HIGH-RISK WORKER NOTIFICATION:

A LITERATURE REVIEW

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1990

This literature review, representing Part One of a two-part project, was supported by NIOSH Contract #900110. Part Two (Evaluating High-Risk Worker Notification Programs) is available separately. The project is under the direction of Paul A. Schulte, Chief, Screening and Notification Activity, Industrywide Studies Branch, National Institute for Occupational Safety and Health.

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High-risk worker notification -- the process of informing workers at risk that past exposure to work hazards has given them increased chances of developing occupational disease -- has emerged during the 1980s as a pivotal issue in United States occupational health policy. In the space of little more than a decade, worker notification has progressed from abstract ethical debate to active programming, in the process generating a sizeable body of literature. Much of this literature is prescriptive in nature, offering moral commentary, sensitizing concepts, and recommendations. Increasingly, however, empirical studies are appearing that describe specific programs of worker notification, in some cases including at least partial evaluation of the intervention's impact. These mark a welcome trend because many vital questions regarding the effects of notification still remain unanswered.

The need for better evaluation is recognized by the National Institute for Occupational Safety and Health (NIOSH), which has played a central role in developing programs for worker notification. The agency is currently devising plans for systematic evaluation of its own notification activities, both ongoing and retrospective. As part of NIOSH's evaluation planning, this paper critically analyzes presently available scientific studies on worker notification, along with other material related to program design and evaluation in risk communication. The empirical studies reviewed here were located through a search of NIOSH's bibliographic database, supplemented by a number of unpublished documents and personal communications concerning completed or ongoing worker notification projects. Where relevant, theoretical and methodological literature has been included from a number of academic disciplines and professional fields -- sociology, anthropology, psychology, communications, social work, public health, and public administration.

The purpose of the analysis is to identify important issues and current gaps in knowledge concerning worker notification, showing how these might be addressed and clarified through evaluation research. This literature review, representing the first stage of a two-phase project, covers: (I) an overview of worker notification policy and programs, (II) examples of notification, (III) critical issues, and (IV) implications for evaluation. The second phase of the project, available separately, consists of a fuller discussion of the evaluation issues involved and detailed designs for several evaluation studies that NIOSH might undertake for its high-risk worker notification activities.

I. Overview

Although worker notification is a public health issue with its own distinct history as outlined briefly below, it shows many indirect links to what has been called the "Right To Know" movement -- a pervasive groundswell of public concern about environmental risk emerging over several decades. As the public has learned more about the extent of known but undisclosed health hazards in the everyday working and living environment, pressure has built for greater access to risk and hazard information of all kinds. Warning labels on consumer products, automobile recall notices, requirements for informed consent in research and medical care, Patient Package Inserts accompanying prescription drugs, labeling of chemicals used in the workplace, disclosure of asbestos hazards in school buildings, public inventories of production plants and waste sites that could pose health hazards to community residents -- all are manifestations of faith in information as a way to control risk (and liability).

As a strategy for protecting public health, information provision alone has some inherent limitations, which have been analyzed in a thought-provoking book by Hadden entitled Read the Label (1986). During the 1980s, Hadden argues, transmission of information to citizens at risk has to some extent become a substitute for the more aggressive hazard regulation of an earlier period. However, the approach enjoys wide popular support and is generally regarded by both its proponents and opponents as a form of empowerment, enabling citizens and workers to take steps to protect their own health.

The course and controversies of the Right To Know movement are too complex for detailed review here; they have been well described elsewhere (Bingham 1983, Magnuson 1977, Tepper 1980, Ochner 1984, Baram 1984, Ashford and Caldart 1985). A number of federal regulatory measures, passed against the backdrop of growing public pressure for hazard information, should be noted here as particularly relevant to worker notification:

1. The Federal Coal Mine Health and Safety Act of 1969 (PL 91-173), which in addition to its hazard control regulations includes provisions for worker health and safety training as well as some worker notification concerning the long-term health effects of coal dust.

2. The Occupational Safety and Health Act of 1970 (PL 91-596), which in addition to its hazard control regulations requires employers to provide workers with certain information about health hazards in the workplace. As noted below, the initial provisions of the OSHAct have been extended subsequently by specific standards related to information access.

3. The Toxic Substances Control Act of 1976 (PL 94-459), which contains testing requirements for industrial chemicals in new use or designated as unusually risky. Research under TSCA generates data on chemical hazards and their health effects (although the majority of common industrial chemicals are exempt, not being in "new" use).

4. OSHA's standard on Access to Employee Exposure and Medical Records (29 CFR 1910.20), which became final in 1980. This standard grants employees a general right of access to medical and exposure records kept by their employer.

5. OSHA's standard on Hazard Communication (29 CFR 1910.1200), a final rule as of 1983 and fully effective as of May 1986. Known as "Hazcom," this standard created a federal labeling requirement for hazardous chemicals in the workplace along with related worker training responsibilities for employers. Court decisions have extended its coverage to virtually all private-sector workplaces.

6. The Superfund Amendments and Reauthorization Act of 1986 (PL 99-499). This act, known as SARA, establishes community access to hazard information through its Title III and expands the mandate of the Agency for Toxic Substances and Disease Registry (ATSDR).

7. OSHA's standard on Hazardous Waste and Emergency Response Operations (29 CFR 1910.120), promulgated in 1989 with an effective date of March 6, 1990. This statute requires a number of health and safety protections, including training and medical surveillance, aimed at special populations at high risk for occupational disease: hazardous waste workers and emergency response personnel who deal with hazardous materials.

The main thrust of both the Right To Know movement and the government response has been primary prevention. The hope is that knowledge about hazards will allow informed individuals to avoid risks in the present and future. But clearly, the millions of American workers who have suffered toxic exposures in the past face a different situation. For them, health damage may be already done. While perhaps asymptomatic currently, they are at risk for chronic illness in the future -- potentially "in the pipeline" for occupational and environmental diseases that can take years to become evident. Ethically, if employers and research scientists know about these exposed individuals' elevated risk of disease, do not the workers themselves also have a right to know? Should they be helped? If so, given that primary prevention is no longer a possibility for them, what form should the help take? If programs are developed for them, exactly which exposed workers should be considered eligible?

Through such questions, high-risk worker notification surfaced early as an independent public health issue (Schulte and Ringen 1984). The need for informing workers with known past exposure to hazards was first raised by ethicists and advocates for workers' rights, who argued that exposed individuals could be helped medically by early treatment and in any case had a moral right to be told of their elevated health risks (see Gewirth 1980, 1986; Richter 1981; Samuels 1976, 1979, 1980, 1982a, 1986; Breslow 1978; Yale Law Journal 1981). The foremost early proponent of high-risk worker notification was Irving Selikoff from the Mount Sinai School of Medicine in New York, working in collaboration with the Industrial Union Department (IUD) of the AFL-CIO. Dr. Selikoff, well known for his pioneering scientific studies of workers exposed to asbestos and toxic chemicals, had hoped to see provisions for high-risk worker notification included in the Occupational Safety and Health Act of 1970. Shortly after the OSHAct became law without such provisions, he met with officials from the IUD and a number of key occupational health academics and professionals to plan a strategy for building support for the concept (Sheldon Samuels, personal communication, 1990). Inspired by Selikoff's initiative, a series of papers and presentations on notification followed, including key papers given by Sheldon Samuels of the AFL-CIO at a 1976 conference on Workers' Compensation and a 1979 international occupational health conference in Tel Aviv (Samuels 1972, 1976, 1977, 1979; Sellivan and Degroot 1973). This collaboration between Dr. Selikoff and the AFL-CIO continued throughout the 1980s, lending force to legislative efforts related to high-risk notification.

A few pilot programs of notification and intervention for exposed workers were undertaken in the 1970s by labor unions, federal agencies, and industries. However, none of these represented a well developed, comprehensive notification program (Samuels 1980). It was not until the early 1980s that the true complexity of the task began to become apparent, through three demonstration projects in worker notification conducted jointly by NIOSH and the Workers' Institute for Safety and Health (WISH). These three projects -- in Augusta, Georgia; Port Allegany, Pennsylvania; and with the Pattern Makers League of North America -- have been well documented. They will be discussed in more detail below along with some of their precursors and other subsequent notification programs. As experience with this kind of intervention grows, the controversies generated have put worker notification on the list of what the Bureau of National Affairs identifies as the "seven critical issues [in occupational safety and health] for the 1990s" (BNA Special Report 1989).

From the start NIOSH found itself at the center of debate over worker notification policy. Created by the OSHAct of 1970 as the federal government's center for epidemiological research

on occupational health hazards, NIOSH quickly became a major repository of exposure data on hundreds of thousands of workers at risk. The agency came under increasing public fire in the late 1970s for not informing the individual study subjects when research findings showed elevated health risk in exposed cohorts (New York Times 1977). Lacking internal consensus on the ethics and methods of notification, and also lacking the funds necessary for a full-scale notification program, the agency went through a protracted period of uncertainty as to the proper course of action. According to Ronald Bayer (1986), an ethicist who has analyzed the agency's internal conflicts over the issue, one of the major unresolved points has been the basic goal of notification: should it be defined narrowly as a strictly medical intervention, or defined broadly as a public health measure aimed at producing health-promoting social changes as well as clinical results? The issue of program scope came into sharp focus through the NIOSH/WISH demonstration projects, particularly in the case of Augusta where considerable social turmoil surrounded the notification effort.

Discussions within NIOSH continued through the 1980s, punctuated by media pressure (Bayer 1986, Omang 1981a, Stone 1986, Health Research Group 1984, New York Times 1984, Health Letter Supplement 1985, Hoffer 1986). Throughout the Reagan Administration the agency was constrained by repeated rejection of its requests for funding to mount a notification program (U.S. Senate Report 1987:12). Documents marking key points in the agency's evolving policy include the following:

1. A 1977 NIOSH document entitled "The Right to Know: Practical Problems and Policy Issues Arising from Exposure to Hazardous Chemical and Physical Agents in the Workplace," which outlines the agency's interest in notification and also its reservations about undertaking this kind of intervention.

2. Early documents produced by other federal agencies considering risk communication activity. These include a 1977 report by the National Academy of Sciences entitled "Informing Workers and Employers about Occupational Cancer," and a 1981 report by the National Center for Health Statistics entitled "A Study of the Issues in Locating, Assessing, and Treating Individuals Exposed to Hazardous Substances."

3. An "Option Paper on Worker Notification," prepared by NIOSH staff in 1982, which identifies 66 agency cohort studies involving 230,000 workers as appropriate for notification. The paper also outlines and projects costs for nine possible action strategies, the most expensive of which (full-scale personal notification) would cost at least $4 million dollars.

4. A report by the Ethics Committee of the Centers for Disease Control (CDC 1983). In 1982 NIOSH requested guidance from this committee because of the agency's deep internal division over notification policy. While acknowledging the ethical complexity of notifying exposed workers, some of whom might be beyond medical help and some of whom might even be harmed by the risk information, the Committee after careful consideration held that NIOSH is morally obligated to undertake notification anyway. The report asserts that "the guiding precept should be to enhance individual knowledge even if the individual may potentially suffer from it."

5. A "Report of the Subcommittee on Individual Worker Notification" prepared by the NIOSH Board of Scientific Counselors in 1986. This report contains "Guidelines for Notification of Individual Workers," recommended as the agency's decision logic for notification.

6. Two internal memos from NIOSH's Human Subjects Review Board, outlining "NIOSH HSRB Procedures for FY89" (10/1/88) and "HSRB Issues Related to Worker Notification" (8/25/87).

7. A statement by the Director of NIOSH, J. Donald Millar, entitled "The Right to Know in the Workplace: The Moral Dimension." This paper, presented at a 1988 workshop held by the New York Academy of Sciences, is published in a special issue of the Annals of the New York Academy of Sciences (Landrigan and Selikoff 1989).

8. The agency's "General Worker Notification Implementation Plan for Studies Completed Prior to July 1, 1988" (NIOSH 1989). This draft document describes a generic plan for notifying individuals who were participants in retrospective cohort mortality and case-control studies completed by NIOSH prior to the specified date.

Meanwhile, a legislative battle for worker notification began taking shape in Congress around the "High Risk Occupational Disease Notification and Prevention Act." This still-pending legislation grew out of a proposal drafted by the Industrial Union Department of the AFL-CIO in 1983. It was first introduced in the 99th Congress (1985-86), in the House as H.R. 1309 by Representatives Joseph M. Gaydos (D-PA) and Augustus F. Hawkins (D-CA), and in the Senate as S. 2050 by Senators Howard M. Metzenbaum (D-Ohio) and Robert T. Stafford (R-VT). The bill establishes a federal responsibility to send individual notification letters to workers known to be at high risk from previous hazardous exposures. The task of identifying cohorts eligible for notification would be assigned to an appointed Risk

Assessment Board within the Department of Health and Human Services. The bill also sets up a national information hotline; a system of designated occupational health service centers with capacity for technical assistance in medical care and counseling; some provisions designed to protect notified workers from insurance and employment discrimination; and funding for related professional training and research. Estimated costs of the program come to $25 million, which its supporters argue would be more than offset by health care savings from disease prevention.

While the original version of the High-Risk Bill did not receive floor consideration, it attracted a great deal of attention. Reintroduced in the 100th Congress as H.R. 162 and S. 79, the bill passed in the House in 1987 but was filibustered and withdrawn in the Senate. It was reintroduced again with amendments in the 101st Congress as H.R. 3067 and S. 582, and remained in committee in both houses. Deliberations on this proposed legislation have been lengthy and heated, with labor and public health groups in strong support and government and business interests taking a mixed but generally opposed position. Over the years of its existence, the bill has generated a large body of hearings and other commentaries including those listed below. (For full reference information, see the bibliography under "U.S. Congress," "U.S. General Accounting Office," and "U.S. Library of Congress.")

House Hearings on the High Risk Occupational Disease Notification and Prevention Act of 1985 (H.R. 1309); October 9, November 6, 13 and 20, 1985; and March 19, 1986.

Senate Hearings on the High Risk Occupational Disease Notification and Prevention Act of 1986 (S. 2050); May 15, 1986.

House Committee Report on the High Risk Occupational Disease Notification and Prevention Act of 1986 (H.R. 1309); July 17, 1986.

Congressional Research Service report titled "Occupational Disease Notification Proposals: Provisions, Issues and Pro-Con Arguments"; 1986.

Senate Hearings on the High Risk Occupational Disease Notification and Prevention Act of 1987 (S. 79); February 24, 1987.

House Hearings on the High Risk Occupational Disease Notification and Prevention Act of 1987 (H.R. 162); March 17, 24, 26, 31 and April 8, 1987.

General Accounting Office Briefing Report to the Ranking Minority Member, House Subcommittee on Health and Safety, titled "Worker Protection: Notifying Workers at Risk of Occupational Disease"; May, 1987.

Senate Hearing on the Impact on Small Business of Legislation Requiring Notification to Workers Who Are at Risk of Occupational Disease; June 10, 1987.

House Committee Report on the High Risk Occupational Disease Notification and Prevention Act of 1987 (H.R. 162); June 26, 1987.

Senate Committee Report on the High Risk Occupational Disease Notification and Prevention Act of 1987 (S. 79); September 23, 1987.

House Hearing on Occupational Disease Notification: Potential Liability Problems; September 23, 1987.

Congressional Research Service report titled "High Risk Occupational Notification and Prevention Act of 1987: Side-by-side Comparison of H.R. 162 and S. 79"; 1988.

Congressional Research Service report titled "Occupational Disease Notification Proposals: Is Legislation Necessary?"; 1989.

Congressional Digest report titled "Occupational Health Controversy: Pro and Con"; 1989.

Against this background, general consciousness about high-risk worker notification has increased dramatically, particularly within the occupational health professional community. The American Public Health Association has strongly supported the concept, issuing several policy statements emphasizing the need for worker notification (APHA 1984, 1986, 1987). A study conducted in 1987 for the California State Department of Health Services surveyed thirty occupational health researchers from various disciplines and found them strongly in favor of notifying study subjects of research results; 70% recommended always notifying, 30% recommended sometimes notifying, and no one recommended not notifying (Labor Occupational Health Program 1988 draft). A similar ethical stance infuses a 1989 special supplement on "Surveillance in Occupational Health and Safety" published by the American Journal of Public Health, which describes NIOSH's current health and hazard surveillance programs. This report presents a broad conception of occupational disease surveillance -- one that goes beyond research alone to include action for improving worker health. Its Preface reaffirms that:

> these analytic results [of NIOSH health and hazard surveillance studies] must be disseminated in ways that will initiate a chain of events to accomplish our ultimate goal, the prevention of work-related injury and disease (Millar 1989b:5).

