Surviving the Dalkon Shield IUD

WOMEN v. The Pharmaceutical Industry

KAREN M. HICKS

FOREWORD BY
Diana Scully

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Foreword

I met Karen Hicks, founder of the Dalkon Shield Information Network (DSIN), on her first trip to Richmond, Virginia, in May 1987. Richmond is the home of the A. H. Robins Co., the pharmaceutical house that invented and manufactured the Dalkon Shield intrauterine device. Karen contacted me because she had read my book, *Men Who Control Women's Health*, and thought I might be an ally in the Dalkon Shield claimants' cause. I clearly recall the day Karen sat in my university office and told me about her dread of coming to Richmond because of all it symbolized for her, about the suffering she had experienced as a result of the Dalkon Shield, and about her insecurity over the enormous task she was about to undertake. I encouraged her to go forward but also warned that she would never again be the same: It would be a transforming experience. I was right!

Surviving the Dalkon Shield IUD is Karen Hicks's compelling account of the Dalkon Shield tragedy and how a small group of women took on the corporate giant, A. H. Robins. It is also a story of corporate greed and callous disregard for the reproductive health and emotional well-being of women told by a survivor of the Dalkon Shield. In promoting and selling the Dalkon Shield, despite knowledge of its defective design utilizing a string that promoted infection, A. H. Robins caused countless numbers of women severe side effects that included bleeding, pain, inflamed and perforated uteri, spontaneous abortions, infertility, sterility, birth defects in offspring, and even, in some cases, death.

There is another side to the Dalkon Shield story. It stimulated a highly effective and passionate grassroots organization, DSIN, and changed the lives of many of the women who struggled to force A. H. Robins to take responsibility for its actions and compensate victims for their suffering and loss. There were major frustrations along

the way, too: As candidly recounted by Karen Hicks, long and draining litigation, A. H. Robins's bankruptcy tactics, the lack of support for DSIN among some feminist organizations, and internal disagreements among DSIN leaders all took a toll on DSIN members. Richmond, if not hostile, was less than welcoming. In fact, at the height of Robins's bankruptcy proceeding, local DJs frequently aired a song that lamented the possibility of lost jobs for Robins's workers and complained about the "selfishness" of Dalkon Shield claimants! Even among local feminists there was apathy for the claimants' cause. Indeed, the 1976 Virginia celebration of the United Nations Decade of Women was held at the Robins Center, a costly athletic facility given by the Robins family to the University of Richmond. Few saw the irony of holding a celebration of women in a facility built, no doubt at least in part, with Dalkon Shield profits.

Yet amidst the frustration and tragedy there was empowerment. I recall the Richmond rally during one of the first Dalkon Shield proceedings. The woman walking beside me, obviously tired and upset, had received a notice of the proceeding from the court. Debilitated by her Dalkon Shield-related injuries and believing that her claim would be settled that day, she used her life savings to fly from New York to Richmond. The cab ride from the airport the day before had taken her last dollar and, with no money for food, she had slept in the park that night. Now she had learned that there would be no settlement that day or any time soon. Yet, as I drove her to the airport that night, she told me she didn't regret her decision to come to Richmond. For her, being with other survivors and participating in the rally restored her sense of personal control and elevated her spirits.

Clearly, through DSIN, members experienced the personal as political and learned that through collective action, women can make a difference. Credit for that goes to Karen Hicks, who undoubtedly knows that empowering women is the best feminist work. *Surviving the Dalkon Shield IUD* is an important chapter in our herstory.

Diana Scully
Richmond, Virginia

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1 The Context of the Injustice

More than 2 million U.S. women and a total of 4 million women worldwide used the Dalkon Shield intrauterine birth control device (IUD) between 1970 and 1974. The Shield was promoted as the "Cadillac of contraception." For three years while the Shield was being prescribed, neither physicians nor women were warned of the dangers it posed as a defective birth control product. Because it was distributed on a mass scale, the Dalkon Shield is now acknowledged as the most notorious contraceptive, one that caused widespread and extensive damages to its users.

