasonable effort has been made to establish the identity of the manufacturer, and that all manufacturers are named as defendants. DES Action pointed out in testimony in Senate hearings on June 30, 1982,

This is an impossible requirement. For example, there were 354 known manufacturers of DES. To bring action against every one of them... to prove the capability of any, let alone each of 354 manufacturers as to the level of knowledge or information about the manufacture and distribution of these drugs [is clearly an impossible task].

Further, the bill provides that if one plaintiff can prove these facts, no other plaintiff could benefit. On this point, the DES Action testimony continues,

Furthermore, there is no sound reason for reinventing the wheel in this way other than to make it more difficult for a consumer to obtain justice to which she/he is entitled. These requirements would add years to each case long before it could even approach a trial stage, discouraging plaintiffs and attorneys alike from pursuing litigation. This seems to be the intent of this section of this legislation.

As of this writing (August, 1982) this bill, which is an attack on the rights of all consumers, and not just the DES-exposed, is still in committee.

It has often been suggested that the drug companies should set up funds for medical care for the exposed. Drug company attorneys discussed such a plan with DES plaintiff's attorneys in 1976.<sup>41</sup> However, it seems that they have decided that it is more effective to pour their resources into battling the cases in the courts. One thing is certain—the drug companies are learning from the DES experience and are taking measures to protect themselves from accountability should they be involved in similar cases in the future.

Many of the tasks that should be performed by the drug companies, the medical profession, and governmental agencies, are being undertaken by the victims themselves. Local groups of exposed mothers and daughters began to form in 1975. In 1977 the groups began to discuss coming together in a national organization, and in 1979 they incorporated as DES Action, National. The need for such an organization is underscored by one of its active members,

I believe that knowledge is power...It disgusts me that men in these powerful positions (of physi-

cian, researchers, pharmaceutical company heads, FDA Commissioners) place the dollar sign and desire for fame/prestige/ego boost before caution and the well-being of human lives... I personally feel less powerless in gathering the truth and disseminating it to others in need of information—exposed people, nonexposed people, health care workers.<sup>42</sup>

#### **Personal Implications**

I first became aware of my own DES exposure about ten years ago. When my mother read some of the early newspaper reports about the link between DES and cancer, she recalled having taken the drug during pregnancy. Several months later, I went to obtain birth control pills from the gynecologist who worked one afternoon a week at my college's student health service. It was my first visit to a gynecologist, and I was timid and generally ill-informed about birth control.

I told the doctor that my mother had taken DES, and before examining me, he explained that I had a 95% chance of developing cancer before I was 22. He then did an iodine stain test\* and found that some areas of my vagina and cervix did not stain. Therefore, he suggested that I contact Dr. Herbst in Boston, but never followed up to see whether I did. In view of the fact that DES daughters should avoid further exposure to estrogens (including oral contraceptives) when possible, <sup>43</sup> it now seems ironically fortunate that he refused to prescribe the pill; but he failed to discuss any alternative methods of contraception with me.

Dr. Herbst referred me to the chair of obstetrics and gynecology department at a medical school that was close to where I lived. Every three months I returned there for an examination including colposcopy\* and occasional biopsies\*. On my fourth visit, a full year later, I finally mustered the nerve to question the doctor about my "95% chance of getting cancer before age 22." He laughed when he heard that the doctor had told me this—then he looked at my face and realized that I did not know it was not true. He then explained that the doctor's comment must have been based on a gross misunderstanding of the Herbst report. Rather than concluding that most victims of adenocarcinoma are DES daughters (as he should have), he concluded that most DES daughters develop adenocarcinoma by age 22!

My experiences cannot be compared to the trauma of the victims of adenocarcinoma and their families. Yet I am like many exposed daughters whose benign conditions form a public health problem of great magnitude that is not sufficiently addressed by the medical profession. As one doctor who has considerable experience with DES-exposed patients recently told me, "DES isn't

interesting any more. It is a self-limiting problem. It's no longer being given, and all those who will be affected have already been born."

As the victims of iatrogenic (doctor-produced) disease, we are caught in the contradictory position of having to seek special medical care from the same health care system that created our special problems. Many of us find that, rather than being investigated and cared for by the medical profession, our problems are supplemented by new ones caused by lack of knowledge, insensitivity, or incompetence. For example, because of the incompetence of the first gynecologist I saw, I lived for a full year thinking that I would almost surely develop cancer in the next two years.

The barriers that we have to overcome to find medical care are illustrated by another example. I was fortunate enough to remain under the care of the doctor at the medical college for six years. He was sympathetic and responded in detail to my questions about my own health and about the current knowledge of DES exposure. But since I moved from that area three years ago. I have several times gone through the frustrating process of seeking medical care in a new community. In one instance, I was told by receptionists in three different doctors' offices that "the doctor doesn't take new patients" even though the symptoms I was describing included two of the seven warning signs of cancer. When I was finally able to make an appointment with a fourth doctor, he was clearly not very interested in my description of the DES-related changes that were "normal" for me. Despite my repeated questioning about the prescription he gave me, I could not get an answer more specific than "It's something to clear it up. You do want to clear it up, don't you?" When I consulted with my regular doctor at home, he suggested that I was probably being treated for my "normal" condition. I did not take the medication. Since then, I have been repeatedly "reassured" that the symptoms which led me to seek medical attention are unrelated to my DES exposure.

I am fortunate enough to know of my exposure, and to have had good medical care for long enough that I am familiar with my medical history and general condition. If this is what I go through to get the care I need, what happens to someone who is unaware of her or his exposure or is not persistent enough in the search for appropriate care?

This search is complicated by our lack of information. The oldest DES daughters are only now entering their forties, and it remains to be seen what problems we will have as we age. Karen (not her real name) is a 31-year-old DES daughter, active in DES Action.

(Continued on page 30)

# RADICAL THERAPY: LIVING FROM THE INSIDE OUT

#### by Patricia Parsons

In this society, verbal skills are considered important and useful; the skill of emotional literacy, or the "capacity to understand and deal with one's and other people's feelings" is not so highly valued. As a child, I learned to read and write, but I was never taught to be emotionally literate. It was not until I reached adulthood that I discovered that I had a right to my feelings —to have them, to identify them, and to express them in my interactions with others. In the turmoil of the late 1960s and early 1970s, I began to make connections between my own feelings and the nature of the society I lived in. Through involvement in the women's movement, I began to understand that "the personal is political." Indeed, there is a profound relationship between feelings and social, political, and economic conditions. The radical therapy movement has been and continues to be a significant source of information and support in my struggle to fully understand the nature of that relationship.

Born of the social upheaval of the times, radical therapy (RT) offered a challenge to the established view of mental health and illness. Although proponents of RT are colorfully diverse, I will venture to summarize the main elements of this approach to psychological problems.

In the tradition of Thomas Szasz² and other critics of modern psychiatry,³ radical therapy rejects the medical model which regards all psychological and emotional problems as symptoms of disease. Rather, RT asserts, these problems (excepting mental disorders that are clearly and directly related to neurological damage, abnormalities, or disease) are the result of very real and oppressive conditions in society. RT goes beyond the critique of the medical model of mental illness by using a Marxist approach to examine the psychological impact of the oppressive conditions of capitalist-patriarchical society. Radical therapists use innovative group processes in problem-solving groups designed to increase

Patricia Parsons is a doctoral student in Health Services Organization and Policy at the University of Michigan School of Public Health. She has been involved in the radical therapy movement for seven years. personal awareness of oppression, to provide support for personal growth, to equalize power among group members, and to encourage social action against oppression.