The AJPH editorial introducing the report offers similar sentiments, congratulating NIOSH for maintaining its commitments under administrative pressure and noting that:

> the data collected in surveillance systems must be used. Unless these systems now being established by NIOSH result in firm and vigorous preventive action at both the state and local level, the systems will be meaningless, and the enthusiasm they now generate will soon turn sour (Landrigan 1989:1602).

Unavoidably, worker notification has a critical role to play in the effectiveness and credibility of the preventive action thus envisioned.

However, the precise meaning of worker notification is still very unclear (see Millar 1988). Does published epidemiological research represent notification? When workers become more aware of work hazards through mass media campaigns and warning labels, is that notification? Is it notification when the findings of health hazard evaluations are sent to employers and unions and posted in the workplace? If notification necessarily means individual contact with those at high risk, are letters the best way? What kind of information should letters contain? How essential is it to include followup services? How important is it to go beyond the specific study cohort to reach other workers with similar exposures? Does notification require information and technical support not only to those at risk, but also to institutions and service providers in the affected community?

Equally unclear is the extent to which worker notification already occurs in unplanned ways, incidental to other goals. Studies undertaken as epidemiological research often have a notification component almost by accident. To take but one example, a 1981 study of asbestos disease in family members of Los Angeles shipyard workers relied on a public media campaign to recruit a study population of 1,017 workers and their wives, sons and daughters (Kilburn et al. 1985). The volunteer respondents were screened briefly by a telephone interviewer to determine if they fit the eligibility criteria, i.e., 20 years elapsed since initial shipyard employment -- a conversation that presumably involved some discussion of asbestos disease, its etiology and its latency period. This research was not reported as a notification intervention, but has notification implications nevertheless.

A good example of how incidental notification falls short of the ideal is OSHA's hazard communication standard. The standard is meant as primary prevention, alerting workers to hazards so they can take protective measures against future exposures. But the required warning labels, Material Safety Data Sheets and training also serve to inform workers of increased health risk from substances they have already been exposed to in the past. This notification aspect of hazard communication has been a major argument raised against the High-Risk Bill: if Hazcom is already doing the job, why is additional legislation needed? However, the two approaches are actually quite different. Unlike intentional notification, OSHA's method of hazard communication cannot reach family members who may be affected, or "separated workers" who have retired or changed their place of employment subsequent to the exposure. Also, if hazard communication is to serve as notification, Hazcom training logically should contain risk information and health advice specially targeted at already exposed workers, in order to maximize secondary prevention of disease. Unfortunately this kind of information seems to be neglected. The most comprehensive evaluation of hazard communication training to date is an OSHA-funded study of five programs carried out jointly by the United Automobile Workers and Ford Motor Company (Robins 1989). The study reports positive changes in workers' knowledge about hazard recognition, work practices and hazard control, but is virtually silent regarding worker education about the long-term health risks of work hazards. The absence of secondary prevention content in the Hazcom training for these five programs probably reflects a compromise between conflicting interests. As noted in another paper related to the main study, Ford's management was quite concerned about the "possibility of a wave of costly workers' compensation claims from workers who were now to be made aware of the potential health effects of what was, in some cases, long-term exposure to hazardous chemicals" (Hugentobler et al. 1989:4).

Another example of indirect (and deficient) notification is NIOSH's Health Hazard Evaluations (HHEs). The main aim of the HHE program has not been worker notification, but primary prevention through hazard identification and abatement. The HHE protocol calls for sending research results to (1) the requester, (2) the company involved, (3) employee representatives, (4) union headquarters, (5) the Department of Labor, and (6) appropriate state agencies. However, since individuals at high risk do get identified from the industrial hygiene and medical data generated by HHEs, these investigations can also serve as an important tool for individual worker notification and secondary disease prevention (see Schulte and Singal 1989:590). Again, the potential benefit has gone underutilized. Cronin and colleagues (1986), in examining how NIOSH recommendations were used by employers and employees in ten HHEs, found disappointing compliance with education and training recommendations and a

general feeling among the workers that many questions about long-term health effects and preventive measures remained unanswered. Another study of the HHE process by Sharp and colleagues (1989) examined 170 reports from lead-related HHEs and found that in 43% of the cases where elevated environmental lead samples were obtained, no blood lead testing or notification of workers followed. They observe, "It is apparent from our findings and from the written comments of former NIOSH officials that the Institute has not defined 'secondary prevention' of toxicity from lead or other hazards to be an important part of the HHE process" (p. 457).

Risk notification -- for exposed citizens as well as exposed workers -- also figures indirectly into the construction and use of exposure registries (see Schulte and Kaye 1988; Int Arch Occup Environ Health 1988 Supplement). For example, the Michigan polybrominated biphenyls (PBB) follow-up registry involved contacting, interviewing and screening about 4,600 persons exposed to PBB (Landrigan et al. 1979); in the process, these individuals were unavoidably notified of their health risk. NIOSH's lists of individual surviving members from retrospective cohort mortality studies represent de facto registries; as discussed above, these have now become the basis for some of the agency's planned notifications. To take another example, the Agency for Toxic Substances and Disease Registry (ATSDR) conducts community health assessments of toxic waste sites and toxic spills, producing toxicological profiles and building toward a national exposure registry (at present working through state registries). In the view of ATSDR administrators:

> We believe there are two primary purposes for an exposure registry. One is to obtain data that can be used in research to clarify the relationship between exposure and human health effects. A second purpose -- and one that in a public health sense is equally important -- is to provide a mechanism for linking back to people who may have need for contemporary scientific or medical information that would be of importance to them in their management of their own health status. . . . Therefore, on occasion, messages will go back to those persons in a chemical-specific exposure registry pertaining to the health effects of their exposure. . . . The message could be that we know exposure has placed persons at a higher risk of development of an adverse health effect. We would advise the registrant to bring the information to the attention of his or her personal physician (Johnson 1987:411).

Risk notification of both workers and citizens has sometimes been forced on the federal Environmental Protection Agency and/or state health departments by environmental accidents or newly discovered community toxic hazards (Thomas 1986, Harris 1983). In addition, the community information provisions of Title III

under the Superfund Amendments and Reauthorization Act of 1986 (SARA) potentially serve as indirect risk notification to workers as well, giving them information about substances to which they may have been occupationally exposed in the past (Hadden 1989a, 1989b). Another federal agency, the National Institute for Environmental Health Sciences (NIEHS), gets involved indirectly in risk notification as part of its Hazardous Materials and Waste Worker Health and Safety Training Program, by contacting and giving risk information to target groups of at-risk workers eligible for the training. Despite their different mandates and program focus, all of these agencies share similar program development difficulties concerning risk communication.

The best way to think about worker notification is probably to consider it as one part of a much larger societal effort aimed at managing health risk by providing risk and hazard information. This larger effort has inspired an explosion of professional literature and activity concerning risk communication in general (Covello et al. 1986, Plough and Krimsky 1987), much of which is highly relevant to worker notification. New professional associations such as the Society for Risk Analysis have appeared, sponsoring annual meetings and a journal (Risk Analysis) devoted in large part to risk communication issues. Established journals have put out special issues on risk communication -- for example, a special double issue of Science, Technology & Human Values (Vol. 12, 1987). At least three national conferences on risk communication have been organized in recent years by foundations and government agencies (Davies et al. 1987, Pavlova et al. 1987, Task Force on Environmental Cancer and Heart and Lung Disease 1988).

The 1980s have also seen a flood of manuals, advice and "how to do it" guides aimed at the increasing number of public health and government officials faced with risk communication tasks for which they are ill prepared by training and experience. Examples of such guides include:

-- the National Research Council's report on Improving Risk Communication (1989).

-- Schulte and Singal's discussion of risk communication in NIOSH field studies (1989).

-- Improving Dialogue with Communities: A Risk Communication Manual for Government by Hance, Chess and Sandman (1988).

-- the Worker Notification Guidelines prepared in 1988 for the California State Department of Health by the Labor Occupational Health Program (LOHP) at University of California, Berkeley, and the Labor Occupational Safety and Health Program (LOSH) in Los Angeles.

-- Effective Risk Communication: Role and Responsibility of Government and Nongovernment Organizations edited by Covello et al. (1989).

-- Environmental Hazards: Communicating Risks as a Social Process by Krimsky and Plough (1988).

-- Halperin et al., Medical Screening in the Workplace: Proposed Principles (1986).

-- Rudolph's State of the Art review article recommending worker involvement in every phase of epidemiologic research and clinical surveillance (1986).

-- A framework of principles for working with communities facing toxic threats, developed by Harris (1983) based on the experience of Love Canal.

-- Samuels' discussion of six essential features for a program of high-risk management (1982a).

-- Guides and reprints available from the Environmental Communication Research Program at Rutgers University, for example:

Explaining Environmental Risk (Sandman 1986a).

Encouraging Effective Risk Communication: Suggestions for Agency Management (Chess 1988).

Evaluating Risk Communication Programs: A Catalogue of "Quick and Easy" Feedback Methods (Kline, Chess and Sandman 1989).

Getting to Maybe: Some Communications Aspects of Hazardous Waste Facility Siting (Sandman 1986b).

Explaining Risk to Non-Experts (Sandman 1987).

Risk Communication, Risk Statistics, and Risk Comparisons: A Manual for Plant Managers (Covello, Sandman and Slovic 1988).

Alerting the Apathetic and Reassuring the Alarmed (Chess and Hance 1987).

Risk Education in New Jersey: A Status Report by Hance, Sandman, Chess, et al. (1988).

-- Materials and reprints available from the Center for Technology, Environment and Development (CENTED) at Clark University, in particular Kasperson's "Six Propositions for

Public Participation and Their Relevance for Risk Communication" (1986).

On a more philosophical level, Hadden's comprehensive book entitled Read the Label (1986) summarizes not only relevant research but also many of the underlying conceptual and ethical issues surrounding risk information as a public policy strategy for improving health. Stallen and Coppock (1987) point out that current risk communication efforts sometimes strive toward contradictory social goals, all of them considered self-evidently beneficial. Otway (1987) and Dervin (1989) explore the tensions between expertise and democracy, as two inconsistent paradigms shaping risk communication.

Somewhat more poetically, Douglas and Wildavsky's book Risk and Culture (1983) raises the unsettling thought that defining and analyzing risks may satisfy psychological needs in Western culture whether the risks are successfully controlled or not. Their essay opens with lines from Empson:

> But wretched Man is still in arms for Fear.
> From fear to fear, successively betrayed --
> By making risks to give a cause for fear
> (Feeling safe with causes, and from birth afraid).

In general, there seem to be separate universes of discourse developing in the risk communication literature, apparently reflecting disciplinary boundaries and collegial networks. Groups of authors tend to cite each other, and to ignore the work of other "circles." NIOSH's evaluations of worker notification will be much richer and more useful if a conscious effort is made to go beyond familiar public health sources to include insights from other disciplinary foci of risk communication interest.

II. Examples of Notification

With the concept of notification so ambiguous and still evolving, it has seemed most useful to cast a wide net in this review of relevant literature. The sections that follow draw eclectically from studies of many different kinds of notification and risk communication, most dealing with occupational hazards but some with other kinds of health risk. Where pertinent, the review also includes insights from social science literature, from Congressional hearings, and from non-empirical literature related to notification and risk communication.

The main body of the review is organized around cross-cutting issues rather than around descriptions of programs one by one. While this approach yields a firmer base from which to design evaluations of NIOSH's notification programs, it unavoidably scrambles the continuity of specific case studies. Therefore, for convenient reference, this section alphabetically lists and briefly describes the major programs analyzed. Each program profile also gives citations to literature describing the notification aspects of the program (not including strictly epidemiological reports). The programs covered -- a combination of worker notification per se and other types of risk communication effort -- include the following:

Anderson, Michigan (MBOCA)
The Asbestos Awareness Campaign (asbestos)
Augusta, Georgia (Synalloy, BNA)
The Bay Area Asbestos Surveillance Project (asbestos)
Cloquet, Minnesota (Conwed, asbestos)
The Community Monitoring Project (toxic waste)
Hazardous Waste Worker Training (toxic waste)
Industry-Sponsored Worker Notifications
Insulation Workers (Mt. Sinai cohort, asbestos)
Kanawha Valley, West Virginia (Union Carbide, chemicals)
Labor-Initiated Programs
Law Firm Notifications
Lock Haven, Pennsylvania (Drake/Kilsdonk, BNA)
Louisville, Kentucky (B.F. Goodrich, vinyl chloride)
Pattern Makers (colorectal cancer, agent unknown)
Plumbers and Pipefitters (Seattle, asbestos)
Port Allegany, Pennsylvania (Pittsburgh-Corning, asbestos)
Rocky Flats, Colorado (U.S. Dept. of Energy, beryllium)
Semiconductor Health Study (California, solvents)
Surveys Related to Worker Notification
Three Mile Island (Metropolitan Edison, radiation)
Tyler, Texas (Pittsburgh-Corning, asbestos)
United Automobile Workers/Ford Motor Co. (Hazcom Training)
United Mine Workers (coal dust)
Uranium Miners (Atomic Energy Commission, radiation)

Worker Notification Project (WIOES, asbestos)
Other Kinds of Risk Notification
(AIDS, genetic screening and counseling, community toxics, industrial disasters, health promotion programs)

Anderson, Michigan

This 1986 NIOSH program was aimed at notifying and screening workers exposed to the chemical MBOCA, a possible carcinogen used in manufacturing polyurethane. MBOCA (also known as MOCA) has been related to bladder cancer. While no longer manufactured in the United States, it is still imported from abroad and is used by about 400 U.S. companies. The project involved 450 workers at a plant in Anderson, Michigan, where MBOCA was produced from 1968 to 1979. All 450 workers were interviewed and urine samples were analyzed for 370 of them. The screening revealed one bladder cancer in a maintenance worker exposed to MBOCA for one year in 1978, representing a sentinel health event because of the worker's young age (under 30). This finding was reported to OSHA in August, 1986, even though OSHA's 1973 standard for MBOCA had been struck down by a federal court on procedural grounds the next year and never reissued. The initial screening also found that another 70 workers in the cohort had some abnormality in the urine such as red cells or atypical cytology, and a second screening by cystoscopy later revealed a second case of bladder cancer. Successful medical intervention was reported. See these sources:

Occ Safety & Health Reporter, 10/22/86
Ward et al., 1988

Asbestos Awareness Campaign

In 1978 the U.S. Department of Health, Education and Welfare launched a massive national effort to notify workers and the general public about the health hazards of asbestos. The program involved a media campaign using materials prepared by the National Cancer Institute, along with about 40 million notices enclosed with social security checks and federal paychecks. About 1.2 million pamphlets were placed in supermarkets and discount stores nationwide. There was also a special mailing to all physicians in the United States, intended to increase knowledge of asbestos-related disease. While no followup services were included, the effort did succeed in raising public consciousness about asbestos risks. However, subsequent surveys suggest that the campaign was more effective as hazard warning than as secondary disease prevention. Information about

constructive health-promoting responses that exposed persons might take apparently did not get effectively communicated. The program and subsequent evaluation are described in:

Freimuth and Van Nevel, 1981
Needleman, 1987

Augusta, Georgia (Synalloy)

This program, at present the most extensively documented example of worker notification and screening in published scientific literature, was begun in 1981 by NIOSH in coordination with NCI-funded activities of the Workers' Institute for Safety and Health (WISH). The project involved a cohort of 1,385 workers, predominantly black males, who suffered a fourfold increase in relative risk for bladder cancer from occupational exposures to aromatic amines during the period of 1949 to 1972. The main substance involved was beta-naphthylamine (BNA), a dye chemical which was used without adequate worker protection by the employer (Synalloy Inc) despite its known adverse health effects. Elements of this unusually comprehensive notification program included not only the mailing of individual letters, but also government-funded medical screening and followup diagnostic services; ongoing medical surveillance; aggressive outreach to locate and motivate hard-to-reach subjects; work with the media; work with medical service providers in the community; information and counseling resources; formation of and collaboration with community organizations; and legal involvement. With some components still ongoing, this program represents an excellent site for evaluating long-term effects of notification on both the subjects and the community. Key references include:

Crapnell, 1981
Omang, 1981b
NIOSH, 1983
Schulte, 1983
Schulte and Ringen, 1984
Schulte et al., 1985a
Schulte et al., 1985b
Stern et al. 1985
Hornsby et al., 1985
Schulte, 1986
Schulte et al., 1986
Ruttenberg and Powers, 1986
Tillett et al., 1986
Baker, Schulte and French, 1989

Bay Area Asbestos Surveillance Project

The Bay Area Asbestos Surveillance Project (BAASP) was undertaken in the 1970s by the Western Institute for Occupational/Environmental Sciences, Inc (WIOES). The goal was to screen persons in the San Francisco Bay Area who had worked in shipyards during World War II, or had handled asbestos as longshore workers and shipyard workers prior to 1963. Main features of the project included worker notification, a public awareness campaign, x-ray screening of 2244 workers, and some assessment of medical and social needs among asbestos-exposed workers and their families. This program is striking for its broad approach and also for the very high rates of disease detected: 46% of the cohort with potentially serious abnormality and 30% with possible abnormality. Key references include:

Polakoff, 1980
Coon and Polakoff, 1982

Cloquet, Minnesota (Conwed)

This project involves the workforce of Conwed Corporation, a large Minnesota-based manufacturer of acoustical tile and wallboard. Conwed has a long history of strained relations with its employees, most of whom are members of Local 158 of the United Paperworkers International Union (UPIU). About half of the company's workers were laid off in 1985 when the plant was sold to U.S. Gypsum Company, and UPIU had to resort to legal action to get union recognition from the new management. It is estimated that some 3,700 to 5,000 Conwed workers may have been occupationally exposed to asbestos between 1958 and 1974, with an unknown number of secondary exposures to family members. Notification efforts for this population have evolved through several distinct stages. First, starting in 1986, the union publicized the exposure problem among the membership and sought personnel lists from the company in order to do individual notification and screening; however, the company refused to cooperate. Using partial lists available from other sources and with help from the state health department, UPIU undertook a small-scale medical screening of 270 Conwed workers in 1986, with alarming health findings. The UPIU continued to seek more complete lists from Conwed without success. Subsequently the State of Minnesota filed suit against Conwed to obtain the lists on behalf of the Department of Health and the Department of Labor and Industry. Meanwhile the Minnesota State Legislature passed a bill to fund a mass screening at state expense. After finally securing the needed information and funding, the Department of Health embarked on a large-scale notification and screening effort in 1988 involving more than 1,100 former Conwed employees and 451 spouses of former workers. The case is notable in

several ways: (1) it set legal precedents regarding access to personnel records for purposes of notification; (2) it represents an unusually active role for a state health department; (3) it covered potentially exposed family members; (4) the union program included strong counseling and social service supports; (5) it has yielded one of the most detailed assessments available concerning the psychological impact of notification; and (6) through the state program, it sheds some light on the limitations of notification without accompanying services. Key sources on the Cloquet notification include:

State of Minnesota District Court, 1988
Sullivan, Affidavit, 1987
Sullivan, Second Affidavit, 1988
Elisburg, Amicus Brief, 1988
Occupational Safety & Health Reporter (2/3/88, 2/17/88, 3/9/88, 3/23/88, 5/25/88, 5/24/89)
The Paperworker (UPIU), May 1988
Meyerowitz, Sullivan and Premeau, 1989
Minnesota Department of Health (Bender et al.), 1989

Community Monitoring Project

This project is a three-year, multidisciplinary study started in 1989 at the Center for Technology, Policy and Industrial Development at the Massachusetts Institute of Technology, supported through a cooperative agreement with NIOSH and the Agency for Toxic Substances and Disease Registry (ATSDR). The research focuses on the scientific, ethical and legal issues involved in monitoring community residents and clean-up workers for exposures and adverse health effects related to toxic substances in communities. Three illustrative cases are analyzed: Love Canal, New York; Woburn, Massachusetts; and PBB contamination in Michigan. The purpose of the study is to establish guidelines for communities and agencies to follow when a health hazard is suspected. As yet only preliminary reports are available on this project, although publications will be forthcoming. For further information, contact Nicholas Ashford, Principal Investigator, or Linda Schierow, Project Manager, both at MIT. See also the American Public Health Association Occupational Health Section Newsletter (Spring issue 1990:4).

Hazardous Waste Workers (Worker Education)

In 1987 the National Institute for Environmental Health Sciences (NIEHS) awarded 11 grants to unions, universities and non-profit groups across the country to provide training to workers who handle hazardous wastes and respond to chemical

emergencies. A second series of awards, including renewals for some of the original grantees, was made in 1990. Although not primarily intended as worker notification, the training does have the effect of informing individuals that materials they have been exposed to in the past may pose long-term health risks. The risk notification aspects of the Hazardous Waste Training Program have not as yet been analyzed in the scientific literature. However, the evaluations of specific programs generated by this initiative should eventually lead to publications relevant to worker notification (Denny Dobbin, personal communication, 1990). See the following sources:

Seymour, 1989
NIEHS, 1989

Insulation Workers (Mount Sinai Cohort)

In 1963, researchers from Mount Sinai School of Medicine's Environmental Sciences Laboratory discovered extremely high mortality rates from asbestos-related disease among a group of New York area insulation workers. The union cooperating with the research, the International Association of Health and Frost Insulators and Asbestos Workers, undertook a large-scale notification and worker education effort concerning asbestos hazards for its national membership of approximately 20,000 skilled tradesmen. Although effective as risk communication, the program did not include much in the way of followup services. However, one portion of this population, a cohort of 1249 men employed as insulation workers in the New York metropolitan area between 1943 and 1963, became the focus of a long-term prospective surveillance project based at Mount Sinai. All members of the group were medically examined at facilities set up in the union halls, complete with x-ray equipment. Each man was informed individually of his test results with a review of the data sent to his personal physician if requested. These workers and their families have been followed subsequently with periodic x-rays and other studies, and the larger cohort (17,800 men as of 1967) has been further studied as well. One related study (Johnson and Heler 1983) gives a particularly useful analysis of the economic and social consequences for families of cohort members who died of asbestos disease, based on a survey of 792 interviews with widows throughout the United States and Canada. Descriptions of various program components can be found in:

Selikoff 1976
Anderson et al., 1979
Hammond et al., 1979
Selikoff, 1982
Johnson & Heler, 1983

Industry-Sponsored Worker Notification Programs

Some worker notification programs sponsored by corporations for their own employees are reported from the 1970s, for example by Selikoff and Hammond (1982) and by Auerbach (1976). These early programs have been described as fairly minimal in nature (Samuels 1980, Schulte & Ringen 1984). In recent years a number of corporations have reportedly undertaken more sophisticated notification programs. Little is published concerning these corporate initiatives. However, a survey of industry-sponsored notification programs has recently been carried out under the auspices of the Organizational Resource Counselors (ORC), a consortium of about 70 large corporations representing the interests of American industry on occupational health and safety issues. The survey was conducted by Martin Reape, director of corporate health services for the FMC Corporation in Philadelphia. He found that 14 of the 17 major companies he contacted had sponsored "HERC" programs (historical exposure risk notification) during the past ten years (Reape, personal communication, 1990). Information on corporate programs used here comes mainly from this ORC survey, which is as yet unpublished. See:

Occupational Safety & Health Reporter, 5/5/89: 2002

Kanawha Valley, West Virginia (Union Carbide)

The "Kanawha Valley Epidemiology Study" was initiated jointly in 1978 by NIOSH researchers and the management of Union Carbide Corporation, for the purpose of examining mortality patterns among Union Carbide workers exposed to ethylene oxide and other chemicals. The project also had the cooperation of the workers' union, the International Association of Machinists and Aerospace Workers. Preceding by half a decade the chemical accidents at Union Carbide plants in Bhopal, India and Institute, West Virginia, the study was prompted by widespread general concern at the time about the health and safety of chemical workers, especially in relation to brain cancer. The epidemiological research focused on a cohort of 29,139 workers at three Union Carbide facilities in the Kanawha Valley (the South Charleston plant, the Institute plant and the Technical Center). NIOSH's role in this project was essentially limited to the mortality study itself. Worker notifications associated with the research were designed and implemented by the company, with supportive technical review by NIOSH. Union Carbide voluntarily undertook to send letters to individual workers in selected high-risk subgroups in the cohort, as an adjunct to filing the government reports required by the Toxic Substances Control Act. All employees and retirees of the South Charleston plant received individual letters in 1986, informing them of the study findings:

excess deaths from liver cancer apparently linked to vinyl chloride exposure in the workplace, and excess deaths from lymphoreticular cancer for which work-relatedness was still being studied. Published accounts of the project's notification aspects do not appear to be available. This description is based on discussion with the NIOSH Project Director for the study (Elizabeth Ward, personal communication, 1990), and file documents from the House Subcommittee on Education and Labor.

Labor-Initiated Programs

In addition to the labor-based notifications described elsewhere on this list, a number of health and safety programs with notification components have been sponsored by unions, labor-affiliated nonprofit organizations, and worker self-help groups such as the Brown Lung and White Lung Associations. These programs consist of screenings, worker education campaigns, and support services for groups of workers known to be at risk from past exposures. Some are large-scale efforts, as for instance the program initiated by the Sheet Metal Workers International Association in 1986, covering some 33,000 members nationwide. Union programs often contract with private medical groups to do the testing, sometimes raising problems of test quality (see Zoloth et al. 1986). While union and other worker-initiated self-help projects are not generally reported in published form, they hold interesting lessons for NIOSH's notification efforts. Accordingly, this review makes use of information gained from personal communication with health and safety personnel of various labor unions, COSH groups, health professionals associated with union screenings, grass-roots worker health organizations, and nonprofits such as the AFL-CIO affiliated Occupational Health Foundation in Washington,. DC.

Law Firm Notifications

In the process of preparing legal cases, law firms engaged in "toxic torts" sometimes undertake what is in effect a notification effort as they try to locate members of an affected class. Some of the well-publicized product liability suits of the 1980s, involving workers exposed to hazards such as asbestos and dioxin, have been reported in enough detail to give some insight into the notification methodology used. For example, see Brodeur (1985) on the Johns-Manville asbestos case; the recent special issue of Environmental Research on Vietnam veterans exposed to Agent Orange (Stellman et al. 1988); Silver (forthcoming) on the experience of 50 plaintiffs and their families in an occupational lead poisoning lawsuit; and Gaskins (1989) on a variety of toxic tort cases. In addition to

published accounts dealing indirectly with notification, many law firms have in their files unpublished internal documents describing the approaches used to locate and communicate with cohorts of exposed workers. The information used for this review includes personal communications with a number of law firms that have handled class-action suits involving exposures to lead, asbestos, and vinyl chloride.

Lock Haven, Pennsylvania (Drake/Kilsdonk)

This project centers around the development of an exposure-based bladder cancer registry for former employees of the Drake (formerly Kilsdonk) Chemical Company near Lock Haven, Pennsylvania. Between 1940 and 1981, the plant manufactured intermediate chemicals --including BNA, benzene and benzidine -- for making dyes, cosmetics, pharmaceuticals, herbicides and pesticides. At least 409 workers, primarily white males, are known to have been employed at the company during this period. The Drake plant is now closed and the eight-acre zone it once occupied has become a Superfund site. Working with ATSDR funding, NIOSH and the Pennsylvania Department of Health undertook notification of the Drake/Kilsdonk cohort in 1985. The 20-year registry project involved (as of April 1988) the notification, screening and in most cases ongoing medical surveillance of approximately 235 exposed workers out of a "potentially notifiable" cohort of 365. The program has been notable for its intensive involvement with the community and local communication media, involvement of workers' families, detailed documentation of cohort members' participation patterns, and the opportunity to evaluate long-term health monitoring. Key references include the project's first year final report and subsequent quarterly reports; two community health surveys done through the Pennsylvania Department of Health; and other manuscripts describing the Drake registry program, currently in preparation for publication in the scientific literature. See:

Occupational Safety & Health Reporter, 8/22/85
Logue and Fox, 1986
Marsh et al., 1987
Marsh et al., 1988
Health and Environment Digest, April 1988
Marsh et al., 1990
Leviton et al., 1990

Louisville, Kentucky (B.F. Goodrich)

In January of 1974, the B.F. Goodrich Company in Louisville recognized that the unusually high incidence of angiosarcoma in its workforce was apparently related to vinyl chloride exposure, and undertook a program of medical screening with follow up medical work-ups where indicated. About 30 employees were identified as having liver abnormalities, and most of them were reassigned in 1975 to a separate facility (a wood pallet plant about a half-mile from the main plant) which the company created as a work alternative. Subsequently, the National Cancer Institute funded a demonstration program of medical surveillance, data-bank management, psychosocial rehabilitation and health education for all workers at the B.F. Goodrich Company. This program, known as the "Vinyl Chloride Project" and carried out through the University of Louisville, provides an unusually complete assessment of the intervention's psychosocial impact (which proved quite negative for those workers given the alternative work assignments). The research team, which included academics from social work and psychiatry, is one of the few to investigate and report on issues of social stigma and discrimination resulting from notification. See these sources:

Tamburro et al., 1978
Sands, Newby and Greenberg, 1981

Pattern Makers

This program was initiated by a union, the Pattern Makers' League of North America, after epidemiological research in 1980 indicated a doubled rate of mortality from colorectal cancer among pattern and model makers. Members of the cohort at risk (i.e., the union membership of 12,000 workers) were not concentrated in one community, but scattered in about 700 workplaces in 27 states and 3 Canadian provinces. In collaboration with the Workers' Institute for Safety and Health, the union carried out a notification effort using newsletters and booklets to contact the membership. Expenses for the related medical screening were covered through the workers' health insurance plan, with the screening itself provided by local community physicians. The program is unusual in two ways: (1) it involves multiple centers and therefore poses special challenges in terms of uniform medical surveillance, and (2) it has stimulated negotiated labor/management plans for exposure control at several hundred plants. Key references for the Pattern Makers project include:

Tillett et al., 1986
Schulte and Ringen, 1984
Also see Swanson et al., 1985

Plumbers and Pipefitters (Seattle, Washington)

In 1982, the Occupational Medicine Program at the University of Washington initiated a general health surveillance program for the membership of two unions representing plumbers and pipefitters in the Washington - Tacoma area. The workers were at high risk for asbestos-induced lung disease, job-related injuries, and noise-related hearing loss. Approximately 4,000 eligible individuals received mailed announcements of the program, and by 1984, 639 had chosen to participate. Expenses for the screening were borne largely by the unions' employer/employee-managed health and welfare trust funds. Details of any health education activities accompanying the screening have not been reported in the literature, but presumably were part of the program. A published description of the program shows two notable features: (1) great attention to cost factors in the screening, and (2) active assistance for workers wishing to file workers' compensation claims, in order to transfer costs to insurers. See:

Schwartz et al., 1988

Port Allegany, Pennsylvania (Pittsburgh-Corning)

This program -- which along with the Drake program is probably the best available example of community cooperation in a notification effort -- has a long history. It grew out of NIOSH discussions in 1971 with the employer and the union (Flint Glass Workers) concerning elevated cancer risk to 1,188 workers exposed to asbestos between 1964 and 1972. A nonprofit community organization called the Port Allegany Asbestos Health Program (PAAHP) was established in 1981 with representation from the union, the company, the medical community and the clergy. PAAHP initiated a program of notification and screening, receiving technical assistance from the Workers' Institute for Safety and Health and from Mt. Sinai School of Medicine in New York. Besides the initial notification and screening, the program includes an ongoing cohort registry and periodic medical surveillance. In addition to unusually strong community support, the project is notable for its emphasis on smoking cessation and health education as risk reduction measures; provision of counseling and psychosocial support; and the inclusion of 3,000 to 4,000 family members potentially at risk from secondary exposure to asbestos. The program has enjoyed good cooperation between outside health professionals and local physicians. Like Augusta, Port Allegany represents a promising site for evaluation of the long term effects of notification. Key references on the Port Allegany program include:

Daily, 1981
Chemical Week, 1981
Schulte and Ringen, 1984
Holstein et al., 1984
Tillett et al., 1986
Houts and McDougall, 1988