The Dalkon Shield became a major women's health care tragedy, one that was caused by corporate misconduct on the part of Dr. Hugh Davis, the Shield's inventor, and corporate executives of A. H. Robins Company, the pharmaceutical firm that began to manufacture the device in the early 1970s. This threat to women's bodies was exacerbated by the failure of the Food and Drug Administration (FDA) to act: It neither demanded the removal of the Shield from the market nor instituted a comprehensive recall of this defective product.

The history of the Shield's development, marketing, and distribution, as well as the complex and lengthy litigation surrounding Robins, has been ably documented (Mintz, 1985; Perry & Dawson, 1985; Sobol, 1991). Among the many people who place the blame for this disaster on the profit motive is U.S. District Court Judge Miles Lord, who presided over some 23 Shield-related lawsuits in 1984. In his courtroom, Lord chastised Robins executives for not warning women and their doctors about the Shield's dangers:

> The only conceivable reasons you have not recalled this product are that it would hurt your balance sheet and alert women who already have been harmed that you may be liable for their injuries. You have taken the bottom line as your guiding beacon, and the low road as your route. This is corporate irresponsibility at its meanest. (Mintz, 1985, p. 267)

The extensively documented Dalkon Shield injuries now on record include severe hemorrhaging, septic abortions, infected mis-

carriages, an epidemic of pelvic inflammatory disease (PID) among users, ectopic pregnancies, perforated uteri, infertility, mutilated and lost reproductive organs, birth defects in children, and at least 20 documented deaths. The psychosocial damages include emotional trauma from infertility and loss of bodily integrity, economic hardship due to lost income or career opportunities, and strained or failed personal relationships.

Thousands of women continue to suffer from injuries that originally were unexplained and often were untreated or misdiagnosed because vital information was suppressed for so many years. Although the litigation surrounding this case has inspired countless newspaper articles and several books, very little has been made public about the specific adverse effects this tragedy has had on the hundreds of thousands of injured women and their significant others.

The victims of cases involving the reckless endangerment of the public health are typically submerged in a culture of silence to the extent that they themselves hardly know the true reasons for their physical maladies; thus they do not understand the connections between those injuries and the resulting array of problems they face. Corporations like Robins have the power and privilege to engage in tactics of protracted denial and cover-up, which have the consequence of delaying early medical treatments and increasing the prospects of chronic and life-threatening damage. Therefore the full scope of the injustice can remain misunderstood and underappreciated for decades, making the social reform of medicine difficult or impossible.

This book examines the embryonic stage of a social movement initiated by a small group of former Dalkon Shield users who became enraged by their circumstances, striking out of isolation and powerlessness to battle the official worldview of them and to propose an agenda for social reform in medical and pharmaceutical practice. The Dalkon Shield users who became members and leaders of the Dalkon Shield Information Network (DSIN) are the subjects of this book. The political activism of the women who formed DSIN was partially a response to their rage about their shared stories of medical horror. These women interrupted the culture of silence and gave voice to the injustice they had lived with for the better part of 20 years.

Because I am the principal founder of the DSIN, its story is, in large measure, my own story. As a Dalkon Shield survivor and a social scientist, I am in a unique position to document the history of this instance of women organizing for social change. I have worked, essentially, in two modes as a researcher: first as an interested party, a participant seeking useful information about the legal process, and

then, after largely withdrawing after three years of direct participation, as a social scientist analyzing the process. The insider's perspective of a social movement in progress is, to my knowledge, almost nonexistent in scholarly studies of social movements. My intent is to document the mobilization impulses that led to political activism, the strategies that emerged to challenge the powerful institutions, the complex web of relations, and the transformation of some "ordinary" women into battleworthy warriors.