The "normal" person is one who acts and feels like a white man. (Significantly, many rapists are found to be no different from a psychologically "normal" person.) Those of us who do not adapt to the "normal" psychological mold are in danger of being labeled "sick." Women who want to be whole, independent persons sometimes end up in mental institutions or hooked on valium because they responded to oppressive sex roles by acting "crazy" or having a bad case of "nerves." People of color who react violently to racial discrimination are called "paranoid." Alcoholics are reassured that they have a disease, while little attention is paid to the social conditions that encourage alcoholic behavior patterns. Many residents of mental institutions and ordinary unhappy "neurotics" are actually normal people trying to adjust to an oppressive, non-supportive environment and a society which does not provide emotional sustenance to its members.

#### **Internalized Oppression**

Successful psychological adjustment to a capitalist patriarchical society requires that we internalize our oppression. We turn our anger and fear in on ourselves and those close to us instead of directing them toward the societal sources of our oppression. We become alienated from ourselves and each other, and we feel powerless to change our situation.

We are taught to swallow our feelings, to hide them from ourselves and each other. Not surprisingly, we are not taught to pay attention to our emotions, to trust them, to express them clearly, to say what we want from each other and from society. If we were, we would have within us the seeds of rebellion. It is a suitable task for radical therapy to sow the seeds of rebellion by helping people to discover and reclaim their unexperienced emotions, to develop emotional literacy, and to explain the relationship between our crippled emotional selves and the nature of our society.

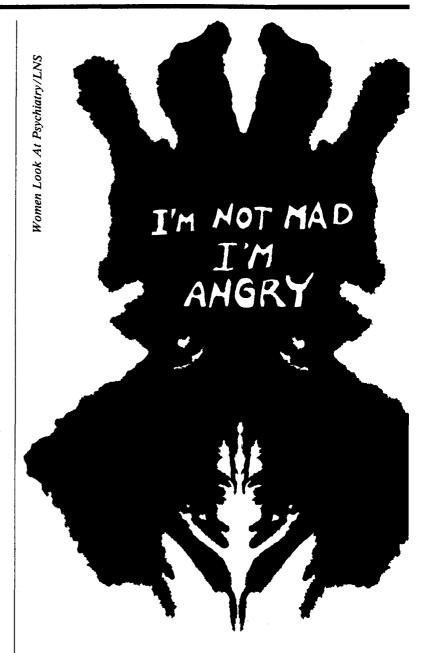
Beginning with the understanding that emotional and interpersonal problems are linked to the conditions of society leads proponents of RT to therapy modes based on groups rather than individuals. The value of meeting in groups to discuss common problems and experiences was well established by the success of consciousness-raising groups in the early stages of the contemporary women's movement. Through communication in these groups, women were able to overcome their isolation from one another and to establish strong bonds based on their common oppression. RT problemsolving groups are grounded in the belief that sharing our common experiences and emotions will increase our awareness of the oppressive conditions that discourage us from intimate emotional contact with each other, and of the forces that prevent us from acting to change these conditions.

Radical therapy ultimately leads to and must include collective action to change society. Unless and until we change the social and economic conditions which oppress us, RT contends, we will not be free of our psychological oppression. Concomitantly, we can not successfully overcome the external conditions that oppress us without addressing our internalization of that oppression. RT can provide the tools to combat that internalized oppression through the development of cognitive and emotional awareness of oppression, mutual support, and individual empowerment. RT can help us to communicate our feelings and wants without lying, without using power plays to get what we want, and without "rescuing" others by doing things we do not want to do.

#### **Equalizing Power**

A central concern of RT problem-solving groups is the equalization of power. Radical therapists do not aspire to the role of powerful professionals who hold the key to personal liberation. Rather, radical therapists seek to share therapeutic skills.

[These skills] can be utilized to demystify internalized oppression and enhance our personal power ...radical therapists develop and collectively share therapy skills without the intervention of professional experts. The democratic framework of radical therapy suggests a therapeutic context in which roles and skills are explicit, teachable, mutual, and negotiable...the 'therapist' puts her/himself out of business by assisting everyone in the group in becoming a therapist. We see a normal transition from an individual who is part of a group as the 'therapist' with skills evolving toward being a 'facilitator' who relies increasingly on the power and developing skills of the group members, culminating in their being an equal group member4



The goal, then, of problem-solving groups is to enable group members to struggle against the psychological hegemony of capitalist patriarchal society and to nurture their abilities to give and receive love unhampered by internalized oppression.

My own experience with RT indicates that the efforts of radical therapists to equalize power in groups have proven to be successful within the RT movement itself. I have attended six of the seven annual Midwest Radical Therapy Conferences held in Iowa, and one of the several Radical Psychiatry Summer Institutes held in the San Francisco-Berkeley area. Each experience was rewarding and energizing, but as with many emerging movements, there have been recurring issues which

cause concern. It was rumored that the latest Midwest Conference was to be the last, a victim of leadership burnout and Reaganomics. Happily, the stated intent of radical therapy to equalize power among group members was not an idle promise. Enough people have been empowered, aroused, and inspired by RT that this movement will fight to live. However, it will not survive unless it addresses the problems that faced and probably weakened the original RT movement and some issues that perplex the whole of the American Left.

#### Challenges

From my perspective, I see three major problems which must be addressed and resolved internally by the radical therapy movement. The first issue requires an evaluation of historical strategic choices. The RT movement includes people who have chosen to focus their energies primarily on the development of therapeutic techniques as well as people who would prefer to challenge directly the abuses and inadequacies of the established mental health system. In the past, this difference caused a split within the RT movement which resulted in a diminished emphasis on direct challenge. This choice should be reexamined in light of the current political situation and in the context of the second problem facing radical therapy.

That second problem is one that pervades the American Left: the failure to attract people of color and members of the working class. Although it is claimed by problem-solving group leaders that many members of the working class participate in groups, few working-class people seem to attend conferences. Also, despite some effort, RT has failed to attract more than a handful of people of color. The general concern is that the style of radical therapy is comfortable for white, middle-class people and requires that people used to a less genteel approach to problem-solving adapt to it. The question of which should adapt—the style of the therapy or the people who want to use it—needs to be examined.

Beyond the style question rests the social impact of the choice made by many proponents of RT to concentrate their efforts on the practice and development of therapeutic techniques as opposed to challenging the medical care system's domination of the mental health field. The majority of low-level health workers and inmates in state mental institutions are working-class people and/or people of color, and many are also women. If the energies of the RT movement were directed more toward activities directly relevant to the everyday working and living conditions of these workers and inmates, the composition of the movement might

If you are interested in learning more about radical therapy:

1. Subscribe to *Issues in Radical Therapy*, individuals \$7/year, \$12/year for institutions. RR #1, Springfield, IL 62707.

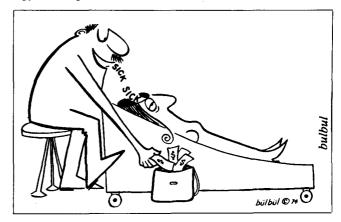
2. Contact Dotty Sandberg (534 W. Lakeside St., Madison, WI 53715) or Candy Hadsall (1314 N. 35th St., Omaha, NB 68131) for information or with input/ideas for the next Midwest Radical Therapy Conference.

change. In other words, RT should reexamine the balance between efforts aimed at fighting internalized versus external oppression.