Rocky Flats, Colorado

Beryllium is a strong, lightweight metal increasingly being used in the nuclear, aerospace, computer and telecommunications industries, and in ceramics, dental alloys and car parts. While finished products containing beryllium are generally safe, exposure to the substance during the manufacturing process can cause allergic reactions leading to berylliosis, a treatable but often fatal lung disease. Cases of berylliosis began to come to light in the early 1980s among workers making plutonium triggers at the federal nuclear weapons plant at Rocky Flats near Denver, operated by Rockwell International under contracts for the U.S. Department of Energy (DOE). The National Jewish Center for Immunology and Respiratory Medicine and the University of Colorado Medical School, with support from Rockwell International and cooperation from the United Steel Workers of America, undertook a pilot study which suggested widespread beryllium sensitivity among the workers at Rocky Flats. Following this pilot study, a five-year program of medical screening was started in 1987 with funding from the National Institutes of Health through the National Institute for Environmental Health Sciences. The screening program functions as a notification intervention as well, partly because of the cooperating union's strict policy of requiring the results of epidemiological studies involving its members to be reported to the study subjects within 60 days. The project's target population is the 750 Rocky Flats employees who were thought at the time to represent the entire exposed population because they fit the definition that DOE uses for "beryllium workers." However, cases of beryllium-related disease have since turned up among Rocky Flats employees with only incidental exposure, such as security guards and secretaries who occasionally walked through production areas where the substance was being used. Since even low dose exposures can apparently cause health damage, the researchers now feel that perhaps as many as 2500 workers in the plant are at risk; they are reportedly having difficulty finding 100 unexposed employees who could serve as the controls called for in the research design (Kathleen Kreiss, personal communication, 1990). As of 1989, the Rocky Flats study has identified 12 cases of berylliosis, eight among current workers and four among retirees. Since some 800,000 American workers may be at risk from exposures to beryllium dust dating from the early 1940s through the 1980s, this project -- the largest workforce study of

berylliosis ever conducted -- is quite important. In response to the early screening results, the Department of Energy has repeatedly announced plans to notify "thousands" of nuclear weapons plant workers of their health risk from beryllium. Responsibility for any such notification has recently been placed with the Department of Health and Human Services, although the exact agency involved has not yet been decided. For discussion of the Rocky Flats project and of risk communication in the nuclear weapons industry more generally, see these sources:

Newman et al., 1989
Kreiss et al., 1989
Denver Post, 1/14/90
BNA Special Report 1989, pp. 62-63
New York Times, 1/14/90
New York Times, 1/15/90
Morain and Jones, Los Angeles Times, 6/20/89
Occupational Safety & Health Reporter, 12/6/89
Lippman, Washington Post, 7/7/90

Semiconductor Health Study

This project, currently underway, is a large-scale, multi-year effort to examine the effects of exposure to reproductive hazards among workers in the semiconductor industry. The study, being conducted by Mark Schanker of University of California at Davis, has been initially cast as epidemiology. However, it is having significant impact as notification as well because individual letters are being sent to potential study participants (Robin Baker, personal communication, 1990). The California State Health Department and the Labor Occupational Health Program at the University of California have played a role in constructing the letters to reflect the department's previously established guidelines on worker notification. No published reports on this project seem to be available as yet, although scientific papers can be expected eventually.

Surveys Related to Notification

Experience with worker notification is moving toward the stage where formal meta-analysis of case studies can be done, generating comparative insight into which program designs and methods prove most effective. Anticipating this development, several surveys related to notification have already been carried out. The earliest example is a survey by the Western Institute for Occupational and Environmental Safety, which focused on ethical concerns. A questionnaire was sent to approximately 50 people who had been engaged in some form of worker notification,

asking them to identify the important ethical issues. As reported by Coon and Polakoff (1982), the respondents varied widely in their ethical positions; the authors conclude that "practical application of any ethical precepts guiding worker notification depends on how the issue is viewed" (p. 253). Another survey was done in 1987 by the Labor Occupational Health Program (LOHP) at the University of California, in collaboration with UCLA and the Occupational Health Surveillance Evaluation Program (OHSEP) of the California Department of Health Services. The purpose was to assess notification experience and methodology for a multi-disciplinary group of 40 researchers nationwide, selected because of their prior involvement or interest in worker notification. The LOHP survey found strong support for the concept of notification, with 70% of the respondents feeling it should always accompany research on worker health, and the rest feeling that it should be used at least sometimes. The respondents identified as major problems the difficulty of determining risk, especially where research findings are inconclusive or experimental; the lack of special funding for notification; and the lack of effective support and medical services as followups to notification. They emphasized that notification cannot take the form of a standardized recipe but must be tailored to each population and setting involved. More recently, Schulte and Singal examined 47 Health Hazard Evaluations carried out by NIOSH over the past 15 years, with special attention to the methods used for individually notifying study subjects of their test results. Through analysis of the notification letters involved, the authors identified a number of critical issues and developed recommendations for notification. For fuller reference information, see these entries in the bibliography:

Coon & Polakoff, 1982
Labor Occupational Health Program, 1988
Schulte and Singal, 1989

Tyler, Texas (Pittsburgh-Corning)

The Tyler Asbestos Workers Program (TAWP) involved a cohort of 1,095 asbestos-exposed employees of Pittsburgh-Corning in Tyler, Texas. The program, funded by the National Cancer Institute (NCI) for the years 1974-79 and carried out through the University of Texas Health Center, was originally intended as a model demonstration program of cancer prevention. However, early in the five-year funding period, emphasis shifted from public health intervention to biomedical research. Planned program elements such as smoking control, health education and interaction with community health care providers were minimized or never implemented. With support among the workers eroding, NCI decided not to renew the grant and the project collapsed.

TAWP is a good example of the tensions, not uncommon in notification, between service and science as distinct project goals. Key references include:

Hurst (1979)
Hurst et al. (1979)
Greenberg et al. (1976)
Brodeur, 1973
Brodeur, 1974
Holstein et al. 1984

Three Mile Island Nuclear Workers

In March 1979, a potentially disastrous accident occurred at the Three Mile Island nuclear power plant near Harrisburg, Pennsylvania. In addition to its community impact the event exposed workers at the plant to radiation in varying doses, endangering their long-term health; attempts were subsequently made to inform them of their risk. While this "notification" of elevated risk status was unplanned, it offers some insights into worker and community reactions particularly in the area of mental stress. Investigations that followed in the wake of the accident included a number of studies focused on the mental health and behavioral responses of workers -- notably a telephone interview survey six months after the accident with 324 TMI workers and a comparison group of 298 presumably unexposed employees at the nearby Peach Bottom nuclear plant. Although this and other studies showed evidence of mental stress among the exposed workers, the U.S. Supreme Court ruled in 1983 that the undamaged part of the TMI complex could be reopened because "psychological health damage caused by risk is not an adverse environmental impact as intended by Congress in the National Environmental Policy Act" (Mental Disability Law Reporter 1983). Discussions of behavioral and mental health reactions of workers and residents in the TMI area include:

Kasl et al. 1981, Part I and Part II
Report of the President's Commission, 1979
Dynes, 1983
Chisholm et al., 1981
Chisholm et al., 1983
Chisholm et al., 1986
Baum et al., 1981
Baum, Fleming, and Singer, 1982
Baum, Fleming, and Singer, 1983
Baum, Gatchel, and Schaeffer, 1983
Cleary & Houts, 1984
Collins et al., 1983
Davidson et al., 1982
Davidson et al., 1987

Dohrenwend et al., 1981
Fabricant, 1982
Fleming et al., 1982
Flynn & Chalmers, 1980
Hartsough & Savitsky, 1984
Houts et al., 1980
Walsh & Warland, 1983
Bromet, 1980
Moss and Sills, 1981

United Automobile Workers/ Ford Motor Co. (Hazcom Training)

OSHA has sponsored a multi-year evaluation of hazard communication training (which as noted earlier has notification implications) in five programs jointly administered by the United Automobile Workers and Ford Motor Company. Started in 1986, the study is now completed and a final report is available. Key references include:

Robins et al. 1989
Hugentobler, Robins and Schurman 1990 (in press)

United Mine Workers

The United Mine Workers of America more or less blazed the trail for notification in the United States. This union began the nation's first comprehensive program of notification and services for high-risk workers -- miners facing coal workers' pneumoconiosis -- in the 1960s. The UMWA program was incorporated into the Federal Coal Mine Safety and Health Act of 1969, and its influence can still be seen in the 1980s in the government-funded coal miners' clinics set up as part of the Black Lung benefits program (personal observation and discussion with staff of Pennsylvania clinics, 1988-89). A description of these developments can be found in Kerr (1980).

Uranium Miners (Atomic Energy Commission)

During the late 1940s to the mid-1960s, approximately 15,000 mine workers were exposed to radon in the course of extracting uranium from sites operated by the U.S. Atomic Energy Commission in Arizona, Colorado, New Mexico and Utah. The health of some 4,200 of these miners was monitored over many years by the U.S. Public Health Service (without notification to the workers), and NIOSH has ongoing epidemiological studies with this cohort. To date more than 400 miners have died of lung cancer, well in

excess of normal mortality. This population's exposure has been the focus of much litigation and political controversy. Representative Owens and Senator Hatch have proposed federal legislation to pay up to $100,000 in compensation to each of 500 injured miners or their survivors. Also, a lawsuit was brought in Marysvale, Utah, against Foote Mineral Company (which had bought out Vanadium Corporation of America, which had leased the land from the Atomic Energy Commission in 1948); this suit was settled in 1985 with awards to 32 miners and survivors ranging from $3,000 to $135,000 each. The main relevance for this review is the fact that for many years, notification did not take place with this cohort, largely because of direct pressure from the Atomic Energy Commission (New York Times, January 9 1990).

Worker Notification Project (WIOES)

This notification project, intended to serve as a prototype, was conducted in California during 1979-81 by the Western Institute for Occupational and Environmental Sciences (WIOES) with funding from the National Cancer Institute. WIOES cooperated closely with two labor unions: the International Association of Machinists and Aerospace Workers, Local 1101 of San Jose, and the International Association of Firefighters, Local 112 of Los Angeles. (Another union originally scheduled to participate, the Boilermakers Union of Seattle, withdrew from the project in 1980 because of unspecified "unreconcilable differences" with the researchers.) The large target population of union auto repair workers and firefighters had for many years faced occupational exposure to asbestos, PCBs and a variety of other carcinogens. WIOES carried out a "Health Action Survey" and assisted the unions in preparing individual notification letters and information booklets, which were sent out at the unions' responsibility on union stationery. While WIOES provided speakers for follow-up lectures, there were no provisions in the contract for follow-up services and screening. In the researchers' view, "many new and unforeseen ethical and legal questions emerged which needed further analysis before the final notification protocols [to guide future programs] could be developed" (Project Officer's Final Report 1981). This project surfaced two concerns that subsequently became the focus of heated debate: (1) what individual notification implies in terms of legal responsibility and (2) whether individual notification is advisable in the absence of medical surveillance and other follow-up services. The project stimulated a conference and related publications on "Ethical Issues in Worker Notification." See these information sources:

Hegyeli, 1981
Western Institute, 1981
Coon and Polakoff, 1982

Other Kinds of Programs Relevant to Worker Notification

Interventions to contact and inform populations at special risk occur in many contexts other than worker notification, raising some of the same ethical and practical issues. For example, programs related to AIDS education and prevention involve issues of confidentiality, employment and insurance discrimination, overreaction, and motivating health-protective responses. Social responses to community toxic threats and industrial disasters involving toxic exposures contain many lessons for worker notification, especially regarding the role played by the media in risk communication, liability concerns, and the social and psychological impact on the exposed population. Useful connections can be drawn between non-occupational genetic screening and counseling (for instance, to guide reproductive choice) and the biological monitoring that accompanies notification. Some health promotion programs related to risk factors other than toxic exposure -- poor nutrition, lack of exercise, hypertension, stress, obesity -- parallel exposure risk notifications in terms of psychological impact and motivation for behavioral change. While this review cannot hope to cover the voluminous literature on related program areas, a few relevant books and articles are included in the citations and bibliography.

III. Critical Issues

We now turn to general themes that cut across these diverse examples of high-risk notification. One important point must be kept in mind: the purpose of the analysis is not necessarily to build a rationale to justify this kind of intervention. The pro-notification recommendations of CDC's Committee on Ethics, discussed earlier, derive from moral imperatives that require no justification in terms of either disease prevention or cost effectiveness.

Nevertheless, worker notifications do potentially accomplish or facilitate a number of desirable outcomes:

1. Effective Risk communication: Increased understanding of hazard and health risk information among the target population.

2. Positive Health Impact: Maximum beneficial effects and minimum adverse effects on exposed workers and their families in terms of physical health.

3. Support for Quality of Life: Maximum beneficial effects and minimum adverse effects on exposed workers and their families in terms of psychosocial, behavioral, financial and legal considerations.

4. Reduction in Ongoing Exposure: A reduction in any ongoing hazardous exposures of workers and their families, both among the notified high-risk groups and among others with similar exposure.

5. Equitable Cost Distribution: Appropriate distribution of the cost burden for screening, treatment and compensation related to occupational disease.

6. Support for Service Providers: Enhanced ability of health and human service providers in the community to meet the needs of exposed workers and their families.

7. Mobilization of Community Resources: Enhanced ability of relevant community institutions and new or existing community organizations to cooperate in managing the consequences of past exposures in an equitable and sustainable fashion.

8. Smooth Program Operation: Efficient, cost-effective operation of the notification process and related activities.

9. Advances in Biomedical Research: Combining the notification with scientific investigations having potential for disease prevention, such as research on preclinical markers of occupational disease.

The discussion below revolves around these nine issues, showing what is known at this point from scientific studies and other literature related to notification, and what remains to be discovered.

1. Risk Communication

Selecting a cohort suitable for notification and accurately characterizing its risk are themselves complex processes, beyond the scope of this review. For discussion of proposed procedures and practical difficulties, see the "General Worker Notification Implementation Plan (NIOSH 1989), and Schulte ~~and colleagues (1987)~~ 1985.

Once a target population for the notification has been defined by some set of criteria, communicating risk information is also no simple matter. The process poses a number of challenges, all of which could become the focus of evaluation. In this review we will consider (a) locating and reaching the cohort members, (b) the notification letter, (c) other media of communication, (d) social networks, (e) content of the message, and (f) confidentiality.

(a) Locating and Reaching the Cohort Members

The experience of reported cases shows that this process can demand enormous time and diligence. Augusta and Cloquet provide "worst case" examples. Researchers in Augusta were dealing not only with a somewhat hostile community, but also with an archetypically hard-to-reach population of low-income minority workers whose exposure had occurred a decade or more prior to the notification. While most still lived near Augusta, some had moved away from the area; in fact, members of the cohort were dispersed over 30 states. The best available address list was an outdated and incomplete microfilm of company personnel records made by NIOSH staff in 1972. Under these circumstances, to get the participation rate they eventually achieved, the researchers had to go to extraordinary lengths -- time-consuming detective work to trace current addresses, second and third mailings, telephone calls and personal discussions with cohort members' friends and relatives (Schulte et al. 1985a). The experience of Augusta probably shows the limits of intensive search efforts. Even with extraordinarily rigorous tracing, approximately 22% of the original target population of 1,385 could not be located (Tillett et al. 1986:724).

In Cloquet, the situation was if anything even more frustrating. A relatively complete cohort list existed, but was inaccessible because the employer actively resisted the notification due to liability concerns. Slow and expensive legal action was required to break loose the information. The United Paperworker's initial screening had to be based on a fragmentary twenty-year-old union list containing only 570 names from a cohort estimated at up to 5,000, and only 332 of these individuals could be located (Sullivan, 2nd Affidavit 1988). If litigation to get the employer's lists had failed, forcing the project to rely only on the cohort information initially available, an estimated one-third of the former workers would have been left out completely and many of the rest would have been unreachable due to missing data (State of Minnesota District Court 1988:7).

Officials in charge of the state health department's phase of the Cloquet notification point out that tracing remains a problem, even with Conwed's lists available. Some of the exposed individuals were "kids earning money for college, who were given summer jobs at Conwed as a favor to their parents who worked at the plant"; these teen-agers were not recorded in the company's personnel records, and do not show up on any cohort lists (Allan Williams, personal communication, 1990). Also, while many family members of living Cloquet workers have been screened for secondary exposure to asbestos, the surviving families of a "couple of hundred" deceased Cloquet workers have received little help; state officials acknowledge regretfully, "we haven't done anything with them" (Alan Bender, personal communication, 1990).