A more thorough understanding of the women injured by the Dalkon Shield, as well as of the range of negative physical, psychological, and socioeconomic sequelae, would reveal how deeply pernicious victimization of health care consumers, particularly women, is and how it is perpetuated by two powerful social institutions—medicine and the law. Individuals who remain isolated from one another as private clients of doctors, therapists, or lawyers are unable to establish the links necessary to fight for just solutions to cases of medical abuse. Documenting the commonalities of experience is a necessary step in focusing on the structural conditions that tolerate this type of medical exploitation of and violence against women. Fine (1986) argues that research on such collective experience is urgently needed in order to draw cases that maintain pervasive victim-blaming ideologies, such as the Dalkon Shield case, into the public consciousness. Only then can programs of reform be formulated.

MEDICAL FRAUD PUTS WOMEN AT RISK

Intrauterine birth control devices are an ancient form of contraception. There are historical references to herders in desert cultures placing stones in the uteri of camels during long, arduous treks across rugged terrain. The first attempts to introduce IUDs into widespread human use during the late 1800s failed because so many women died of massive infections.

Most modern IUDs are made of polyethylene, and many medicated models contain copper or hormones. They require sophisticated physician/clinician skill for insertion and removal as well as for patient management during use. IUDs are inserted into the uterus via the vagina. The cervix (which connects the vagina to the uterus) must be stretched with a special instrument during insertion and removal. Most IUD models have tailstrings attached, which hang down into the vagina and are used to check for proper placement and for removal. The medical literature is inconclusive on the precise mechanism of

IUD action. The IUD may prevent fertilization of the egg (if it contains copper or hormones), but, more often, it interferes with implantation of an embryo. Therefore it can be categorized both as a contraceptive and as a contragestive device.

The development of modern antibiotics in the early 1900s made IUDs feasible, and the "pill scare" in the late 1960s led to an era of intense competition among pharmaceutical companies to find a profitable alternative to the early oral contraceptive, which had caused serious injury. In 1973, Dr. Joseph Mamana, the chief of the FDA's Medical Devices Compliance Section, was quoted in a newspaper interview:

> Anyone—it doesn't even have to be a doctor—can go down to his basement, get a few hairpins, stick them together, and call it an IUD. There's nothing we can do about it until someone is injured or dies. ("Interview . . . ," 1973, p. 16)

The Dalkon Shield IUD was A. H. Robins's first plunge into gynecological/reproductive products. For the previous hundred years of its existence, this family-owned and -operated pharmaceutical company had built a strong, positive reputation on cold and flu remedies. Robins's aggressive marketing campaign and advertising literature claimed that the Dalkon Shield was "the superior" birth control method, with *no* systemic bodily harm or ill effects. These claims turned out to be not only patently false but life-threatening to the women who entrusted their family-planning needs to this product. In the early weeks of the Shield's mass distribution, physicians began sending in alarming reports of injury to Robins's medical staff; yet company executives embarked on a strategy of deliberately and willfully suppressing the vital information that could have prevented the coming mass tragedy (Mintz, 1985).

The leading theory about how the Dalkon Shield causes injury cites a phenomenon called *wicking*, involving the multifilament tailstring, that hangs downward from the uterus into the vagina. All previous IUD models had monofilament tailstrings. The grooves in the twisted filaments, which were tied into a double knot on the Shield, allowed bacteria to settle there and ultimately to travel up into the sterile uterus. Wayne Crowder, a quality control supervisor at the Robins's manufacturing plant, observed problems with the strings and speculated about the dangers of infection and septic abortion. He recommended methods to correct the problems, but company officials ignored him. When he persisted in his demands, for reasons of conscience, he was fired: Julian Ross, his supervisor at the plant, told him his conscience did not pay his salary (Mintz, 1985, p. 141).