The final question which must be addressed self-consciously is the following: Is radical therapy merely radicals doing therapy, or is it therapy grounded in a radical analysis of contemporary society and rooted in radical political and economic theory? At present, I think it is some of both. Certainly, radical therapists who have devoted their energies to the development of RT started from a radical critique of capitalist society. As noted earlier, an effort has been made to link the structure and workings of capitalist patriarchal society with the personal pain and alienation which we all experience as a result. However, this connection between the personal and the political has not been explored as fully as it must be.

#### Collective Action and Social Change

Radical therapy has, in my estimation, the potential to make important contributions in three areas. The first is in elucidating the connection between the personal and the political, and the relationship between external and internal oppression. The mechanisms which encourage us to internalize our oppression are not all known to us. We must combine theoretical and practical work in a dialectical process to develop "a new social psychology which locates a person within a specific social, political and economic context; a social psychology developed and nurtured by the inherent contradic-



tions of these contexts". It is in this theoretical area that RT can make a significant contribution to understanding the nature of oppression and, thereby, to its elimination.

RT also has a significant contribution to make through "the use of problem-solving groups to establish prefigurative relationships among us".7 Prefiguration is the exploration of the future liberated society in present practice. Even though we live and love in an oppressive society now, we must learn to behave and relate as if we were free of sexism and racism and other forms of oppression. For example, some people have found traditional marriage to be unsuitable for their needs. But human beings need to be close to one another to bond, to share, to make commitments, to have families. If "marriage" seems inappropriate for some people, what will replace it? RT, by providing the skills for the communication of human emotions and wants and by supporting people's rights to meet their basic human needs, will help us to explore the possibilities for alternative forms.\* Emotional literacy will allow us to equalize power in our personal relationships as well as in groups. Women have had the advantage of working together in the women's movement to begin to redefine what it means to be a woman. Men have not been as fortunate emotionally. While the "macho man" image may not be as compelling a model as in the past, men have suffered a greater estrangement from their feelings and each other than have women. Many feminist men who are in the process of redefining what it means to be a man find themselves afloat without the support needed from other men. Again, radical therapy can support both men and women in the struggle to find our feelings, to express them, to understand them in the context of our society, and to begin to relate to one



another on more equal grounds. Knowing what we want to be in a new society will help us to create it. If we do not try new ways of relating to one another now, perhaps we will always find ourselves trapped in the old ones.

Finally, RT can support the efforts of groups working collectively for social change in a wide variety of areas. Collective work is very difficult. The decisionmaking process is often time-consuming and tedious, and the means for conflict resolution are frequently not well-defined. Women in mixed social-change groups often are confronted with the sexist behavior and attitudes of their male counterparts, certainly an added barrier to effective social action. Lesbians and gay men also encounter heterosexist and homophobic behavior which interferes with the struggle toward common goals. Social-change groups are not immune to racism or classism. Group process techniques developed by RT which are especially attuned to the desire to use democratic methods can be very helpful. RT skills include democratic agenda-setting, simple ways to express feelings and wants without engaging in heated exchanges or power struggles, and mediation techniques for resolving disputes that take sexism, racism, and classism into account. Certainly, social-change groups could benefit from RT training on the one hand, and RT could become more useful by addressing the practical problems of social-change groups on the other. This is clearly a direction in which RT might productively exert some energies.

On the whole, I am excited by the possibilities presented by an enlivened radical therapy movement. The potential benefits to political activists on both a socio-political and a personal level are enormous. Our collective work to change society can be more productive and our personal lives can be more fulfilling at the same time. A friend once said, "We are not meant to live from the outside in". Radical therapy can help us live from the inside out.

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# INSTITUTIONALIZED RACISM IN THE MEDICAL PROFESSION

#### As Told By Rod Toneye

In March 1982, Science for the People published an interview with black psychiatrist Dr. Alvin F. Poussaint. As a political activist and former Associate Dean of Students at Harvard Medical School, Dr. Poussaint detailed the inherent racism within the health care system.

In the following narrative, Rod Toneye relates the multiplicity of ways in which racism restricts the education and career choices of black medical students in particular. Drawing on his own experiences as a black medical student at the University of Michigan, he describes the institutionalization of racism that is a general phenomenon in U.S. medical schools.

In style the article deviates from usual *SftP* fare because it was spoken and excerpted from a considerably longer transcript.

The University of Michigan Medical School faculty consists of white, upper-class men who are doctors—now you can't get more upper-class than that. Doctors are next to God in terms of the way society looks upon them. You can avoid military service with a note from your doctor; you can't avoid military service based on your conscience and on the fact that you disagree with killing. That's not good enough, but if

Rod Toneye describes himself as an agent for change in the black community and currently works as a community organizer for a low-income housing project in Michigan.

you get John Smith, MD to say that you are sick and would not make a good soldier, there you are. So this is the status and power that white male MDs have. With that power and status, they reflect upon what they believe to be reality in a world in which life and death seem to be regulated by some understanding of which doctors have a monopoly. And this gives them a tremendous sense of arrogance.

Doctors are influenced by racism in their hierarchy of values; in that hierarchy, black people fall at a very low level, while medicine falls at a very high level. It seems incompatible to them that black people should be in medicine. It's too large a conceptual leap for these men to make. Their highly distorted perceptions of black people lead them to believe that blacks shouldn't be able to achieve that kind of status without paying some tremendous cost for it. During the period of civil rights activism, many people with these attitudes were upset because they thought that black students were being admitted without the usual scrutiny to qualifications. They thought that motivation and social responsibility should not be real factors in choosing medical students. The criteria should be those of academic excellence, potential for research, Nobel Prizes, that sort of thing.

#### 1960s Activism Effects Change

The University of Michigan had a very liberal profile during the 1960s as one of the first institutions to accept the concept of increased recruitment of black students. In 1970, during the Black Action Movement strike,\* the activism of black students around ad-

\*The 1970 Black Action Movement (BAM) strike succeeded in closing the University of Michigan and pressured the University Administration to commit itself to seeking a 10% enrollment of blacks.

mission to college and graduate schools was high all over the country, and the institutions had to respond. And the University of Michigan did.

Some programs, in their rush to take in black students, decided that academic performance would not be the major criterion for deciding admission; degree of motivation would be, sense of purpose would be, and so forth. The University of Michigan Medical School was one place that had a large influx of black students from fields covering a wide range of undergraduate disciplines. Because these programs increased minority enrollment, there were more blacks going to medical school, especially here at the University of Michigan. Michigan had a relatively large percentage of blacks in the classes that began to graduate in the early 1970s.

So, one would think that they were very encouraging and enthusiastic in support of the black medical students' presence. That was only the case for perhaps five or six years during the aftermath of the activism in the 1960s but that changed drastically around 1977. In my class—I was admitted in 1977—there were only 12 black medical freshmen in a body of around 185 new students.