By contrast, Port Allegany and Lock Haven represent "best cases." The subjects were already interested in the notification; relatively complete and current lists were available; and from the start both projects enjoyed support from the company, the union and the community. But even where conditions were favorable, not all cohort members could be located. In Port Allegany addresses proved unobtainable for 20% of the cohort (Tillett et al. 1986:724) and in Lock Haven 33% of the potentially notifiable Drake cohort could not be located (Marsh et al. 1987:46). Difficulty in actually locating cohort members is what lowered the participation rate in Lock Haven to 48% of the total cohort. Once contacted, the exposed workers were "very successfully enrolled into the program" for a participation rate of about 82% among contacted individuals (Marsh et al. 1987:16-17).

Marsh and Enterline (1979) note that the "completeness of cohorts identified for historical prospective studies of occupational diseases is subject to many sources of error," particularly when the cohort list is based on plant records (p. 665). Company files and also union lists are often poorly maintained, especially for inactive employees or members. It is

not uncommon to find inactive personnel files stored in "attics, cellars, closets, and abandoned tool sheds or warehouses" (p. 669). To solve this problem, Marsh and Enterline recommend a method for independent verification of company and union lists through Internal Revenue Service records (IRS Form 941, Employer's Quarterly Report on Earnings). Developed for use in a study of man-made mineral fiber workers, this method succeeded in locating 1,990 additional cohort members -- an increase of over 20% in the employee lists originally supplied by the six participating plants.

What these experiences show for notification program design and evaluation is that

-- Locating cohort members should be planned and evaluated as a multi-stage effort in which the list is built and improved over time. Detective work, community organizing, media publicity and even legal action may be required to build the list.

-- Participation rates, tempting as an evaluative measure, should be seen clearly as an indicator of process rather than outcome. They do not necessarily give a good picture of a notification program's "success" because some cohorts pose greater contact problems than others. A uniform rate of success in locating cohort members should not be expected across notification efforts.

-- Planning of notification needs to include adequate resources devoted to locating cohort members, especially where the exposed workers are disadvantaged, geographically dispersed, or unrepresented by unions. These hard to reach cohorts may well be the very ones that need notification most, lacking the alternative sources of information and support available to exposed workers with more resources.

-- More needs to be known about the risk characteristics of non-participating cohort members, and about more effective ways of contacting and/or enlisting them.

-- The practical significance of independent list verification (and methods for accomplishing this step) need more consideration.

-- Consideration is needed concerning the ethical, health and legal implications of excluding deceased workers' surviving family members from the notification effort, since they may be at risk from secondary exposure or have legitimate compensation and legal claims.

(b) The Notification Letter

Where cohort lists exist, individual letters have been the main method used for notification. Some evidence suggests that participation in screening can be greatly increased by reinforcing the letters with a more personal contact. For instance, in Lock Haven "it was necessary to contact many of the respondents by telephone before they agreed to participate"; the response rate rose markedly (95.7% as opposed to 81.8%) when personal contact was made by the project coordinator (Marsh et al. 1987:14, 40). Personal contact also seems to be important in reinforcing the information contained in letters. In Cloquet, the program director comments: "I think the most useful part of our screening program was the one-on-one time with the interviewers, who were supposed to be collecting data but wound up spending a lot of time answering questions" (Bender, personal communication, 1990).

A problem with letters, of course, is that the recipients may not be able to read them. Authorities on education estimate that as many as 25 million American adults presently lack basic literacy skills (Kozol 1985). Worse yet, a Hudson Institute study predicts that more than three-quarters of the new entrants into the labor force during the next decade will have limited verbal and writing skills, at Level 1 or 2 of the Labor Department's six-level reading skill scale (Business Week 1988). Patterson (1987) recently surveyed 130 safety professionals and found that 59% of the 78 who responded felt it possible for illiterates to be hired at their worksites. However, most (over 80%) had never evaluated illiteracy rates at their workplaces, even though they felt that illiterates could not properly comprehend hazard communication training. Patterson also concludes that the symbolic pictographs often used on warning labels do not adequately communicate hazard information to illiterate workers. Such findings, obviously important for primary prevention and service access (Larsen 1979, Grueninger 1986) have implications for notification as well. Evaluation of the target population's English-language literacy clearly needs to be part of the pre-notification community assessment (see section below on the community context).

Even where researchers have felt concern about the cohort's reading skills, as in Augusta, they have generally wanted to send individual notification letters anyway. This seems appropriate, since illiterate adults are known to rely on friends and family for help with written messages that look important (Kozol). However, there are degrees of literacy, and even those with basic reading skills may have trouble with a poorly designed letter. One frequently voiced complaint is that written notification materials are "often too detailed and written at a level higher than the average worker can understand" (Occupational Safety & Health Reporter, 5/24/89; see also Manning 1981 and Walker et al.

1980). In Cloquet, the state health department researchers were concerned with the literacy of their bluecollar target population, so they solicited considerable input from the union membership in developing materials. Still, they found problems:

> When we handed out our one-page summary sheet at the meetings, many of the workers refused to take it. We later learned that they couldn't read it. It's not that they can't read in the sense of being illiterate, but they just don't work in terms of written communication. (Bender, personal communication, 1990).

Making a letter readable needs to go beyond the oft-recommended avoidance of scientific jargon. It should include an analysis of the reading level the letter requires (perhaps using computer software such as "Right-Writer" or "PC Stylist"). It should include consideration of graphic and visual appeal in much the same way that these factors are considered in commercial advertising. Letters also need at least a cursory field test with key informants or focus groups to get rid of potentially alienating problems with reading level, format, tone or word choice. This pretesting step is an important one, because without it, avoidable mistakes may be made without the researchers' knowledge. In most published accounts of notifications, pretesting is not mentioned. Augusta and some of the union based projects are exceptions; in these notifications, pretesting of letters seems to have happened naturally in the course of interaction with the target population and its representatives. NIOSH currently includes pretesting of letters in its Notification Implementation Plan (although not yet, apparently, in its procedures for Health Hazard Evaluations; see Schulte and Singal 1989:592).

(c) Other Media of Communication

In addition to individual letters, many other communication media have been employed in notification: radio and TV announcements, newspaper articles, union newsletters, pamphlets and flyers distributed in the community, posters placed in local businesses, a newsletter put out by the notification program itself, a documentary film shown on TV. These other approaches are ways to reinforce the letters, and at least potentially they can reach members of the target population who have problems with literacy. Also, health educators (and advertising agencies) have found that message repetition is important in getting a response. Given these realities, the deliberate use of multiple media and followup messages would seem to be advantageous (see NIOSH 1977).

It is important to recognize that additional media of communication will come into play whether they are planned for or not, if there is a general public health or human interest angle

to the story. This could be helpful, especially in emergencies. For example, a European study shows that in the days following the Chernobyl disaster, 80% of the at-risk population surveyed got their information about health countermeasures from the mass media, which they reported trusting more than they trusted their governments (Cannell 1987).

However, the press has its own agenda. In Augusta, the role played by the media was reportedly a complex one, sometimes helping and sometimes complicating the project -- but in general demonstrating that a free press goes its own way regardless of the preferences of notification experts (see Schulte et al. 1985a). This showed up also in the Asbestos Awareness Campaign of 1978, where mass media were the primary notification vehicles. Some key parts of the detailed risk information that the National Cancer Institute supplied to broadcasters got dropped, underemphasized, or buried in late-night time spots that reached few people; in general, the hazard itself got much more coverage than the health countermeasures that exposed individuals could take (Needleman 1987). A similar pattern occurred in Lock Haven, where community awareness was assessed after the project's initial media publicity campaign. The survey showed that while 55% of the 232 respondents knew that working in Lock Haven chemical plants had put people in danger of developing bladder cancer, only 12% understood that the early stages of disease could be asymptomatic and only 23% knew that the disease was curable (Marsh et al. 1987:42-43). The latter two facts are the important ones in terms of motivating people to participate in screening.

The role of the press is extremely important because media coverage has the potential to overpower the notification message in ways that do not benefit the at-risk population. For example, recent anecdotal evidence suggests that in Augusta, where media treatment of the notification effort gave an extreme view of the health hazard, at least some notified workers remain convinced they have bladder cancer despite negative test results (Laura Leviton, personal communication, 1990).

Working with the press and other mass media might as well be factored into the notification planning in the first place, so as to enhance support for the program and improve the completeness and accuracy of coverage. Some sources relevant to working with the press include:

"Telling Reporters about Risk," by Sandman (1988)

"Environmental Risk Reporting" (Sachsman et al. 1988a & 1988b)

Environmental Risk and the Press by Sandman, Sachsman, Greenberg and Gochfeld (1987)

The Environmental News Source: Informing the Media During an Environmental Crisis by Sandman, Sachsman and Greenberg (1987)

Some researchers have documented the way the press handled the notification (Schulte et al. 1985a, Marsh et al. 1987). We need more research of this kind, focused on:

-- patterns in the news treatment itself (the media involved, the amount of coverage, the nature of the message, timing considerations).

-- how different media are perceived by the community (e.g., different levels of trust, different levels of accessibility).

-- how different media interact with each other and with the notification program, in terms of communicating to those at risk (conflicting information or reinforcement of the message).

(d) Social Networks

Whatever media are chosen for notification, a process that communication theorists call "social amplification" is likely to occur (Kasperson et al. 1987, Kasperson et al. 1988, Kasperson et al. 1989). That is, in general, the notified individuals will not decide on their response in isolation. Instead, they will turn for cues to their reference groups and significant others -- family, friends, unions, co-workers, clergy, mass media, trusted authority figures in the community. As Samuels (1980) has pointed out, interventions with high-risk workers often ignore such social processes.

In the few cases where this process has been investigated, consultation with social networks was reported as common. In Augusta (see Schulte et al. 1985a:23), over three-fourths of those who received the letter said they had discussed it with another person. In Cloquet (see Meyerowitz et al. 1989:471), there was much discussion within the union and the notified workers talked to their spouses (36.6%) and/or friends (41%) about how to respond. The Cloquet experience also illustrates that decisions about response are not necessarily immediate. Some workers took a long time to make up their minds, as shown by the fact that 57% of those who missed the initial screening indicated that they would like to attend a screening program if another one were offered (Meyerowitz et al. 1989:471). The behavioral significance of support from social networks came through most clearly in Lock Haven, where one-half of the workers

coming in for screening said they had discussed the decision with someone, primarily family members, friends and other workers. The researchers note: "Many of these workers reported that they would not have come in for screening if they had not been encouraged to do so" (Marsh et al. 1987:41). See Vernon (1989) for discussion of social factors influencing participation in an occupational health screening program for colorectal cancer, and Bone (1989) for use of followup by community health workers to boost participation in a hypertension control program.

Augusta, Lock Haven and most union-based programs provide good examples of how to work closely with the cohort's social networks so that these networks will be supportive of the notification effort. In Augusta, establishing a local group called the Committee of Concerned Citizens is thought to have played "a critical role in contacting workers, encouraging their participation in the study, and serving as a liaison between the workers and the researchers (Labor Occupational Health Program 1988 draft: 9). In general, this whole area needs much more study than it has currently received. As Kasperson has noted (1986:280):

> The public consideration of risk characteristically occurs in a social group or community context, consisting of multiple sources and channels of information, peer groups, and an agenda of other ongoing social issues. Much more is known about the response to risk by members of the public as individuals than as members of social groups. Improved understanding is needed of the social dynamic of risk consideration in the context of actual controversies and community processes.

Preliminary information from the second (state-sponsored) phase of the Cloquet program suggests that ignoring social networks and providing only written notification may produce disappointing results. Alan Bender of the Minnesota State Health Department says that the main lesson learned from the state-sponsored phase of this notification effort is that "written notification is inadequate in situations involving complex health and medical issues. . . Written material may satisfy legal and possibly ethical responsibilities, but does not satisfy the need to communicate" (Occupational Safety and Health Reporter, 5/24/89).

(e) Content of the Message

The core of the risk communication message usually consists of information about the exposure in question and its potential effects on health. Problems and issues of getting this content across in notification letters have been summarized by Schulte and Singal (1989) in an analysis of NIOSH Health Hazard Evaluations over a 15 year period.

One aspect of message content not yet well studied concerns what communications theorists call "framing effects" -- i.e., how the information is organized. Notification letters filled mainly with information of interest for planning and research purposes (such as a detailed description of the cohort) may seem irrelevant to the individual letter recipient whose frame of reference is his or her personal risk (Needleman 1987). Also, messages may elicit different responses depending on whether they are cast in advocacy terms or clinical terms, and whether they seem warm and caring or cool and distant. These effects are amenable to experiment, and may have been already investigated in other contexts. Relevant psychological, communications, and market research literature might be worth exploring (see Kahneman and Tversky 1984).

The message in an individual notification has a double purpose: (a) to inform the exposed worker and his or her personal support groups; and (b) to inform the physicians and other professionals who may provide services to notified workers. Some of the controversies surrounding how to phrase the letter may stem from tensions between these two purposes, since the worker needs the information couched in a framework of summarized action-oriented advice and the physician needs the information given with precision and technical detail. If professionals trained in occupational health will be doing medical screening as part of the notification effort, the second part of the message is perhaps less important. However, if the notified workers must find medical care and other assistance from professionals unfamiliar with the occupational health problems described in the notification, the letter has to serve both purposes simultaneously. This issue has been handled most commonly by keeping the letter short and aimed at the worker, but enclosing separate, more technical fact sheets with information for the use of the physician.

Some careful evaluation of how well the current approach of letters plus factsheets actually works in practice, both for workers and for their physicians, would be helpful. A recent study by Meyerowitz and colleagues (1989:473) suggests some problems in workers' understanding of information in fact sheets. A dissertation currently underway at Medical College of Georgia may shed some light on how notified workers interpret the materials given them (Laura Leviton, personal communication, 1990).

A much broader approach to notification content was taken in Augusta, and to a lesser extent in Port Allegany, Lock Haven and the union phase of the program in Cloquet. In these projects information flow between subjects and researchers was interactive rather than one-way, was sustained over a long period of time, and was heavily reinforced through multiple media and close involvement with community institutions. In effect, notification

was viewed as a "health education program for the entire community" (Schulte et al. 1985a; see also Holstein et al. 1984). This approach, which intuitively seems superior in terms of potential for correcting misunderstandings and stimulating positive responses, needs to be evaluated for long-term effect.

The risk message in a notification letter walks a tightrope between being too alarming and too reassuring. Ideally, it should avoid creating unwarranted anxiety but still convey a serious enough risk to motivate constructive behavioral responses such as smoking cessation and participation in ongoing medical surveillance. Some of the literature related to environmental risk communication cited earlier is highly relevant to this issue of balancing alarm and persuasion; see especially Chess and Hance (1987). Social psychologists have produced a sizable literature on the use of "threat appeals" in health promotion campaigns (Beck and Frankel 1981, Higbee 1969, Janis 1967, Leventhal 1965 and 1970, Rogers and Mewborn 1976). However, we do not as yet have any studies specifically dealing with high-risk worker notification, to indicate how letters with different "fear" content might compare in terms of stimulating the recipient to action.

Notifications have differed widely in the scope of the information included. Those done by law firms tend to be quite minimal, aimed only at establishing the fact of exposure in a legal class without much health explanation. Notification efforts by federal agencies emphasize health implications along with the notice of past exposure, but typically have not gone much further. By contrast, projects initiated by labor unions and some state health departments tend to include information about a wide array of service and compensation issues. Compensation information and advice to see a lawyer are standard parts of the notification material used in the California Occupational Health Plan (COHP, formerly known as OHSEP) run by the California State Department of Health (Glenn Shor, personal communication, 1990).

It would be interesting to examine the differential impact, if any, of letters cast narrowly and letters cast broadly. In particular, we need to know more about the health and other implications of addressing versus omitting workers' compensation issues in the notification. Workers' compensation, discussed further below, is an information area strongly recommended for inclusion by some (Labor Occupational Health Program, 1988) but not at present a feature of NIOSH's notification plans.

One other issue that crops up concerning message content has to do with timing. For notification programs associated with ongoing epidemiological studies, should individual workers be sent their test results as the data become available, or should all individual notifications wait until the data can be put in

the context of the entire group's results? Strong arguments can be marshalled for both positions, and at least one large state health department is currently in sharp internal disagreement over the issue (Glenn Shor, personal communication, 1990).