The transcripts of a 1973 congressional hearing and Robins's company records that were part of a federal grand jury investigation reveal the magnitude of the corporate and medical misconduct. The 1973 hearing, conducted by the U.S. House of Representatives, was precipitated by the Dalkon Shield crisis. Pressure for the hearing came from doctors and women's health activists alarmed by the proliferation of severe and life-threatening injuries to Dalkon Shield users. The congressional hearing was necessary before the FDA would regulate IUDs.

The documents from the congressional hearing and the federal investigation reveal a scientific fraud with far-reaching consequences. Dr. Hugh Davis, professor of obstetrics and gynecology and head of a gynecologic clinic at Johns Hopkins University, co-invented the Shield with Irwin Lerner, an inventor and electrical engineer. Davis falsified his original experimental data, had his research published in a prestigious medical journal, and then lied under oath about his personal financial stake in the manufacture and sale of the device (Mintz, 1985). In 1970, Davis sold the Shield's distribution rights to the A. H. Robins Company, which rushed the Shield into production in order to capitalize on the birth control pill scare.

The Dalkon Shield studies were dangerously defective. Only Dr. Davis conducted the brief (12 months) and severely flawed research. He counted his 640 subjects as a grand total of 3,549 woman-months of experience, but this figure was grossly misleading, since the average user in his study used the Shield for only five months (Mintz, 1985, p. 31). Davis recommended that these women use a back-up method of birth control in the first three months post-insertion (Perry & Dawson, 1985). Additionally, his study had a 60% discontinuation rate. Because Davis used the established "life-table" method (the benchmark protocol used in contraceptive trials), the women who dropped out of the clinical trials were lost to follow-up, so complications were not included in the study's results (Committee on Government Operations, p. 61). Clearly, data about the women who discontinued use during the trials would have been invaluable.

Davis wrote a laudatory article on the Dalkon Shield, which was published in the *American Journal of Obstetrics and Gynecology* (Davis, 1970). He claimed both a superior low-pregnancy and low-complication rate for the Shield relative to other IUDs then on the market. Davis's study slipped through the system unchecked: No physician appears to have examined the validity of his study before its publication. Davis himself never conducted a safety study, never identified himself as co-inventor of the Shield, and never mentioned his recommendation of a back-up method. His article was misrepresented

"as the work of an unbiased, scientific observer" (Perry & Dawson, 1985, p. 35).

Davis actually submitted the draft of his article only days after the study was completed, which meant that his pregnancy statistics did not reflect women who might have become pregnant in the latter part of the study. In fact, that is exactly what happened. The actual pregnancy rate was between 3% and 5%, which proved the Dalkon Shield to be decidedly inferior to both the pill and other IUDs on the market (Perry & Dawson, 1985). By 1971, the Dalkon Shield had become the most popular IUD on the market, primarily because of the favorable reception of Davis's published article.

A. H. ROBINS SHIELDS ITS ASSETS

Following a series of lawsuits between 1978 and 1984, the A. H. Robins Company petitioned the U.S. Bankruptcy Court in 1985 for protection under Chapter 11 of the U.S. Bankruptcy Code. Chapter 11 requires a distressed business to formulate a plan of reorganization in order to satisfy all its debtors. At the time of the Robins petition, the company was financially robust, with cash on hand and virtually no corporate debt. The company claimed, however, that the escalating number of Dalkon Shield lawsuits would jeopardize its solvency. This petition for protection from bankruptcy coincided with a growing number of monetary damage awards to women in state courts around the country.

Although the initial injuries occurred in the early 1970s, most women did not discover that the Dalkon Shield was the actual cause of their physical damages until around 1986, as a result of the publicity surrounding these bankruptcy proceedings. The bankruptcy court ordered Robins in 1985 to implement a publicity campaign to notify injured parties of their rights to file claims for damages. More than 327,000 women filed injury claims against Robins in bankruptcy court by the court-imposed deadline of April 1986. However, court-imposed protocol reduced that original number to approximately 197,000 legitimate claims.