The following year, admission went down to nine. Interestingly enough, the University of Michigan at that time began to emphasize its minority enrollment statistics as opposed to its black enrollment statistics. There was also a large percentage of women in the class. In that area they seemed to be making a lot of progress. But the black population was dwindling, dwindling rapidly. In the area of admission and enrollment of black students, the medical school seemed to be falling way short of the goal of even 10% which was the University's concession to the Black Action Movement in 1970. In the class that was admitted in September of

1980 there were 23 or 24 black students. The effort to get those students admitted, however, tells a story in itself.

Somewhere at the end of the academic year of 1978, medical schools as a whole began to put out the PR that there was an oversupply of doctors, and doctors are very sensitive about oversupply of people in their profession. The University of Michigan administration began to worry about decreasing the numbers of students that would be enrolled in medical school across the board. Meanwhile the number of black physicians had not increased in proportion to the population since Howard University graduated its first classes of black physicians during the 1870s.

In fact, in Harlem, in the late 1960s, the average black physician was somewhere around 55 to 65 years old, and had an expected continuation in his profession of another four or five vears. These were for the most part primary-care physicians, family practitioners and so forth. At retirement, there were not enough new MDs to replace them, in spite of the fact that their numbers were quite small compared to the population in Harlem. In Harlem, as in most black communities, most people don't have a private physician. I grew up in Harlem and the Bronx, where a private physician was someone I saw once in a while. He was a very mystical kind of person, because, you know, you had to seek this person out—I remember taking about two weeks before getting an appointment, and never coming back again. Since poor people can't afford a personal physician, the hospital clinics have to serve as their medical facility in a major city like New York. So personal physicians—the concept is just strange to me.

What happened in the entering class of 1980 had to do with some political activism on the part of a number of black students who saw that the University of Michigan had backslid completely on its commitment to educating larger numbers of black students. These students realized that with the medical profession talking about there being an oversupply, black enrollment would be threatened. When the University of Michigan hired an admissions director who was totally off the wall, this gave further credence to these fears. She would say things like, "We're

doing everything we can, it's just going to take time." She was saying this in 1978. And most bigots and uninformed people had learned quite some time previous to that, that you didn't say these things anymore-"We're doing everything we can, you just have to be patient, it's just a matter of time." And she pointed out how, many years ago, there were no women in the profession and now, there are some women who are chairmen of departments, and areas, units of the hospital at the University of Michigan, and that if blacks could just be patient, things would get better.

A number of faculty people and students, who had some contact with a state legislator, decided that no, this would have to change. Through a series of meetings and caucuses held with the medical school administration and with the admissions director, and with political pressure from without, they forced the medical school—and I mean literally forced—to admit more black students. All of a sudden, against the wishes of the director of admissions, against the wishes of the dean of the medical school, the number of blacks admitted was high again.

#### Class Status

The University of Michigan is not a supportive atmosphere for black medical students. During the 1960s and early 1970s, many universities, in order to recruit black students, hired staffs



that were responsible and accountable for recruiting, admitting, enrolling, and retaining black students. And money for this purpose was placed in the hands of the dean of students or the admissions office-it varied in different universities. The University of Michigan never did that. What the administration did do was to take a member of the faculty who got an appointment as an assistant dean of students and who happened to be black, and give him the function of serving as the representative for minority concerns. This person functioned in that capacity in an erratic manner, and this person is still at the University, operating in that fashion. He's not paid to deal primarily with black students, yet black students who come to the University think that he is. And because they take their concerns to him, they find that they are either being addressed because he likes them personally, or their needs are not being addressed because this assistant dean is powerless to really effect any change around the status of black students. I think he is not competent to be the minority representative but is maintaining that position because he is essentially doing what the administration wants done for black students—nothing. His stance seems to be that of, "If you're having difficulty here at the University of Michigan, which is highly competitive, you are an embarrassment and I certainly don't want to jeopardize my position to go out on a limb for you. I'm here not to rock the boat, but to maintain the status quo. On the other hand, if you are a highly prepared student and you are an academic credit to your race, then I'm all for you."

This particular assistant dean of students is a product of middle-class environment, so he naturally seems to take a liking to students of that sort, and has difficulty with students who represent a different socio-economic stratum.

This is one of the tensions within the black community itself. There are students like myself, who are from lower economic communities who decided they wanted to go to medical school because they thought they could fulfill a need in the community where the number of physicians was minimal. (In New York City, they were closing hospitals; medical care was a privilege and didn't seem to be a right, and quite a few people were suffering.) You have

students like that who were admitted during the heyday of activism in the late 1960s and early 1970s, as well as the students who were the sons and daughters of physicians or lawyers or middle-class families, who had good preparation due to the advance planning of their parents and who recognized that the way in which you become successful is by climbing the ladder towards middle-income and middle-class credibility. Middle-class status has a lot to do with one's success in academic endeavours in general and especially in medical school.

There had always been a sense, prior to the 1960s that if you were to be qualified for medical school, you couldn't be poor and black. In fact, you couldn't be very dark of complexion. You had to represent a stratum of the black community that could be considered "acceptable," in which you would appear to have as many characteristics as possible reflecting the general white, middle-class norms of heritage, color, and class which the medical profession tends to embrace. So prior to the 1960s, physicians who were trained in highly competitive schools-Harvard, Yale and so forthtended to come from the black aristocracy, whatever that means. These were students who came from black families that were middle-income rather than working-class.

#### Alienation

When I was at the University of Michigan, I found that the few black students who were there were not involved in any extracurricular activities involving the medical school. I believe that had to do with their deep sense of alienation from the medical school environment and the white students who represented a different culture and different sense of values. For example, even now, in the University of Michigan's medical school, one will probably encounter no more than five black lecturers. The whole time that you're going through all these courses, for months on end, the largest number of black faces you may see lecturing to you is five. And that's if all the black faculty get to lecture.

So the atmosphere is one in which you get your support from your fellow student. You don't have anyone who is in a higher position to make a welcome mat for you. You have no role models. You have a sense of, "Do I really belong here? Am I part of the 'in' crowd?" The answer is no. "Am I accepted here?" Maybe. And those are questions that a black medical students should not have to ask, but because of the whole history of our society, these questions do get asked.

The white student has any number of choices of faculty members who represent different specialties and aspects of medicine to serve as role models. It is very important for students to talk to people, and develop a sense of comraderie with physicians who are now practicing and who can relate some of their experience and some of their philosophy to the student who is still struggling and learning, and trying to figure out, "what am I going to do with my career? Am I going to be a surgeon, a cardiologist? I need someone to talk to who can help me see through all this." So that's another difficulty the black student has, there are not enough role models to relate

It's been determined through studies that were conducted some years back (as reported in the Journal of Medical Education,) that students' choice of speciality is most influenced by a role model. I found that black students at the University of Michigan—and I guess it's true of other places, except maybe Howard University and Maharry University\*—are without the role models to influence their direction.

So, without these black role models to help develop the medical student in the ethos of being a physician and so forth, I think what happens is that young black physicians who move out into the community still perceive themselves as second-class citizens. Those who I've seen graduate from the University of Michigan still have a sense of not being accepted, of not being good enough. Therefore, they cannot help but shy away from the arena where they will have to speak against and challenge a medical system that has a great many inequities in it. Many of them have had such a hard time at the University of Michigan that they only want a rest now, and I'm concerned that this will continue to happen. Medical school doesn't develop



leadership potential in the black student, I'm not sure if it develops it in anyone. I thought medical school might develop it in black students, but it doesn't.