(f) Confidentiality

In principle the notification letter represents a private communication to the exposed individual. However, confidentiality problems have come up fairly frequently in actual notifications, sometimes in ironic ways -- as in Augusta, for instance (see Schulte et al. 1985a). Here the researchers considered the notification to be "a multistage process rather than a single act," and expected that media, community groups, local agencies and individuals within the cohort would supplement the notification effort triggered by NIOSH. They welcomed the help of the County Health Department and the community-based Committee of Concerned Citizens (CCC) in locating missing members of the cohort, so as to link more at-risk workers into the program's screening and services. However, it was something of a surprise when the CCC, with the best of intentions but no authorization from NIOSH, got the names of 121 hard-to-find exposed workers published in a local newspaper in possible violation of the Privacy Act. The news announcement did actually help in locating an additional 40 cohort members, none of whom objected to the publication of their names.

A similar issue arose in the Lock Haven program (Marsh et al. 1987:14-15). Here announcements to the media were deliberately discontinued at the stage where the screening coordinator began trying to trace former workers through neighbors. The neighbor was not supposed to be told that the person being sought had worked at Drake/Kilsdonk, in order to protect cohort members' privacy. The researchers felt that media coverage during this stage -- especially identification of the screening coordinator through photos or television -- would have jeopardized the confidentiality of the tracing.

As noted by Schulte and colleagues (1985a), there is a real tradeoff here between confidentiality and public health outreach. The same tradeoff will arise in any notification situation where public identification might help locate missing members -- and the researchers must make the decision because the subjects do not know a choice exists. At present a narrow interpretation of the Privacy Act of 1974 (4 USC 522) would seem to weight the scales in favor of privacy. However, the issue is far from settled, especially in light of the long history of tension between individual rights and public health concerns in the United States (Beauchamp 1985, Waters 1985). Exceptions to doctor-patient confidentiality are currently being hotly debated in other areas of public health such as genetic screening (World

Medical Association 1987, Seller 1982, Arnold and Mosely 1976, West 1988, Gillon 1988) and partner notification in AIDS screening (Avins and Lo 1989, Potterat 1989, Zonana 1989).

In thinking through the proper ethical balance of individual privacy rights and public health in the context of worker notification, it would help to have more evaluation data on

-- the health fate of notified versus non-notified workers with similar past exposures, and

-- the opinions of workers who were notified through means that infringed on their privacy rights.

It should be noted that professed concern about confidentiality has been used by employers to obstruct worker notification, as in the case of Cloquet, Minnesota. As discussed earlier, Conwed Corporation possessed personnel lists with all the data necessary for notification, but for years resisted making the lists available to the union and the state health department for notification purposes. Conwed's legal defense, which the District Court Judge found unpersuasive, was based largely on protection of the employees' privacy (State of Minnesota, Judicial Order 1988). For uranium miners, confidentiality concerns of a different sort -- national security -- were used by the Atomic Energy Commission in the 1950s and 1960s to pressure the Public Health Service into agreeing "not to tell the miners why they were undergoing periodic physical exams, chest X-rays, and blood, urine and sputum analysis" (New York Times, 1/9/90: A20). Dr. Victor E. Archer, who served as the principal investigator for the uranium miners study, is quoted in a December 1989 interview as saying: "Looking at it with the standards of today, you could take the attitude that the miners were being used as guinea pigs, and we were essentially watching them die. . . At the time, the situation was that we couldn't do anything to alarm the miners or we wouldn't get our studies done" (New York Times, 1/9/90: A20).

In the literature, most concerns about confidentiality revolve around a very different issue: the potential for social stigma and discrimination against individuals in the notified cohort (Sands et al. 1981, Needleman 1990). This issue is discussed in more detail below, but it should be noted here that some instances of job and credit discrimination resulting from notification have been reported. Accordingly, we need:

-- systematic assessment of how effectively the present methods for handling confidentiality actually do protect against discrimination.

-- if indicated, research that would aid in developing better methods for protecting notified workers.

2. Impact on Health

NIOSH has estimated that as of 1972, as many as 21 million workers had exposure to federally regulated substances (US DHHS, NIOSH 1977). In many -- although unfortunately not all -- cases, diseases resulting from these exposures could be successfully treated if caught early enough. For example, Hill (1984) estimates that a 13% reduction in mortality rates for bladder cancer could be achieved by early detection. Hill's estimate, based on differences in survival rates between patients treated early and patients treated for advanced disease, applies to the general population. Populations at unusually high risk for bladder cancer, such as the 6,000 American workers with known past exposure to aromatic amines, would presumably show an even greater positive health effect from early medical intervention (Schulte et al. 1986).

At present we have little insight into whether mortality reductions of this magnitude are in fact being realized through current notification approaches, because no long-term evaluations have been conducted. Notification in some cases focuses on diseases that are essentially untreatable, where patient comfort rather than increased longevity is the main goal of medical intervention; black lung disease is a good example (Kerr 1980, PA Dept. of Health 1989). For treatable diseases, at this point we do not know whether risk information necessarily leads to early disease detection, especially where the notification is unaccompanied by a program of screening and medical surveillance. We also do not know if early detection necessarily leads to effective treatment, especially for those lacking adequate health insurance. Much more needs to be learned about both the potential for long-term health gains from notification and the circumstances that permit or hinder these gains.

For some occupational exposures, followup screening of family members when a worker tests positive represents a logical way to increase notification's positive health impact. Indirect exposures of family members have been documented for a number of substances, including asbestos (Anderson et al. 1979, Kilburn et al. 1985, Anderson et al. 1976) and lead (Baker et al. 1977). Several notification-related screening programs have included the workers' family, notably Port Allegany and Cloquet. However, the health implications of testing (or not testing) family members have not been sufficiently reported.

(a) The "Yield" of Notification Screenings

Establishing screening programs and interpreting their results involve conceptual and practical tasks of extreme complexity. Two special issues of the 1986 Journal of Occupational Medicine (August and October) report on

presentations and discussions of the subject at a Conference on Medical Screening and Biological Monitoring for the Effects of Exposure in the Workplace, held in Cincinnati in 1984, sponsored jointly by NIOSH, the National Cancer Institute, and the Environmental Protection Agency. See also the American Journal of Public Health's 1989 Special Supplement on Surveillance in Occupational Health and Safety, edited by Edward Baker. Additional discussion of screening can be found in Schilling (1986), Schulte and Halperin (1987), and numerous other sources.

Still, despite this complexity, notification programs that include a screening component do at least make it possible to count the number of disease cases detected earlier than they otherwise would have been, among those who are notified and screened. The following list shows the "yield" for various projects (some of which are still ongoing) two to six years after the start of notification/screening:

--- In the Augusta cohort of 1,385 individuals at risk for bladder cancer, 1094 were located, notified and urged to participate in the project's screening program. Five hundred and sixty-six workers completed the primary screening. For the total cohort, 14 confirmed cases of bladder cancer were identified, including 4 ascertained from death certificates; 7 already under treatment by community urologists; and 3 that came to light through the first phase of screening (Tillett et al. 1986, Baker et al. 1989). Since that time two additional cases have been identified. The initial screening also disclosed 22 abnormal test results that may be early signals of bladder cancer. Schulte and colleagues (1985b:121) point out that more cases are to be expected because "the majority of the cohort has not yet achieved the average latency period of 21 years observed for the cases detected thus far."

--- Among the pattern makers, in a cohort of 3131 individuals at risk for colon cancer, 1513 workers completed the screening examination. Among those examined, 12 cases of malignancy and 219 cases of colorectal polyps were found (Tillett et al. 1986:725).

--- In Port Allegany, in a cohort of 1186 individuals at risk for asbestos-related lung cancer, 594 workers were examined. Only one case turned up in the screening initially -- not surprising because most members of the cohort are still within the 20 year latency period for lung disease caused by asbestos exposure (Tillett et al. 1986:725). Additional cases will appear as the program continues. Since lung cancer resists treatment, a more important health impact of risk information in this population may lie in the area of smoking cessation, which is a significant risk reduction measure. Follow-up surveys (Tillett et al. 1986:725)

revealed a lower prevalence of smoking among program participants (30%) than among non-participating members of the cohort (47%). This difference could, of course, have resulted from self-selection. More to the point, a large proportion of the cohort (43%) were ex-smokers, and 25% of the ex-smokers surveyed (N = 96) reported they had quit because of their previous contact with asbestos.

--- In Cloquet, the first screening sponsored by UPIU examined 270 asbestos-exposed Conwed workers thought to be at particularly high risk, and found that 167 persons (61%) had chest x-rays showing asbestos-related pathology (District Court Findings of Fact 1988, Robins and Green 1988). The second phase of notification and screening, under the auspices of the Minnesota Health Department, covered 1552 individuals including 451 spouses of former Conwed employees. Health findings of the second phase are still to be reported scientifically, but are described in the Minnesota Health Department's Preliminary Report to the Minnesota Legislature (1989) as follows. Among male Conwed workers, the overall prevalence of X-ray abnormalities was 18.9% (22.2% among those with 20 years latency). Among female Conwed workers, the overall prevalence was 3.3% (3.7% among those with 20 years latency). Among the workers' spouses included in the screening, most of whom had laundered contaminated work clothes over many years, the overall prevalence of X-ray abnormalities was 7 cases, or 1.6% of the 451 screened (1.8% if only those with 20 years latency are considered).

--- In Anderson, Michigan, 450 workers were identified as being at high risk for bladder cancer related to MBOCA exposure. All 450 were interviewed and urine samples were analyzed for 370 of them. The screening revealed one case of bladder cancer, representing a sentinel health event because of the worker's young age (under 30), and also found that another 70 workers in the cohort had some abnormality in the urine such as red cells or atypical cytology. A second screening by cystoscopy later revealed a second case of bladder cancer. See Occupational Safety and Health Reporter (10/22/86) and Ward et al. 1988.

--- In Lock Haven, researchers developed a study roster of 412 former Drake/Kilsdonk employees at high risk for bladder cancer related to chemical exposures. Of these, 220 were contacted, the rest being either deceased or impossible to trace. Among those contacted, 180 agreed to participate and 151 were actually screened during the project's first year. Test results yielded 17 "positives" and 21 "monitors" (i.e., abnormal findings). So far none of the 11 "positives" who received follow-up diagnostic evaluations have tested positive for bladder cancer. However, in light

of bladder cancer's 20 to 40 year latency period, cancer cases are expected to appear eventually in the program's ongoing surveillance. Because of a surprisingly high proportion of non-negative cytologies among those classified as low-risk based on work history, the researchers have reconsidered their original rescreening protocol. They suggest that it is "premature" to drop from the program those low risk workers with negative results on the first screening (Marsh et al. 1987:39).

-- In Rocky Flats, the cohort of workers with presumed beryllium exposure numbers approximately 750. Among those notified as of 1989, 12 cases of berylliosis have been identified, 8 among current workers and 4 among retired employees of the Rocky Flats nuclear weapons plant (New York Times, 1/15/90; Denver Post, 1/14/90). Additional cases of beryllium sensitivity and berylliosis have been found among Rocky Flats workers not originally considered exposed, suggesting to the researchers that beryllium disease is not dose-related and that many more workers than the original 750 should be considered at risk (personal communication, Kathleen Kreiss, 1990). This development has left the researchers (and the union representing the Rocky Flats workers) with serious concerns about how to fund additional screening for the rest of the 2500 individuals now estimated to be at risk, the majority of whom are ineligible for free screening through the NIH study now underway.

Several studies of screening results indicate that dividing up the cohort into risk categories based on work history data does not seem to predict very well the actual distribution of pathology, even for diseases known to be dose related. For example, a fairly large proportion of individuals thought to be at low or medium risk turned up positive in screening in both Lock Haven (Marsh et al. 1987:39) and Cloquet (Allan Williams, personal communication, 1990). This finding suggests that targeting screening or rescreening only at presumed high-exposure cohort members may be a mistake. Length of employment and job category, the two variables most commonly used to predict level of risk, may be poor indicators of actual exposure for individuals.

On the other hand, a screening of Seattle-area plumbers and pipefitters reported by Schwartz and colleagues (1988) had good success in identifying indicators of high risk from self-administered individual occupational histories. It also seems that racial and ethnic factors may turn out to be fairly good predictors of exposure. Ruttenberg and Powers (1986) note that in Augusta, black workers were at 14 times greater risk of contracting bladder cancer than white workers. One of the lessons of the Augusta screening, they argue, is that black workers in a cohort deserve special attention because they

probably got dirtier, more dangerous job assignments than their white counterparts. (On this point, see also Robinson 1984, Davis and Rowland 1983, Walker 1988, and Coye and Fenske 1988.) The utility of work history and demographic indicators for shaping the screening protocol needs to be analyzed more carefully and various alternatives explored.

Screening is no panacea, especially if it takes place in a context of poverty and underservice, or if the diseases being detected are ones not amenable to treatment. However, as the most common (and sometimes the only) service accompanying notification, screening may implicitly carry the burden of somehow providing a total answer to the needs of notified workers. As pointed out in one particularly sensitive discussion of this problem (Schulte 1986), screening may be established as a "surrogate for other kinds of support programs that do not exist in society today" -- even when the screening tests offer little hope of improving long-term survival rates. Schulte recommends:

(1) recasting the "screening debate" to include not only survival as a criterion of program effectiveness, but also broader quality-of-life considerations.

(2) including tests aimed at the earliest possible detection of disease (biomarkers and indicators of multistage transformations) so that chemopreventive and behavioral modification treatment strategies can be brought to bear.

(3) establishing a "systematic and comprehensive program" to deal with notified workers' broader needs more directly.

Evaluation should take this kind of thinking into account in assessing program effectiveness.

(b) Notification without Screening

What if there is no organized medical followup accompanying the notification, but merely advice to see one's personal physician? Does risk information effectively motivate exposed workers to seek medical diagnosis on their own? That is, do notified workers react "rationally"? This is one of the most obscure areas of notification evaluation. When notification programs lack medical screening, surveillance and other service supports, they usually also lack the resources and data necessary for investigating worker responses. As one researcher at the New Jersey Health Department notes ruefully,

> We had silicosis screening data for about 200 heavily exposed foundry and ceramics workers, showing maybe 20 to 30

> positive x-rays. It took us a long time, about a year, to get back to these workers. When we did, we sent a cover letter, their test results, a fact sheet for them to take to their physicians, information on smoking cessation, a booklet on workers' compensation, and a telephone number here at the health department for them to call. But you know, we didn't get a single call. We just don't know what they did or what happened to them (Stanbury, personal communication, 1990).

The field badly needs some assessment of what happens when notified workers are given information alone with no supporting services, and how the response might vary in relation to education, cultural values and personal resources. Polakoff and Coon (1982) suggest:

> While there is general agreement that followup services are desirable, an ethical question arises in a situation where notification is warranted but where there are few resources for mobilizing the services. That is to say, there is an ethical question as to whether notification should proceed or be abandoned or delayed because followup and support services are not in place. . . . This dilemma might be resolved in part by finding out what resources are already available to the cohort. . . . In situations where the workers are relatively stable in their own communities, have an adequate health plan, are on the higher level of blue-collar incomes, and are accustomed to dealing with problems through their own family and community resources, it appears that the ethical thing to do is to notify them at once, acting with some confidence that notified persons have their own resources on which to draw. . . . In cases where professional and financial resources to support notification are limited, self-help methods of disseminating information and organizing screening programs, such as those used in the formation of the textile workers' Brown Lung Association, can be applied (pp. 262-263).

The issue is an important one because many of the notifications being planned by NIOSH and by state health departments will consist mainly of risk information without accompanying screening or services.

Several large bodies of scientific literature are relevant here, listed below (with a few references meant simply to be indicative):

Literature on risk perceptions and choices.

- Bloom et al., 1987
- Douglas and Wildavsky, 1983
- Douglas, 1985
- Morris et al., 1980

Viscusi and O'Connor, 1984
Johnson & Covello, 1987
Tversky and Kahneman, 1974
Kahneman and Tversky, 1984.

Literature on health beliefs.
The widely used "health belief model" and "locus of control" scales have been updated in recent years by more complex "health decision" models and other constructs with greater predictive power. See:

Maiman and Becker, 1974
Rosenstock, 1974
Miller and Seligman, 1975
Maier and Seligman, 1976
Pennebaker et al., 1977
Bandura, 1977
Bandura, 1986
Leventhal, Meyer and Gutmann, 1980
Ajzen and Fishbein, 1980
Weinstein, 1988
Eraker et al., 1985

Literature on coping and help-seeking.

Menaghan and Merves, 1984
Banks and Keller, 1971
Brody, 1988
Bachrach and Zautra, 1985
Baum, Fleming and Singer, 1983
Billings and Moos, 1981
Cronkite and Moos, 1984
Fleishman, 1984
Janoff-Bulman and Gunn, 1988
Krantz, 1983
Lazarus, 1966
Miller and Seligman, 1975
Pearlin and Schooler, 1978
Quarantelli and Dynes, 1977
Suchman, 1967
Thoits, 1982

Literature on illness behavior.