This decade-long delay in public acknowledgment of possible liability exacerbated the early injuries and left thousands of women at grave risk for developing serious, even life-threatening, disease. Even throughout the bankruptcy proceedings, A. H. Robins Company spokespersons continued to assert that "the product is pure" (Morris, 1988c). They implied, as they had in the earlier lawsuits, that the

alleged sexual lifestyles of women (promiscuity and poor hygiene) caused the physical injuries.

In 1988, the sale of the A. H. Robins Company to American Home Products (AHP), a pharmaceutical giant, emerged as the bankruptcy court's solution to the litigation. In February 1988, the reorganization plan was submitted to the bankruptcy court, presided over by U.S. District Court Judge Robert R. Merhige, Jr. By July, Robins's stockholders and a vast majority of the nearly 200,000 women, men, and children whose claims had survived several of the previous court-imposed protocols and deadlines voted on and overwhelmingly approved the plan. By becoming "claimants" against the company, these people surrendered their legal rights to pursue individual lawsuits against Robins, Aetna (Robins's insurer), their doctors, or any other potentially liable entities.[1] The Dalkon Shield Claimants Trust (referred to herein as "the Trust") was infused by $2.45 billion in cash in December 1989, the official date of the plan's consummation. The creation of the Trust was a contentious and heated process during the bankruptcy proceedings, involving the pharmaceutical and insurance industries, court officials, and plaintiffs' attorneys.

In spite of the dazzling size of the Trust, most of the claimants will receive what they and many experienced personal-injury lawyers consider inadequate compensation. As of July 1992, approximately 137,000 of the 197,000 claims have been settled. Of these, 115,000 women received settlements of $1,000 or less. Other women have received various amounts ranging from $1,000 to more than $150,000. A few "baby cases" (children born with birth defects) are reportedly worth about $1 million each. Due to the secrecy of the Trust's operations and the lack of access to information imposed by the Trust officials on almost all facets of the Trust's operation, only Trust officials have specific information about the process used to determine the settlements.

Several new legal precedents were established during Robins's Chapter 11 litigation, including (1) allowing immediate reimbursement to stockholders at the time of the sale, contrary to the existing Bankruptcy Code, which specifies that stockholder payments are to be made only *after* all outstanding debts are settled, (2) giving immunity to third parties not under bankruptcy law protection, in this case the Aetna Insurance Company,[2] and (3) assigning greatly increased authority to the judge sitting on this case[3] in managing the Trust. Indeed, Judge Merhige has been the subject of criticism over his handling of the case and the Trust (Labaton, 1988a, 1988b; Mintz, 1986a, 1986b, 1989b, 1989c; Sobol, 1991).

SILENCING THE VICTIMS

In the Dalkon Shield case, an essentially private source of suffering and injustice, with a private and intimate meaning based on women's sexuality and reproduction, was compounded by a deliberate and cynical pattern of control and manipulation of information that in fact contributed to a secondary victimization of these women. The unwavering public posture of denial from A. H. Robins—which insisted that its product was pure—and the corporation's amply documented complicity in deception and cover-up of its direct role together demand that women's reality about the initial and subsequent victimization be publicized and validated.

The silencing of victims is demonstrated by the repeated use of two mechanisms of information control and manipulation that put the victims at a disadvantage relative to the corporate, medical, and legal interests in this case: (1) denial of wrongdoing on the part of A. H. Robins officials, as already mentioned, and (2) withholding of vital information necessary for the women to receive just treatment and the fullest guarantee of their legal rights. This pattern of withholding vital information by everyone—first by the inventor, then by the A. H. Robins Company and the courts, and now by the Dalkon Shield Claimants Trust—compounded the problems these women have faced for decades. Women were also managed behind closed doors by a varying group of experts, such as doctors, therapists, and lawyers. They had little, if any, opportunity to discover that so many other women had had similar experiences. The victims, as a collective, were socially invisible until the grass-roots activism began in 1987 during the Robins bankruptcy proceedings. The early letters and phone calls to DSIN speak to this effect. The following letter sent to DSIN is typical of thousands of women's responses:

> It has been 16½ years since my Dalkon Shield was removed along with all my reproductive organs and until now, I have felt so totally alone in my agony. Until I read your comments in *The Wall Street Journal*, my emotional, physical, and legal problems seemed insurmountable. (Letter #306)

During the early phase of the bankruptcy proceedings in Richmond, public perception surrounding the case was shaped by the carefully constructed press statements from high-status officials in Robins's public relations department and from the court. The impression created in the media was that Robins was bankrupt, which was

far from the truth. And during the first two years of its Chapter 11 petition in the bankruptcy court, the presiding judge granted Robins six extensions on the submission of a reorganization plan, further delaying the process. As some women experienced it, this was business as usual for Robins, with injured women hanging in limbo indefinitely.

The inadequacy of the court-imposed campaign to locate users was dramatized by the unexpected deluge of telephone calls from women who read an April 1989 issue of *Women's World*, a supermarket tabloid, which ran a story on the Shield and listed DSIN's telephone number ("Are You a Victim . . . ," 1989). More than 500 women called the DSIN hotline over the next several weeks. Most of the women calling claimed that this was the very first piece of information they had ever seen about the dangers of the Dalkon Shield. A preliminary analysis of those telephone call records revealed that women were calling from virtually every state in the United States.

Other anecdotes continue to indicate the lack of resolution to this tragedy. In July 1992, the DSIN hotline received a call from a woman who was still wearing the Shield. She was experiencing traumatic reproductive health problems, and an x-ray had revealed the device. She had been told years ago that it had fallen out.

CORPORATE, MEDICAL, AND LEGAL INTERESTS

According to Petchesky (1984), the real power base that defines women's contraceptive choices resides in the juncture of medical, corporate, and legal interests. Throughout the series of events detailed in this book, I expand Petchesky's hypothesis to include the notion that the consequences of contraceptive tragedy are also defined by the same triad of power. An analysis of the material basis of this case demonstrates that socioeconomic inequities, which favor corporate interests over the rights of injured parties, have prevailed. The sizable assets of the errant corporation have been kept in the hands of A. H. Robins officials and other economic elites, in the following ways:

1. In 1987 alone, Robins's total disbursements for the bankruptcy litigation exceeded $13 million, with payments going to 16 law firms, 6 accounting firms, and 13 court-appointed professional consultants ("Professional Fees," 1988). In 1988, Robins paid $25 million to Rorer, another large pharmaceutical company, as a merger termination fee for reneging on its agreement. (Several companies had

courted Robins, but AHP won the bidding war.) By contrast, not one Dalkon Shield claimant received a penny of financial compensation for life-threatening injuries or urgently needed medical treatments until the bankruptcy litigation was completed at the end of 1989. More than 35,000 claimants are still awaiting review of their claims as of 1992.

2. The value of A. H. Robins shareholders' stock increased fourfold as a result of the merger deal. The Robins family and corporate officials, who owned 42% of A. H. Robins stock, exchanged their shares in Robins for AHP stock. In this transaction, Robins family members and executives, taken in the aggregate, became the largest shareholder of AHP. Additionally, AHP received sizable tax breaks for buying a so-called distressed company.
3. The Robins Company and family successfully separated a substantial portion of total assets and net worth from the Chapter 11 proceeding because many of Robins's subsidiaries were not included in the Chapter 11 proceeding. Furthermore, the Robins family owns other valuable enterprises, including several telecommunications businesses and a wine import business. In 1992, Dalkon Shield women and attorneys were shocked to learn about the election of E. C. Robins, Jr., to the post of honorary president of the American Pharmaceutical Association (M. Pretl, personal communication, February 18, 1992).
4. The Chapter 11 reorganization plan granted the corporation, the Robins family, and all other third parties (primarily the Aetna Surety and Casualty Company) permanent and total immunity from any further Dalkon Shield–related civil litigation. Therefore Dalkon Shield injured parties can turn nowhere else for financial settlements if the Trust is inadequate to provide compensation for their injuries.
5. The Trust has a 20-year lifespan, and its administrative costs have been estimated variously at between 10% and 25% of the total funds. Every important sector of the Trust's operation utilizes services in Richmond, Virginia, Robins's hometown–including the bank that handles the accounts; the real estate leased to house the claims facility; the legal counsel representing the Trust; trade services such as printers, computers, and so forth; and the more than 200 employees, who were recruited principally from the Richmond area.
6. If women hire attorneys, they will pay contingency fees. Many of the lawyers are charging standard contingency fees (roughly one-third) or higher, plus expenses, in spite of the fact that the case preparation to the Trust is straightforward and simple in comparison with pursuing of an individual lawsuit and going to trial. One DSIN leader was awarded a $127,000 settlement by the Trust in 1992; after her lawyer subtracted his fees, she was left with $84,000.