#### Patronizing Vs Vicious Racism

Black students are given the sense and the feeling that they are at the University of Michigan because someone has gone out of their way to admit them, that they would not be there if a special effort hadn't been made to open the door. There are faculty members who think that all black students are admitted under some special admissions policy. They support the idea that there should be more black medical doctors, but they relate to you as if you are one of the students who are having difficulty, because they think all black students they encounter will be students who are not adequately prepared. Their attitude is more benign than others, but it's just another way in which racism expresses itself.

The black medical student tends to be, especially now, a very conservative student; it could be because of the studying one has to do in chemistry and biology all the time, that one tends to shut oneself off from the rest of the world. Where the student is not very conservative, he or she still tends to be ignorant of the conditions in the world, especially regarding the nature of institutional racism. Many students get caught in the climb for upward mobility and striving for status that has always been a part of the black middle class, and perceive their opportunity for admission to medical school as a free ticket to what black students commonly call "getting over." They think,

<sup>\*</sup>Howard University and Maharry University are the two predominantly black medical schools in the United States.

"once I have gotten into medical school, my problems are solved. It's all over; I've made it," and, "I know that it's a four-year process, and I had better not rock the boat while I'm here, because I recognize that some great white father somewhere has gone out of his way to undo what he usually does, and has given me a break. And I don't want to upset him." They think, "Well, now that I'm here, the most important thing is that I'm here, and not that I change anything, that I become a radical, that I speak out. So I will just keep my nose clean, study hard, and prove that I'm worthy."

#### Financial Aid

One way in which classism operates in medical school is exhibited in the lack of financial aid. Initially black students who were admitted here were given complete financial coverage. When I was admitted to medical school, part of the recruitment effort for black students involved pronouncements such as, "don't worry about financial aid, don't worry about it, that will not be a factor in our decision." And it wasn't. Yet, had I continued, my debt level would have been at least \$50,000 right now. After four years that's what I would owe-the state of Michigan, University of Michigan, I don't know who else.

In the past, loans always had grace periods. You didn't pay it back while you are going to school. Once you graduate, if you went into certain areas, they deferred so much of your payment. If you were really broke, you just paid the interest. Now they have loans that require you pay the interest while you are a student. It's just like going to the bank and saying, you know, "could you guys loan me a thousand?" And they say, "sure, OK, and you start paying us 18% thirty days from now." I mean, what good is that? You're in debt and you need a job to pay off your loan-while you're going to school. This is what's available outside of the Public Health Service. So I think the students who got in this year and last, and maybe in 1982, will be the last group of students who will go into medical school thinking that money is no issue.

#### **Paying Back The Government**

The federal government has recently clamped down on its loans to medical

students. To get federal government assistance now, you have to join the Public Health Service, or something like that. If you join the Public Health Service, you can only be a certain kind of physician, because the government will allow you only three years after graduation from medical school before you start working for them to pay the debt that you owe the government for putting you through school. Most residencies that lead into the higher, elite realm of secondary and tertiary medical care specialties, take more than three years. So, in three years you can only go into pediatrics, obstetrics and gynecology, and family practice—the primary-care, less prestigious special-

Now the Public Health Service offers fewer benefits than they gave some years ago. At one point, they had a stipend of \$750 a month. That's nice! Plus they paid all your tuition. They cut that out. They pay all your tuition, but the stipend went down to something like \$400 per month, max. Didn't matter whether you were married, whatever-\$400 max, which was difficult to live on. And in addition, they instituted some penalties to prevent new MDs from using them to get through school and then deciding that they didn't want to work for the government. In such an event, you owed, on the spot, that very minute, twice the amount of tuition they had paid, plus interest based on the amount of money and the number of years you had been getting it. And it was due immediately. So, if anyone went into the Public Health Service lightly, they were in big trouble.

Once you got out of residency, they sent you out to Oshkosh, Wisconsin, that's where you went for three years. I know a fellow now who's graduating, finishing his residency in psychiatry, and now he has to go to Public Health Service. He had a choice between someplace in Louisiana and someplace in Texas. And he's from Detroit. So when he goes to Louisiana and begins to set up a practice there, it will be more harmonious if he then remains there. And part of the Public Health Service philosophy was to get physicians into areas which are underserved. Once you settle into an area and get a client-patient load, the Public Health Service hopes that you will remain in that area. That's an additional burden.

You have to be poor to want to go into Public Health Service anyway. Then they send you to areas in which there is a shortage of physicians. There isn't a shortage of physicians in New York, even though there's a shortage in Harlem. So you get sent to Iowa, Minnesota, the bayous of Louisiana-you're not from there. So what happens to your career choices and your dreams?—Eventually you want to go back to Harlem Hospital. become part of the internal medicine department there, move up, become chairman of that department, make some influence on this hospital in this community-forget it. In order to make those kind of decisions, you have to be able to avoid indebtedness to the government. To have the power to make career choices based upon aspirations and dreams, you need not to have accumulated a great deal of debt through medical school.

Those economically disadvantaged students who are entering now are going to be debt-accumulators. My class, that graduated in 1981, I think is the first class of black graduates from medical school to have graduated with tremendous debt. The classes before them had gotten a good deal of financial aid. The black medical establishment, as well as the country as a whole, is not prepared for this reality-that these new doctors aren't able to afford to locate in Harlem or the east side of Detroit, that these new doctors are economically poor. They have potential. but they are in \$30 to \$40 thousand worth of debt. And that's rough, that's real rough.

In order to set up a practice now, there are probably two traditional ways: to inherit one, that means to take over from a doctor who's retiring; or to establish your own. To establish your own requires a great deal of money. Few, if any, black doctors who graduated from medical school can do that, can afford to get enough money in terms of a loan to just open up an office wherever they want to and buy all their equipment on loan-it's not going to happen. That question is going to be another critical awakening for the black medical school graduate, who will confront, perhaps for the first time the reality that, "I still don't have what it takes to be an upper-class elite white male."  $\Box$ 

Feminist Health Activism in Chicago

# STEERING CLEAR OF THE MEDICAL MAINSTREAM

#### by Bonnie Kay and Carol Regan

In terms of influencing the system which produces medical services in the U.S., one of the best things that has ever happened to women seeking abortions is that a large part of the abortion services delivery system has stayed outside the traditional hospital-based system of medical care. Staying outside the medical mainstream has permitted the development of services which are responsive to women's needs and has allowed women greater power to effect changes. Understanding the characteristics of abortion as a medical service and their implications may suggest ways of thinking about change in other well-health and elective health care services.

The struggle over how abortion services are organized, controlled, and quality-enforced has been fought on many fronts. The case of a group of women in Chicago and their fight for changes in abortion and other health services for women provides an exciting example of this struggle. Before telling their story, we first highlight some of the characteristics of abortion services that have made them more conducive to influence and control by women.

Knowledge of medical procedures is usually in the exclusive domain of the medical practitioner. In the case of abortion, however, this is no longer entirely true. The women's movement is to be credited with encouraging women to participate actively in their health care as well as developing a supportive climate for health-consumer activism generally.