Mechanic and Volkart, 1961
Yelin, 1986
Watson, 1983
Greer and Silberfarb, 1982
Apple, 1961
Freeman, 1960
Kasl and Cobb, 1966
Kasl and French 1962
Liposwski, 1970
Stoeckle et al., 1964
Rosenstock, 1966

Literature dealing with health education.

Green, 1986
Green, 1984
Gillon, 1987
Suchman, 1967

What we know from such literature does not support much optimism about positive health effects from risk information alone. For instance, assessing the premise that people use information rationally to avoid risk, Hadden (1986) reviews a number of empirical studies and concludes: "These studies provide evidence that people do not always use new risk information to dictate their choices even when they understand it" (pp. 216-218). It may well be that notification, even with screening attached, is essentially "ritualistic" if it lacks meaningful sociological and psychological connection to the workers' lives through reinforcing social networks, reference groups and organizational systems (Needleman 1987).

A related and equally troubling issue is that even when individuals are highly motivated by the notification to seek medical check-ups, they may be blocked from doing so by inability to afford care (Needleman 1990). Currently some 37 million Americans, including many high-risk workers, lack health insurance. Even the insured may be poorly covered for preventive care. Confirmation that medical access is a matter for concern comes from two of the NIOSH/WISH demonstration projects. For the pattern makers, the economic recession of 1982 brought massive unemployment to the union's membership, raising the jobless rate from 3% to 53% during a two-year period that roughly coincided with the notification effort. Many of the laid-off pattern makers lost their medical coverage and therefore become ineligible for the program's screening component. Tillett and colleagues (1986:724) attribute the notification's disappointing participation rate of 48% at least in part to this problem. In the second case, Augusta, diagnosis was accomplished by free screenings funded by NIOSH. It seems clear that the low-income, largely minority target population would have had difficulty affording medical checkups on their own (Ruttenberg and Powers 1986). Another example is Rocky Flats, where as mentioned above, a research project appears to have uncovered previously unsuspected risk to thousands of workers with only light exposure to beryllium, but there are no funds to support expanded screening beyond the original cohort. We shall return to this issue in later sections on financial impact and cost distribution.

(c) Test Reliability

Unfortunately, test reliability may be an increasing problem in notification screenings, especially when the testing is done by contracted providers untrained in occupational health. Zoloth and colleagues (1986) evaluated an asbestos disease screening program provided by a corporate medical service, typical of the type of provider increasingly prominent in occupational clinical services. Their reexamination of medical records and x-rays of more than 800 sheet metal workers who participated in the screening revealed "inadequate record-keeping procedures, a lack of a comprehensive occupational history, poor notification and absence of any form of health education. . . [and] an extreme lack of concordance between the staff radiologist and the specialist readers in the interpretation of x-rays" (p. 1392).

Even with good test quality, results may be misunderstood by participants. For instance, negative screening results could lull some individuals into a false sense of security, making them feel disease-proof when actually they are still at risk. Recognizing this possibility, the letters in some notification programs have stressed the necessity of continued health monitoring even if no symptoms are presently apparent (Schulte et al. 1985a:21; Schulte and Singal 1989:593). How well patients comply with such advice has not been systematically assessed, again pointing up the need for long-term evaluation.

Conversely, the initial screening could turn up what appear to be false positives -- abnormal test results not confirmed as pathological in subsequent clinical evaluation. This has been reported in several programs, notably Lock Haven where none of the abnormal screening test results led to findings of malignancy in diagnostic follow-up, at least in the first year of the program (Marsh et al. 1987). In Louisville, some 30 workers were transferred to less desirable jobs after being identified as having health damage from vinyl chloride, but additional tests done several years later showed that for some the early test results had been in error. The researchers comment:

> The sensitive screening instruments that were used had identified workers with peripheral damage that had other etiologies. These workers went through the emotional experience of being at risk and placement in the pallet plant only to learn later that their conditions were not related to vinyl chloride. While physicians prefer to err on the side of caution, a number of individuals suffered unduly from the fear of dying, isolation, and stigmatization. Future programs should take into consideration the impact of mass screening on those who turn out to be health "mistakes" (Sands et al. 1981:373).

Such results underscore the need to evaluate at least three additional issues not yet well studied:

-- the interpretation placed on initial screening results both by individuals and the cohort as a whole.

-- the role that is (or could be) played by counseling accompanying the screening, to avoid unnecessary anxiety and to forestall cynicism about the ongoing surveillance program in the case of false positives.

-- the implications, including possible litigation, if at-risk workers suffer discrimination as a result of false positive test results in a notification screening program.

These issues are especially relevant where the screening investigates biological markers that indicate exposure but not necessarily disease.

3. Impact on Quality of Life

In recognition that notification is much more than a health intervention, the literature is beginning to reflect serious concern about the broader ways that being labeled "high-risk" can affect the lives of notified workers and their families. For general discussion, see Needleman (1990), Nelkin and Brown (1984), Lawson (1987), and Nelkin and Tancredi (1989). Areas assessed in detail for this review include (a) psychosocial, (b) behavioral, and (c) legal and financial impacts of notification.

(a) Psychosocial Aspects

With the possible exception of liability, no aspect of notification has generated more unsubstantiated assertions than its presumed "negative psychosocial effects." The specter of notified workers suffering needless anxiety and depression pervades opposing testimony on the High Risk Bill, but with little evidence adduced that notification would actually produce such an outcome. Published reports of psychogenic illness ("mass hysteria") among health-threatened workers may have some relevance, but this phenomenon has not been examined in relation to notification (see Sinks et al. 1989, Boxer 1985, Boxer et al. 1984, Smith et al. 1978, Faust and Brilliant 1981, Guidotti et al. 1987, Hocking 1987, Hall 1989). The posttraumatic stress reactions sometimes noted among injured workers have also not been linked explicitly to notification (see Lawson 1987, Schottenfeld and Cullen 1985). Some psychological studies of workers with serious occupational disease or injury do report considerable psychological distress (Lebovits et al. 1983, Sands

et al. 1981). However, as Meyerowitz and colleagues (1989) point out, the distress seems more attributable to the workers' illness and reduced employability than to notification per se. In the context of heart disease not related to worker notification, it has been noted that while knowledge of health risk does create fear, the resulting reactions can range all the way from psychological distress and denial of risk to adaptive coping (Horowitz et al. 1980; Horowitz et al. 1983; Horowitz 1976, 1985).

One article frequently cited to show negative psychosocial effects from risk notification focuses on 208 steelworkers identified through a health promotion program as being hypertensive and therefore at risk for cardiovascular disease (Haynes et al. 1978). The researchers found that in the year following the screening, absenteeism due to illness rose only slightly among those previously aware of their hypertension. However, among the 138 members of the group who had been previously unaware of their risk status, the rate of absenteeism due to illness rose "dramatically" (from 2.7 days a year to 8.4 days).

A study of this phenomenon in a much larger population, however, reveals a more complex picture (Polk et al. 1984). Polk and colleagues examined patterns in disability days for 10,940 individuals identified as hypertensive through the Hypertension Detection and Follow-up Program (HDFP), a mass screening done in 14 U.S. communities during 1973-74. They found that "in large representative samples of previously unaware hypertensives, labeling alone does not have unavoidable adverse consequences manifest by increase in disability days" (p. 52). In addition to this general finding, certain sub-patterns in the Polk study hold interesting implications for notification. As part of the HDFP design, the newly diagnosed hypertensives had been randomly assigned for treatment to either "referred care" by their personal physicians or to a special "stepped care" program with extra supports and services. In general, patients in stepped care showed no increase and even some decline in disability days, while patients in referred care showed either no change or an increase. The increase was strongest among referred care patients for whom treatment was irregular. The authors conclude: "Labeling and initiation of drug therapy may increase absenteeism, especially among noncompliant individuals, unless vigorous, personal, and positive support and follow-up are provided" (p. 52, emphasis added).

A study by Horowitz and colleagues (1983) further confirms that psychological reactions to risk notification can be made more constructive by providing special supports. They studied 1,447 men advised of high risk for coronary heart disease, dividing the group into "usual care" and "special intervention" subgroups and following the entire cohort for three years. The

special intervention subgroup consistently showed "a far greater level of coping and mastery efforts regarding their risk status" (p. 31). See also related conclusions in Lam et al. (1989) and Lefebvre et al. (1989). This idea -- that support services may mitigate the negative psychological effects of risk notification -- is quite promising. Unfortunately, other researchers have documented a tendency among health care providers to "underrecognize" psychosocial distress in patients undergoing medical screening (Thompson et al., 1983).

On the same issue of illness behavior following notification of risk, some extremely important findings come from research by Sands and colleagues (1981). They investigated patterns of dispensary use among three groups of B.F. Goodrich workers who were screened through the Louisville Vinyl Chloride Project. The company's nursing staff complained that the workers designated as high-risk were coming into the dispensary with great frequency, creating the impression that these workers were either unduly anxious or malingering. However, analysis of dispensary records showed that the high-risk workers were not in fact making any greater use of dispensary services than comparable groups of lower-risk or test-negative Goodrich workers. Their illness behavior was more or less the same as everyone else's, even when visits to personal physicians were taken into account. The "reaction problem" among these notified workers was not based in fact; it represented a misperception of their behavior by a social audience who viewed them as stigmatized. The high-risk workers also experienced major psychological stress from being reassigned to a separate facility that employees in the main plant referred to as "skid row," the "funny farm," and the "old age home." From these and other data Sands and colleagues conclude that the higher incidence of psychopathology among the high-risk workers was probably related not to awareness of health risk per se, but rather to the objective employment disadvantages and social stigma they suffered following notification. They point out the "ethical responsibility to consider workers' psychosocial as well as medical needs," and urge that notification programs should:

> attend to more than "early detection and prevention"; that they consider people as well as issues; and that they avoid creating new problems [of stigma and discrimination] in the process of solving others (p. 373).

Other studies focusing directly on the psychological reaction of participants in screening associated with notification have not found negative psychological reactions. Houts and McDougall (1988) studied long-term psychological effects of notification and screening for the Port Allegany cohort through telephone interviews several years after the start of the program. Comparing 133 program participants and 137 workers who had not been exposed to asbestos, they found no

differences between the two groups on various measures of psychological stress. What they did find was "overwhelming (90%) consensus among workers that they want to be informed of their risks due to exposures to toxic substances in the workplace" (p. 277-78). Hornsby and colleagues (1985) examined both immediate and longer-term psychological effects in the Augusta cohort, administering a battery of tests to 140 participants at 1 month and 7 months following their screening. They found nothing to suggest that the notification and screening had caused family dysfunction, marked psychopathology or maladaptive reaction to stress.

However, many unanswered questions remain. Do notified workers experience psychological and interpersonal effects that fall short of pathology but still indicate a need for counseling and support? What is the psychosocial experience of exposed workers who are notified but who choose not to be screened? What about exposed workers who are notified and wish to be screened, but who cannot afford it? Suppose they can afford it but cannot locate appropriately trained health professionals? What about psychological distress among other members of the worker's family, related to the notification? Could it happen -- as suggested by Horowitz (1983 and 1985) and Watson (1983) -- that a few notified individuals experience extreme need for counseling even when the group in general does not? If some individuals are at greater risk for distress, is there any way to identify them in advance and give them special supports?

Some of these questions have been at least partially addressed in a comprehensive study of the Cloquet program participants, by Meyerowitz, Sullivan and Premeau (1989). These researchers assessed psychological reactions among 247 (90.8%) of the notified workers who attended the union's screening and 53 (51%) of the notified workers who chose not to attend. They found that:

> a majority of respondents reported that they had worried when they first learned of their high-risk status. However, the worries that were expressed were few in number and were directly related to risk (i.e., worries about future health) rather than more generalized anxieties or fears. . . . Thus, individual notification, per se, does not appear to be a major cause of these worries. Nor was there evidence to suggest that distress led to nonadherence. Reports of worrying and distress were associated with a greater, not lesser, likelihood of attending the medical screening program (p. 472).

While cautioning that the respondents in the study had access to both a strong local union and a free screening program, the authors conclude:

> The benefits of notifying workers of increased risk for asbestos-related illness appear to outweigh the psychological costs of such notification. Notification of risk did not seem to create undue psychological distress or avoidance behavior for most people and, indeed, may have led to active and appropriate coping (p. 474).

Areas that Meyerowitz and colleagues recommend for further research and/or program development (p. 473) include:

-- the potential of notification to produce positive, adaptive coping. "The possible costs of notification can only be fully understood when considered in relation to possible medical and psychological gains."

-- clarification of the type of supportive services best suited to encourage positive coping by notified workers and their families.

-- the potential of notification to stimulate family discussion of the health risk, "particularly in light of the possibility that family members of asbestos-exposed workers might need to cope with the worker's debilitation or early death and might also be at increased risk for contracting asbestos-related disease themselves."

-- the possibility that revisions in notification letters could decrease minimization and avoidance due to poor understanding of the information. The study revealed a problem in this area: "One-fifth of workers indicated that screening was unnecessary because they were in good health, despite the fact that the asymptomatic nature of early respiratory disease was described in the fact sheets that the workers received with their notification letters."

-- the characteristics and experience of workers lost to the program, who after being notified neither come in for screening nor respond to mailed questionnaires. In the study, 16% of the notified workers fell into this category; the authors speculate that some of them may have been currently employed at the plant and fearful of reprisals for participating in the screening.

-- the psychological effect of notification in populations where the exposure involves substances less familiar than asbestos, which many workers generally recognize as a health hazard.

-- the psychological effect of notification in populations where the special features of a strong union and a free screening program are lacking.

Finally, the Cloquet case raises the interesting point that failure to notify might have negative psychological effects, perhaps more so than notification does. From national surveys (Quinn and Staines 1979) and interview studies (Nelkin and Brown 1984), we know that many workers suspect they have suffered toxic exposures, and worry about the health consequences. Meyerowitz and colleagues suggest that notification might "enhance psychological well-being by providing workers with an increased sense of control through reducing uncertainty about the nature of possible exposure" (p. 474). In Cloquet, the UPIU's Occupational Health Specialist reports that while the company dragged its feet on releasing the cohort lists, her office

> received nearly 180 requests for future screenings from persons who had to hear about their risk through local media, which tended to sensationalize the situation, rather than through the individualized mailings by, and educational efforts of, the Union. These individuals have been living with the concern that they may have asbestos-related disease, for over a year, the time that has elapsed since our initial efforts to obtain these documents began. . . . Conwed's intentional delay and continued misrepresentation has created a very stressful and emotionally trying time for them and their families (Sullivan, Affidavit 1987:9-10).

Other cases (Augusta and Lock Haven, for instance) confirm that notified workers often have some prior knowledge about their exposures -- too imprecise and error-filled to stimulate constructive action, but alarming enough to create psychological stress. More insight into the stress experienced by high-risk workers who are not notified would be very useful in understanding the psychosocial aspects of notification.

(b) Behavioral Aspects

One of the key behavioral goals of many notifications has been smoking cessation among exposed workers, especially when the hazard is asbestos. Experience with this kind of intervention suggests that the success rate will not be high. In Port Allegany the results of anti-smoking programs were fairly disappointing, with smoking prevalence in the cohort showing a small drop from 35% in 1979 to about 30% in 1984 (Tillett et al. 1986:725). Among the Sheet Metal Workers screened and counseled through a union-sponsored program, smoking patterns and other behavioral reactions are currently under study among 400 cohort members; at this point, the smoking cessation rate is thought to be quite low (Laura Welch, personal communication, 1990). Alan Bender of the Minnesota State Health Department comments with some frustration that in Cloquet, "we couldn't get even one person to quit smoking" (personal communication, 1990). He explains that two-thirds of the asbestos-exposed Cloquet cohort

were smokers, so the health department arranged with the American Lung Association and the American Cancer Society to offer three excellent community-based anti-smoking programs -- but "not a single person in the cohort came in."

The reason is not necessarily a matter of bluecollar commitment to smoking. In addition to cultural and sociological forces, a sort of reverse healthy-worker effect may also be operating. That is, many asbestos-exposed workers who were smokers have already quit prior to the notification in response to general public health education, leaving only the most tobacco-addicted workers still smoking. This pattern was quite noticeable in Port Allegany, where 43% of the cohort described themselves as ex-smokers. One issue to explore is whether smoking cessation methods aimed at hard-core, seriously addicted smokers would be more effective than general health education on the subject.