It is the view of many Dalkon Shield users and all the DSIN leaders that the financial compensation program resulting from the Robins bankruptcy settlement does not represent social justice. Their concept of social justice involves three themes. First, DSIN sought to have a major health agency sponsor and conduct a comprehensive, worldwide product recall of the Dalkon Shield. Second, the leaders demanded an investigation of the FDA and its mishandling of the regulatory process. Strengthening the FDA is seen as necessary for the protection of future populations of women and other medical consumers. Third, DSIN was passionate in its desire to see criminal charges brought against the inventor and corporate officials in Robins and Aetna who were responsible for this tragedy. In spite of repeated pleas by DSIN leaders and other public interest groups throughout a three-year period, the Justice Department dropped its criminal investigation within one month of the Robins–American Home Products merger (Geyelin, 1990).

THE BOOK

The task of this book is twofold: The first task is to document the continuing victimization of and injustice to Dalkon Shield users during the years 1986–1990, during which corporate interests took precedence over human welfare. The second task is to describe and analyze the educational and political strategies of a small group of Dalkon Shield women who challenged the legal system and presented their own definition of social justice for this population of women and medical consumers.

This book provides a rare perspective in the literature on social movements in two ways. First, this case study covers the formative period of the movement. Most studies of social movements take place after the movement is over and stress the end, not the beginning. This book can add valuable data on the ideas, tactics, personalities, alliances, and decisions that contributed to the successes and limitations of this instance of women organizing for medical reform. Second, as a former Dalkon Shield user and founder of DSIN, I offer an insider's perspective on the mechanisms of oppression, the nature of the

injustice as it is viewed and interpreted by the victims, and the transformation of women from the status of socially invisible and powerless victims to that of empowered survivors. The central themes in this book include the psychological and philosophical roots of activism, the conditions under which activism became necessary, and the particular issues that consumed the leaders of this organization. The outcome of the analysis is a model curriculum of empowerment applicable to other cases and circumstances of victimization.

DSIN members transformed the private trauma into a public agenda of social reform. Their activism asserted the victims' perspective and challenged the dominant worldview of events, particularly about the legal solution. Their rage upon gathering and learning the true cause of their personal health misfortunes led them to thrust themselves into a legal process that neither asked for nor wanted their participation. The women presented the contradictions and discrepancies in experience reported by those in high- and low-power positions (Kidder & Fine, 1986). The women in DSIN have also publicly articulated the negative human consequences of high-tech contraceptive methods, challenging the population control movement's enthusiasm for widespread distribution of IUDs and other high-tech methods of birth control that alter a woman's body, either chemically (through synthetic sex hormones) or biologically (through implanted devices).

Records of victimization and models of empowerment are an essential contribution to our understanding resolutions to social problems of exploitation and people's attempts to challenge the status quo. "When previously private problems become visible, social scientists and activists must expose ideologies such as 'they must have asked for it' that justify inequitable social arrangements" (Kidder & Fine, 1986, p. 57).