Control of the demand for abortion rests with women seeking the service. A woman who has decided to have an abortion has made several critical decisions

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Carol Regan is a Research Assistant and graduate student in the School of Public Health, University of Michigan. She has been active in women's and health advocacy organizations. which, for many medical services, are usually made by the medical provider: she has assessed the "symptoms," she has diagnosed the condition (sought a pregnancy confirmation), she has made a decision as to the appropriate treatment. The important question then becomes "Which provider?", and the outcome depends on how much information she has about the characteristics of different providers and whether she uses such information in making a choice. Providers who organize their services to meet consumer expectations will thus be at an advantage.

There has been a gradual but steady decline in the number of abortions performed in hospitals since 1975. This trend is of concern in terms of its negative impact on geographic access to services. Much of the research concerned with the availability of elective abortion services has concentrated on attitudes of physicians and the subsequent actions taken by hospitals to curtail or eliminate elective abortions due to pressures from their professional staff. While attitudes are of great importance, economic factors also play a role.

Trends since 1973 show an increasing number of providers who are delivering services in the form of free-standing clinics which specialize in ambulatory abortion and which have large caseloads.<sup>2</sup> By specializing in one surgical procedure, clinics realize savings from performing a large number of procedures because the fixed costs of operation are spread over a large number of cases. Depending on the degree of control women as clients and potential clients can exercise, part of these savings could be passed on in the form of lower prices or used to improve the quality of care.

Since 1973 the increases in the price of an abortion at clinics have been substantially lower than increases in the cost of living and increases in hospital and physician fees during the same period. A national sample of prices charged for first trimester abortions over the period

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<sup>\*</sup>Well-health care refers to services which are intended to sustain a state of good health or prevent the onset of poor health.

1978-1981 indicates a 2% increase in the average price paid.<sup>3</sup> This is in contrast with yearly increases on the order of 15% for hospital services generally.

Hospitals must contend with restrictions in pricing and publicizing services. When elective first trimester abortions are treated as inpatient procedures, as they are in many hospitals, costs are well above those for clinic services. Even for outpatient care, pricing data suggest that hospital costs which include substantial fixed costs for the institution are considerably higher than those of a free-standing specialized clinic. Furthermore, limited third party coverage provides another disincentive to providing services. We would suggest that the clinic has become the predominant provider because it can produce a lower-priced service at a higher level of quality and an environment where women have considerable control over the service and are able to exercise this control.

Unlike other personal medical servies, information on abortion is available through the public media. Abortion is unique in that it is one of the few medical services that is advertised, making it possible to compare and evaluate alternative providers. Much of the information women consider important in this selection can be obtained from a telephone call. Facilities which can publicize their phone numbers and are organized to routinely handle information-sharing in this manner are at an advantage in terms of making their services known. This is the case chiefly for clinics, which can provide staff for telephone and outreach activities. It is generally not the case for hospitals, which handle elective abortion as individual cases referred by private physicians.

Due to the key political and economic characteristics of elective abortion, women have been able to effect changes in the way abortion and well-health services are provided. Through the initial focus on making abortion legally available, women gained political organizing skills. Since organized, they have used economic pressure to influence the way abortions are provided. The information, advocacy, and monitoring network that grew out of the fight for abortion services in Chicago helps illustrate this.

#### Roots Of Health Activism In Chicago

Since the mid-1960s, Chicago has been the site of considerable grass roots activity connected with the women's movement. The Chicago Women's Liberation Union (CWLU), formed by many with earlier civil rights movement experiences, used health care as a central organizing issue in the city. Control over their reproductive health was one of the most fundamental issues for women.



Liberalization of restrictive state abortion legislation was a major focal point of organizing, but political lobbying was not the only tactic. The Abortion Counseling Service, which became known as the "Jane Collective," was a part of CWLU and was responsible for providing over 11,000 abortions to Chicago-area women in the three years prior to the January 1973 Supreme Court rulings making abortion legal. By the time of the rulings, there existed a substantial network of women in the city with not only organizing skills but skills as providers of abortion services, including the medical procedure, advocacy and informational counseling, and administration.

Because of these rulings, activists in the abortion struggle were now becoming involved in influencing how legal abortion services should be organized and delivered. Some took staff positions as counselors and patient advocates in clinics which were opening throughout the city. One outgrowth was the permanent incorporation of counseling as information-sharing, as well as the encouragement of active participation of women in making decisions about their health as an integral part of the clinic's services.

There were frustrations too. After the initial glow, some staff found they had been hired as "window dressing"—a means to attract patients to a facility. In Chi-

cago in particular, counseling staff became the most expendable personnel when licensing regulations, created by the Chicago Board of Health, were written with an almost exclusive emphasis on the medical care component of the service. Even with the best intentions, one clinic with a strong counseling and patient advocate program was forced to cut back counseling staff and rechannel resources in order to remodel their facility to meet hospital-like facility codes.<sup>8</sup>

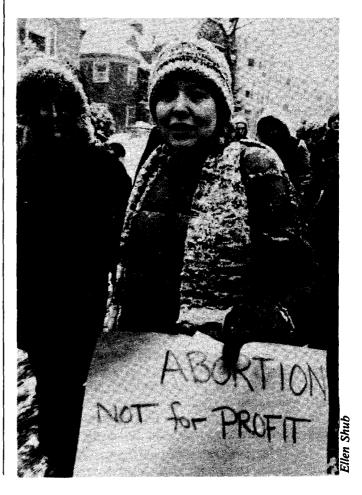
The creation of the Abortion Task Force by CWLU members was another result of post-January 1973 activity. Joined by women from the "Reproduction and Its Control Committee" of the Chicago chapter of NOW, nurses, and other health workers, it prepared guidelines for high-quality abortion care from a woman's point of view. The Task Force met with officials of the Illinois Hospital Association and the American College of Obstetricians and Gynecologists to enlist their support in influencing local licensing regulations. The Task Force's efforts were met with cautious enthusiasm by these organizations. Though they were sympathetic in some ways to these women's concerns, attitudes of their constituencies and political pressures made open support unlikely.

Because of Home Rule\*, the Board of Health which is the city's policy formulator regarding health services. was able to effect legally binding regulation of health services within Chicago boundaries. Members of the Board are appointed for life by the Mayor (then Richard J. Daley), and on the issue of abortion, reflected the anti abortion views of the conservative state legislature. The political strategy of anti abortion forces was to press for the most conservative interpretation possible of regulations left to state and local discretion. The result for Chicago was facility registration requirements which focused almost exclusively on creating a hospital-like environment within a facility despite the fact that most procedures were performed in free-standing clinics. The regulations reflected little of what the Abortion Task Force had lobbied for. Members of the Board admitted the requirements were probably too restrictive and would eventually be declared unconstitutional.9 Politically, this amounted to a delay tactic and provided support for future anti abortion amendments. The Abortion Task Force filed suit in August 1973. A year later, the regulations were judged too restrictive by a state court and declared void.

In the meantime, clinics were opening their doors, one of them performing as many as one hundred procedures a day. Despite all the activity surrounding the creation of regulations, the power of the Board of Health, and the relative powerlessness of the Abortion Task Force to influence the regulations, the city had few resources to devote to monitoring the care provided by facilities. It was this weak link between regulation and implementation which provided the opportunity for Chicago women to begin to influence the system.

#### **HERS**

The Health Evaluation Referral Service (HERS) was formed as the day-to-day operational arm of the Abortion Task Force. Using the telephone tape machine inherited from "Jane" and operating out of a room in CWLU offices, HERS began as a 24-hour callback telephone referral service with information about abortion services in Chicago. With the Task Force guidelines as a beginning, members of HERS developed a set of evaluation criteria and began to visit and monitor clinics in the city. Women calling in for referrals were requested to call back and provide information about their experience at a facility. A list of recommended providers was developed and sent to a wide range of organizations



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<sup>\*</sup>Home rule is a concept of local government involving a legal division of power between the state and certain local governments. The Illinois constitution provides that a home rule unit may exercise the power to regulate for the protection of public health, to license, to tax, and to incur debt.

which were involved in abortion information-referral. Clinics began calling and requesting HERS to make visits to their facilities. When feedback from women revealed unethical practices at one clinic, members of HERS posed as patients, documented the complaints and were instrumental in initiating a grand jury investigation. As a result, Women's Medical Facility, Inc., the clinic in question, was closed shortly thereafter. HERS' reputation as a watchdog organization for women's health care grew.

But this struggle was complex. By being responsible for closing a clinic, HERS appeared on one level to provide support for Chicago's anti-abortion forces. When that story, as well as a larger-scale investigation of clinics four years later, hit the press, <sup>10</sup> it was difficult for the general public to determine whether clinics were being closed because of unethical medical practices (e.g. performing abortions on women who were not pregnant) or whether the closings were a result of anti-abortion pressures.

In the meantime, an increasing number of requests from callers for gynecologists and related well-health services prompted the formation of a "doctor book." Initially a three-ring notebook with general practice information on physicians and blank pages following for call-back reactions and comments, the doctor book grew. A filing system was needed as well as a more orderly process for scheduling clinic visits, assigning telephone watching responsibilities, and other tasks. One clinic had agreed to offer a number of reduced-fee abortions if HERS would screen callers and evaluate those most in need.

As an organization, HERS functioned as a non-hierarchical group making decisions chiefly by consensus. With a core of about ten women, the agreed commitment was to "phone sit" a minimum of several hours each week. Clinic visit responsibilities were shared initially but began to fall on those whose work and personal life schedules were freer. Office continuity was needed; two or three volunteered hours a week in the office were not enough. The administrative tasks resulting from a growing accumulation of information were not getting done. Most importantly, HERS wanted to use this information to influence how health care services were being provided.

In 1975, members began pledging each month what money they could afford to support a part-time staff person. Money-making projects and several small grants followed in the next several years. HERS applied for tax-exempt status as a nonprofit organization and solicited contributions on a wider scale.

By 1978, two full-time staff were hired. The doctor's directory had grown to cover several hundred

Chicago-area practices and was reorganized and cross-referenced by medical specialty, geographic area, hospital affiliation, and practice characteristics such as whether the doctor accepted Medicaid patients or treated teenagers without parental consent. The outward structure of the group changed, forming an official Board of Directors as the decision-making unit. HERS contracted with the Illinois Family Planning Council to operate a Teen Hot Line and was faced for the first time with losing some of its autonomy. After a year, the contract was terminated and the group resumed fundraising through grants and contributions, returning decision-making to the group.



At present, over 300 medical practices, 35 psychotherapists, and 6 abortion clinics are on HERS' referral lists. Members answered 3000 calls in 1981. Now even physicians call the office asking if they can be put on the list. HERS feels it has made an impact on changing the way health care services are provided. In the words of Mary Lou Gallagher, HERS Executive Director,

We believe women can evaluate health care, and through our buying power as the major health consumers in this country, we can and should be making changes in the system. We see women choosing doctors by their affiliation with those hospitals with the most flexibility in maternity areas. Women have changed the way hospitals deal with labor and delivery. Family-centered maternity units have increased phenomenally over the last several years in direct response to consumer demand.

Abortion clinics, too, have made major changes in the provision of services to qualify for HERS' referral list. In Chicago, 22 health and social service agencies, refer women to HERS for information.

HERS elected to critique the system, but more important, to go beyond that point and organize women to bring about change. Once providers knew that women

made choices using information provided by HERS and knew the number of women was significant, changes occurred. Once they perceived this, it did not matter whether every woman coming to a particular clinic had been referred by HERS. Information was an effective pressure because our medical care system functions by keeping information relatively inaccessible.

Understanding the history of the abortion movement and how women's health organizations grew out of this is critical if we are to continue in the fight for an equitable health system. Also, it gives us a starting point for examining issues of quality of health care services and control over those services. At present, abortion is being attacked on all fronts. Issues of access are at stake, but the defensive stance required by pro choice advocates just to maintain the right to a safe and legal abortion has not prevented women's health groups all over the country from continuing to push for changes in many different health services for women.

Given the present political and economic climate, we can be sure that if abortion services were in the exclusive domain of hospitals, those services would be the first to be eliminated due to "budget cuts." So, as the word "health" becomes synonymous with the idea of cost containment for the Reagan Administration, we must begin to examine the alternatives that are presently working, and propose new ones, as ways to combat future cuts.

The struggle for abortion rights has had a powerful influence on women's experiences in medical care. From these experiences, a feminist critique of obstetrics and gynecological care developed. The growth in obstetric technology in the past few years has resulted in women challenging medical domination of the processes of childbirth. Alternatives to hospital deliveries, such as birthing centers and homebirth, are becoming more common.

Understanding how women have used economic pressure and political organizing to effect change in reproductive health services provides us with a model for reforming other health services. Further examination of these characteristics and better understanding of the economics of health service delivery may open up other avenues for change.

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#### The Wonder Drug

(Continued from page 16)

"Since there are so few women in this group, it is difficult to predict what the outcome will be. I feel like a living determinant of the graph." She points out another reason for our lack of knowledge, "We're a medical embarassment. We're living reminders. I think that the whole medical community would like to forget that DES ever happened."

The philosophy of a substantial segment of the medical community is now to convince DES-exposed people of our "normality" rather than our "abnormality." One physician responded to a DES Action questionnaire: "More time should go to convincing them (DES daughters) of their normalcy. You people frighten me! I will accept your referrals, but will downplay the condition." As a result, when we seek medical care for problems ranging from menstrual irregularity to frequent vaginal infections to infertility, we are often told not to worry—it is not DES related. What they really mean is that they do not know, and they do not want to discuss the possibility with us. To admit this would erode some of the power that they as "experts" have over us.



Of course, it serves no one to become alarmist about our exposure. The known risk of cancer is relatively low, and there certainly are illnesses among DES-exposed people that are not DES related. The trouble is that the bland reassurances of the doctors are

not very reassuring. They are the same people who told our mothers "don't worry, take the 'vitamins'." We will not accept the same patterns of paternalism and sexism in health care. Our reassurance will come from knowledge, participation in our own health care, and control over our own bodies.

#### **Political Implications**

When I started trying to come to terms with my DES exposure on a political level, I found myself facing many unanticipated conflicts. Sorting through these conflicts required deepening my understanding of the notion that "the personal is political." I had to acknowledge a tension between collective action and individual struggles, and to recognize the differing roles played by those who are directly affected by a particular issue and by those who participate but are not so directly affected. The insights that are coming from this process have a significance that goes beyong the issue of DES itself.