The Structure and Method of the Book

Chapter 2 reviews the medical literature on contraceptive development and IUDs and describes specific experiences of women worldwide. It details the misogyny and patriarchial control of contraception that subjects women to this form of medical violence. Chapter 3 provides the chronology of events in the life history of DSIN, spanning a three-year period. The complexity and urgency of developing relationships to other organizations and other Dalkon Shield women is treated in Chapter 4. Chapter 5 presents an analysis of the strengths and limitations of this social movement. The final chapter provides a model,

or curriculum of empowerment, and suggests other investigations that are still urgently needed in order for us to understand the comprehensive impact of this case.

The research for this book was praxis-oriented; that is, the research applied a critical and empowering model of inquiry and action for building a more just society (Lather, 1986). In my original mode as a woman struggling to understand what had happened to me, I searched continually for data. I was driven to know and understand what was going on in the long, drawn-out bankruptcy proceeding involving A. H. Robins because I had suffered a life-threatening injury as a direct result of using its product. These considerations also affected many thousands of other injured women, entwining our lives in that litigation. My intense personal stake in obtaining information plunged me into tedious searches of court records, many trips to Richmond, endless telephone conversations with women and lawyers, and direct, ongoing, daily contact with many of the principal legal parties to the case. This continued for the better part of a three-year period.

In my determination to make sense out of the process I was engaged in, I kept detailed notes of every telephone conversation as well as a voice-tape diary. In no other way would I have been able to gather the enormous quantity of data now in my possession.

As I came to appreciate the complexity of this case, I decided to keep track of all the people, places, and events that I participated in, believing that a detailed, written record would ensure that I could accurately reconstruct and interpret information given to me and that it would generally aid the process of informing other women of the case's progress. In short, all data collection has been systematic and structured from the beginning of my participation, even though the original goal was not research, but action.

I used the following data collection techniques:

- Handwritten notes (duly dated and timed) of virtually every telephone conversation I have had with Dalkon Shield survivors, many lawyers who are principal parties to the case, court officials, allied organizations, and numerous national press people with whom I have had continous contact
- The voice-tape diary I started keeping on almost a daily basis for a two-year period (now entirely transcribed into more than 200 pages), which stands as my field notes
- Newspaper clipping files, organized by month, of most national news stories that appeared during the Chapter 11 negotiations

- Voluminous files of related newspaper and law journal articles, magazine interviews, and analyses
- Videotapes of DSIN events, television news stories, and interviews with survivors, recorded by DSIN and other women around the country
- Court documents and briefs related to the estimation-of-claims process and most other court events during 1988
- More than 400 unsolicited letters received from Dalkon Shield survivors who wrote to DSIN and volunteered parts of their stories
- Correspondence and other documents generated by other Dalkon Shield survivors working on special projects
- All correspondence between DSIN and other Dalkon Shield groups, allied organizations, the court, and plaintiffs' lawyers
- All press releases, press statements, news reports, and speeches produced by DSIN during its period of greatest activity between July 1987 and December 1988, including 12 major public press- and court-related events.

SUMMARY

The Dalkon Shield tragedy has far-reaching consequences for women's reproductive health care, contraceptive development and distribution, and the legal rights of people injured by products known to be defective or dangerous. In the case of the Dalkon Shield, young and healthy women at the height of their childbearing potential were exposed to life-threatening and sterility-producing iatrogenic illness. Any disease or illness resulting from medical intervention or treatment is iatrogenic: The development of disease is an unintended outcome arising either from medical error or from unknown risks of a medical procedure or medication.

This story of Dalkon Shield women who became part of a grassroots organization called the Dalkon Shield Information Network (DSIN) and who publicly delineated the catastrophic results of a particular form of contraception on their lives may help to promote reform in women's reproductive health care, contraceptive development protocols, and medico-pharmaceutical practices.