A few years ago, although I would have seen the importance of a social solution through collective action, I would not have worked in a group like DES Action because I would not have considered the issue "important enough"—not as important as many other social and political issues. Eventually, through various political activities, I came to believe that most people are drawn into working for social change not through an intellectual process as I was but through their own experiences with the social and economic system as it affects them. In such a context, DES-exposed people are a group who have very directly felt the effects of a health care system which is organized for profits rather than to serve our medical needs.

When a local chapter of DES Action formed a year ago, I joined. I expected to be able to formulate a coherent analysis and share it with the group, and that as a DES daughter, my direct involvement should contribute to my motivation and energy to work in the group. Instead, I often felt politically myopic and slow to make connections. When I was more removed from concern about my own health problems, I felt I contributed more to the group. My participation in the group did not work as I thought it "should."

While it is true that long-range solutions are necessarily social ones and will be won through collective action, we still have to wage our day-to-day individual battles. We as DES exposed people have no alternative but to deal with the medical establishment and cope as best we can with the resources we have at our disposal. We have no choice but to undertake both the collective and individual struggles, but we must

recognize that they sometimes compete for our energies rather than complementing and contributing to each other.

Our exposure to DES may, in the long run, motivate us to political action, but at some levels our immediate health concerns can interfere. Karen, the DES Action member mentioned earlier, talks about this conflict in terms of her own involvement.

You don't think of it initially. At first, you're really concerned about your physical well-being and your future. It's something you eventually get up in arms about.

Judith Baker is a nonexposed member of DES Action. Regarding the way our exposure or nonexposure affects our involvement with the group, she observed.

it's also sometimes hard for me to take the lead because I am not exposed and do not suffer from the fear and potential/actual ill health the DES exposure can/does create. I'm afraid I'm not compassionate enough.

Nonexposed people, although they have these special concerns can make important contributions to such a group. Since they are not caught in the same individual/social contradiction, they can offer a slightly different perspective and their presence can tend to moderate that conflict for the exposed. In talking about why she chooses to stay involved, Judith recognizes the tensions that exist between independence and collective action,

In little steps, I work to change people's lives so they will be better equipped to stand up for themselves. The lessons learned about DES can enable exposed and nonexposed people to stand up, to question authority, become more selfconfident and self-assured, and yet gain strength from working collectively.

To recognize the importance of the role of the nonexposed in these activities is to reject the more general idea that it is only those who are directly affected by a certain form of oppression who must struggle against it. As I think about my own failure to come to terms with my DES exposure over certain periods of time, analogies from contemporary politics come to mind. One is that many women have at various times suppressed questions about our experiences as women either because we thought them not of general importance or because we accepted, at some level, the argument that raising these questions was "diversionary." As our feminist perspectives developed, we changed not only our work on "women's issues", but challenged the political framework that led to our previous positions. Another analogy is the emphasis on support work among the U.S. left. While we must stress the importance of supporting the struggles of peoples around the world, this support should come in the form of solidarity and not as a substitute for confronting and struggling against oppression in our own country, our own neighborhoods, and our own lives.

We must demand our place in the formulation of health policies and research, which far from being objective processes, have generally been controlled by the medical establishment and the drug companies, who stand to gain fame and profits.

By no means am I suggesting that single-issue politics should become our main focus. Neither do I mean to imply that these issues can be completely resolved in the absence of more fundamental social and economic transformation. But until we are able to acknowledge the ways in which we are most directly affected by the system in which we live, and integrate these analyses into our view of the world, we will be unable to understand how others in similar positions can be moved to new understandings and activities. Until we are able to confront our own oppression, we will be saddled with simplistic and arrogant analyses that fail to take into consideration the sometimes contradictory relationship of survival in the system and collective action for change.

In response to the greed, sexism, and elitism that characterize the health care system that gave us DES and continues to profit from its use, we are raising the demands of control over our own bodies and participation in our own health care, both at a personal level and at a social level. At the personal level, we must develop the self-confidence to question our doctors, find information about our illnesses and alternative treatments. At a social level, we must demand our place in the formulation of health policy and research, which far from being objective processes, have generally been controlled by the medical establishment and the drug companies who stand to gain fame and profits. We catch glimpses of what can happen when we, the subjects, take a role in the process. It was the mother of one of the original victims of adenocarcinoma—hardly a disinterested scientifically objective observer—who first suggested that DES played a role. Like workers concerned about occupational health or the residents of Love Canal, we who have compared notes in groups like DES Action know that in many cases we are finding out is wrong with us before the "experts" are. What would happen if, rather than covering their tracks, they could listen to what we know and use it as a basis for their research? We must demand to take this active role.

#### **GLOSSARY**

Adenosis: A benign condition in which glandular tissue is present in the vagina, where this type of tissue does not normally appear.

Biopsy: A diagnostic procedure in which a very small tissue sample is obtained for microscopic examination.

Cervical Incompetence: A condition in which the cervical muscles in a pregnant women are not strong enough to bear the weight of the developing fetus. This often results in miscarriage or premature birth.

Colposcopy: A method of examination which uses a colposcope, a magnifying lens designed to examine the tissue of the vagina and the cervix. A camera may be attached to take pictures of the tissues.

Ectopic Pregnancy: Pregnancy occurring outside the uterus, often in the tubes. It is a potentially life-threatening condition for the pregnant woman. Epididymal cysts: Cysts in the epididymus, the collecting structure in the back of each testicle where mature sperm are stored.

Hooded, collared, or cockscomb cervix: Abnormal ridges of tissue around the cervix.

In utero: In the mother's womb. DES sons and daughters were exposed to DES in utero.

lodine stain test (also known as Schiller's or Lugol test): A dilute solution of iodine is applied to the cervix and vagina. Normal tissue stains brown; adenosis and other abnormal tissues do not.

Microphallus: An abnormally small penis (less than 4 centimeters while flaccid).

Placebo: A "sugar pill" similar in appearance to a drug being tested.

Undescended testicles: Testicles which remain in the abdominal cavity rather than descending into the scrotal sac. Men with undescended testicles (even if they are not DES-exposed) have a greater rate of testicular cancer.

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Bitter Fruit: The Untold Story of the American Coup In Guatemala, Stephen Schlesinger & Stephen Kinzer, Doubleday & Company (501 Franklin Avenue, Garden City, NY 11530), 1982, 320 pp., \$16.95. About United Fruit's solution to the "land reform problem".

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#### **ENERGY**

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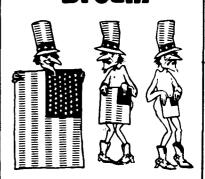
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#### CORRECTION

In the Sept/Oct 1982, vol. 14 no. 5, SftP, several paragraphs in the article, "Asbestos in the Classroom" were incorrectly ordered. The paragraph on page 19 that begins, "The federal government stepped cautiously." through the end of that page should be switched with the paragraph beginning, "In the early years the task forced tried..." until the paragraph ending with "the 1974 appropriation, but much remained..."

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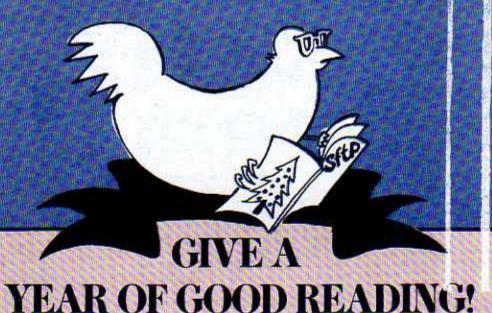
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