In general, the whole subject of smoking cessation as a followup to notification -- how to make it more effective and how to tailor intervention for different populations -- needs more attention, especially regarding the role of social networks and family support. On this point, see Eraker and colleagues (1985). See also Green (1986) for a discussion of "predisposing, enabling and reinforcing factors" in health education.

Drug and alcohol abuse and other maladaptive personal behavior might conceivably be generated by notification, if the information is experienced as extremely traumatic. The literature on psychological reactions reviewed above suggests that this kind of response is probably not common. One study, a survey of nuclear workers at the Three Mile Island plant six months after the TMI accident, found no evidence of any substantial rise in substance abuse related to the exposed workers' knowledge of their high-risk status (Kasl et al. 1981). However, the issue should be further investigated. Some research on the behavioral aspects of posttraumatic stress (LaCoursiere 1980, Krupnick and Horowitz 1981, Horowitz et al. 1980), stress from unemployment (Brenner and Mooney 1983, Rest 1986) and disaster responses (Mitchell 1983, Moore and Friedsam 1958, Luchterhand 1971) may be applicable here.

Other health-relevant areas of behavioral response to notification (some of which could be positive rather than negative) are still very unclear. We know practically nothing about issues such as the following:

-- Do notified workers become more generally health conscious?

-- How are their family life and social activities affected, for better or worse?

-- Does the knowledge of risk makes them more vigilant about hazard avoidance in their present employment and recreational activities?
-- What role, if any, do informal self-help support groups play in workers' responses to notification?

-- What kinds of professional counseling support would be most helpful to notified workers?

-- Does knowledge of a shared occupational health problem increase union participation and/or other forms of worker organization and collective action?

Research on such issues would have to be exploratory and qualitative, based on interviews and sensitive participant observation with workers and their families. There is no way to know in advance exactly where the research will lead. Surprises are almost guaranteed. For example, a recent investigation in Augusta, using anthropological methods, found something quite unexpected: after being notified of their high risk for bladder cancer, some of the workers had stopped having sex with their wives because they thought of cancer as a communicable disease (Laura Leviton, personal communication, 1989). We badly need to know more about effects of this sort, and should be prepared to use the "soft" research methods and non-experimental research designs that it takes to investigate them.

(c) Financial and Legal Aspects

Clearly the actual onset of occupational disease can prove financially catastrophic for exposed workers and their families (Johnson and Heler 1983, Selikoff 1982, Buchan 1986, White 1983, Dawson 1986). But does notification of high risk, in and of itself, have any financial impact on the lives of asymptomatic workers? Two areas are of special concern:

-- the notified worker's ability to afford screening and ongoing medical surveillance

-- possible negative effects on the notified worker's employability and insurability.

Little systematic data has been collected on either point, and more study is needed (Ruttenberg and Powers 1986, Needleman 1990). In most of the cases described in the literature, costs of screening have been supported by federal agencies, state health departments, unions, or company health plans through special arrangements. We need to know how well such programs work for long-term costs of surveillance. We also need to know how the medical costs of diagnostic screening and lifelong health monitoring affect the lives of notified workers not included in a

special screening program. This would be particularly important if the notified workers lack health insurance. See the section below on cost distribution for fuller discussion.

Turning to the second point, several studies report anecdotal evidence that notification can lead to discrimination or the fear of discrimination. In Augusta, for example, the researchers report:

> One worker was temporarily suspended by his current employer (not the company that owned the plant in question) until he had been screened at the Medical College Clinic. Another worker, attempting to borrow money at a bank, was told that his credit rating had been lowered due to his membership in the high-risk cohort (Schulte et al. 1985a:26).

The study by Sands and colleagues (1981) on B.F. Goodrich workers in Louisville suggests that discrimination and stigma can result from notification even with sympathetic and responsible corporate management. In Louisville, the employer went to considerable lengths to give the high-risk workers medical removal protection. They were reassigned to make wood pallets in a separate facility specially created as a safer work alternative, without loss in their hourly pay rate. However, they did lose the opportunity to earn extra income through overtime, because the new assignment operated a day shift only. The new work also required less skill and more physical labor than their old jobs, causing a loss of social status and self esteem.

Nelkin and Tancredi (1989) have considered the entire issue of discrimination based on risk status in a short but thought-provoking book entitled Dangerous Diagnosis. They discuss the possibility that advanced diagnostic techniques might create a "growing class of unemployables, not on the basis of existing symptoms but on the anticipation of possible future symptoms" (p. 102). The caution is an important one. In some of the programs now being planned through NIOSH, the federal High-Risk Bill, and state health departments, employers may administer the notification and thus have direct access to high-risk employee name lists. It cannot be assumed that the lists will be kept confidential or separate from personnel decisions; the temptation to use the information to contain health care costs through exclusionary practices will be tremendous. Insurance trade associations already speak of screening and monitoring programs as a way of "finding potential loss factors in allegedly healthy job applicants" (Guthier 1986:765).

The possibility of discrimination based on at-risk status, currently unclear in the literature on notification, is one of the great moral minefields of the entire enterprise. Evaluations of notification programs need to give special attention to

investigating this issue thoroughly, both in terms of what happens and how best to protect the interests of notified workers.

Some relevant ideas may flow from the literature concerning employment discrimination against cancer survivors, successfully treated but still at elevated risk. Even though asymptomatic, these persons often find employers reluctant to hire them (Johnson 1979, Mellette 1985, Rossiter 1980, Bergholz 1988, Moneysworth 1981, Silk 1981, Tobin 1983, U.S. News and World Report 1981). That is, they already face some of the job discrimination problems that might be anticipated for notified workers. Their plight has stimulated attempts at the federal level (thus far unsuccessful) to protect their employment rights through specific legislation -- notably the "Cancer Patient's Employment Rights Act" introduced in 1987 by Representative Mario Biaggi. The American Cancer Society has held workshops on the problem of cancer-related discrimination (ACS 1987), and several Congressional hearings and reports have dealt with the issue:

> House Committee on Education and Labor, Subcommittee on Employment Opportunities. Hearing on Discrimination Against Cancer Victims and the Handicapped; June 6, 1985.
>
> House Committee on Education and Labor. Cancer-Based Employment Discrimination: Report to Accompany House Congressional Resolution 321, 1986.
>
> House Committee on Education and Labor, Subcommittee on Employment Opportunities. Hearing on Discrimination Against Cancer Victims and the Handicapped; June 17, 1987.

See also Feldman, Work and Cancer Health History: A Study of Blue Collar Workers (1980); the National Cancer Institute's pamphlet on Coping with Cancer (US DHHS, NCI 1982); the American Cancer Society's pamphlet titled Cancer, Your Job, Insurance and the Law (1984); and Paddock (1989) on insurance discrimination issues.

At present, the primary federal-level recourse against discrimination for cancer survivors is Section 504 of the Federal Rehabilitation Act of 1973 (29 USC 706), prohibiting discrimination against the disabled by federally-funded programs or activities. Under this act, a handicapped or disabled person is defined as one who "(1) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (2) has a record of such an impairment, or (3) is regarded as having such an impairment" [29 USC 706(7)(B); emphasis added]. The third point, which has been used to qualify recovered cancer patients as legally "handicapped," could conceivably apply in a similar fashion to at-risk workers facing discrimination as a result of notification. However, the Rehab Act covers only that part of the workforce associated with

federal funding -- and in any case, the full legal and social implications of seeking "handicapped" status for at-risk workers would need to be assessed carefully (see Ashford et al. 1984)

4. Ongoing Exposures

Just as primary prevention efforts serve indirectly as notification, notification programs can indirectly have a primary prevention payoff. Having learned of their elevated risk status, notified workers might take steps to reduce future exposures for themselves and others in various ways. They could, for example:

-- change jobs or job assignments, with or without medical removal protection.

-- be more vigilant about hazard avoidance in their present jobs.

-- bring hazards to the attention of management.

-- exercise their legal rights under OSHA to obtain better hazard control in their workplaces.

-- work through their unions to achieve better hazard control through collective bargaining.

-- share their knowledge concerning work hazards with others who are at risk but not notified.

Although these indirect effects of notification are clearly desirable, the current literature reveals little about how often they occur or how to maximize them. What we do know comes mainly from union-based programs. For instance, the Pattern Makers' notification resulted in "negotiated agreements with management of several hundred companies for implementation of efforts to reduce potentially hazardous workplace exposures" (Tillett et al. 1986:720). In Cloquet, it is thought that the widespread publicity surrounding the notification effort has probably raised general consciousness about workplace hazards among Minnesota residents -- a very positive development because workers in this region have a cultural tradition of being somewhat fatalistic about the dangers of work (Alan Bender, personal communication, 1990). It would be quite useful to examine more closely the primary prevention potential of notification interventions.

Another way that notification can yield primary prevention is for the notifying agency to report ongoing exposures to appropriate regulatory bodies with hazard abatement enforcement authority. NIOSH has done this, for example, in the program at

Anderson, Michigan. There a case of bladder cancer in a very young worker exposed to MBOCA was reported to OSHA as a sentinel health event (Ward et al. 1988). The frequency of such actions and how much effect they have for actual exposure reduction need to be analyzed.

5. Cost Distribution

In one sense the distribution of costs may seem like a side issue, when the main point of notification is to save lives. However, confusion and interest-based conflict on the question of cost creates opposition to notification that may block the whole effort, making concern about the health impact immaterial. Therefore it makes sense to consider patterns of cost distribution as part of a comprehensive evaluation for notification programs. However, in part because of the complexity of the task, the full measurement of costs and benefits has yet to be done.

Ruttenberg and Powers (1986), attempting to document the costs of the Augusta program, note that

> not all economic impacts of a notification and intervention program are negative, not all occur immediately or directly, and not all have dollar values associated with them. As a result, conventional analysis [based on direct, time-limited dollar costs] breaks down (p. 757).

These researchers identify several distinct "client groups" (sometimes called "stakeholders" in evaluation literature) whose costs and benefits should be figured separately. These are (1) the business community, (2) workers and their families, (3) the local and regional public sector, and (4) the federal government. While developing a useful inventory of direct and indirect cost items for each group, Ruttenberg and Powers found that missing data prevented a complete cost-distribution analysis for the Augusta program -- even though this program represents one of the best documented notification efforts to date. They comment:

> Had economic analysis been important to researchers initially, a great deal of missing information in this paper could have been supplied by the surveys that were an integral part of the program evaluation. Personal interviews could have provided additional data. And, of course, more extensive research might have provided still more. But not until researchers fully realize that more than the dollar cost of a notification and intervention programs is required to determine economic impact will research designs and protocols begin to incorporate efforts to collect critical economic data (p. 764).

Most discussions of notification's economic impact take a less conceptually sophisticated view, limiting the calculation to measurable dollar costs. On this level, two issues have been especially controversial: (a) direct costs of notification/ screening, and (b) liability costs from litigation generated by notification.

(a) Direct Costs of Notification/Screening

Direct program costs have figured prominently in testimony opposing the High-Risk Bill, especially from small business interests (Occupational Safety & Health Reporter, 9/23/87). Notification itself is conceded to be fairly cheap, although expensive in the aggregate for large numbers of workers; NIOSH estimates $33 per worker for government-sponsored notifications (BNA Special Report 1987). What business opponents fear is the cost of the medical and legal followup. They argue that even if the government pays for notification, the followup screening and ongoing surveillance could place an unreasonable financial burden on employers. A particular sore point is that current employers might have to pay (directly or through health insurance) for surveillance related to exposures the worker suffered under a previous employer.

Unsubstantiated estimates for the cost to employers range all over the map. The House Committee Report on H.R. 162 estimates $20 to $250 per worker per year for medical monitoring and health counseling. The Senate estimates are about the same, $224 per worker, for a cost to private sector employers of $7 to $22 million. Industry estimates, on the other hand, run far higher. A study produced for the National Association of Manufacturers by Robert R. Nathan Associates projects a cost to the private sector of $5.8 to $6.4 billion (Pinkham 1988). An "Open Letter" circulated to legislators by business interests in 1987 estimates the costs of employer-funded notification at $25,445 to $32,245 for a small company with 10 employees, and at $34,746 to $72,966 for an average-sized company with 39 employees (file memo, Senate Committee on Labor and Human Resources). The estimates in this document figure the cost of the notification itself at only $3 per worker. The big cost items consist of surveillance/testing ($20-1,000 per worker), idle equipment during the testing ($5,194 for the average company), and medical removal protection ($25,541 for the average company); for insurance rate changes and compensation claims, only blanks are listed. The chart's bottom line is an item ominously titled "U.S. jobs lost due to U.S. product price increase," with a question mark beside it. Such estimates from partisan groups may of course be questioned as biased. True costs could be lower, and it could turn out that businesses actually gain from lower health care costs through secondary prevention of disease -- as suggested in testimony by Lester Cheek, representing one of the

nation's largest workers' compensation carriers, Crum and Foster Insurance Company (Congressional Record, Dec 2 1987, H 10864). Either way, it would be helpful to get solid data on the actual financial impact of notification on employers.

If not picked up by the employer, the costs for medical monitoring may well fall on the exposed workers themselves, excluding many of them from diagnosis and treatment for the reasons discussed earlier. This obviously negates the potential benefit of early detection. Unmonitored workers are also likely to carry a major cost burden if and when manifest illness starts to develop. Studies by Selikoff (1982, see esp. p. 459), Buchan (1986), Johnson and Murphy (1975) and Dawson (1988) confirm that individuals with serious occupational diseases often go for long periods without income support from compensation or disability benefit programs. They commonly exhaust their personal savings, lose their homes, and turn to public and private sources of help such as Food Stamps and charity aid. Among Selikoff's cohort of notified insulation workers, Johnson and Heler (1983) computed the average gross economic loss from death caused by asbestos-related disease at $201,125 per individual in 1983 dollars, with more than two-thirds of the cost being borne by the victims and their families. Of course, the immediate concern here is the cost of notification per se and not the added cost of subsequent treatment. However, from the exposed worker's point of view and in terms of public health benefit, the two are hard to separate.

In recognition of this medical monitoring expense problem both for exposed workers and for individual companies, some states are experimenting with paying for high-risk worker screening and ongoing surveillance through state-level taxation or workers' compensation insurance. New York State has for several years been debating a Medical Monitoring Bill that would make screening available for workers in approximately 32 designated high-risk occupations, covering the expenses through an assessment on worker's compensation insurance carriers and self-insurers (Governor's Program Bill 1989; Occupational Safety & Health Reporter 1/11/89). In Minnesota, the legislature has appropriated funds from general state revenues for the screening of asbestos-exposed workers and their family members at Cloquet, at a planned cost of approximately $100 per individual (Occupational Safety & Health Reporter, 3/9/88). To date, including new funding for an effort to reach the rest of the nearly 5,000 individuals in the total Cloquet cohort, the state of Minnesota has committed almost a million dollars of public support to the project (Allan Williams, personal communication, 1990).

Less directly, the costs for medical monitoring and associated treatment get socialized through publicly funded health insurance programs like Medicare, Medicaid and Social Security Disability, used by elderly or medically indigent high-

risk workers once symptoms of disease start to develop. As has been frequently pointed out, federal/state medical insurance programs often absorb health care costs that properly belong with workers' compensation (see U.S. Dept. of Labor 1980, Selikoff 1982, Barth and Hunt 1980, Ringen and Smith 1982, Gaskins 1989, Buchan 1986, Ruttenberg and Powers 1986).

Schwartz and colleagues (1982) report an interesting analysis of costs for a notification/ screening program directed at a high-risk worker population (plumbers and pipefitters in the Seattle - Tacoma area). Their findings suggest that costs can be significantly lowered by "tailoring" the medical examination -- that is, targeting individuals at highest risk and emphasizing specific tests and procedures closely linked to the anticipated occupational disease or clinical risk factor. This approach loses the general health benefits that some notifications have sought when dealing with a service-deprived population (such as in Augusta); however, it may make screening programs more affordable. In the Seattle-Tacoma project, program staff also assisted workers in filing for compensation, thus promoting the "appropriate transfer of cost for the identification and management of occupational diseases from traditional forms of payment to workers' compensation insurance programs (p. 241).

In evaluating notifications, it would be useful to analyze in detail the cost distribution among all sources, public and private, for different kinds of notification programs -- those that include screening and those that don't, those that inform about worker's compensation and those that don't, those that provide counseling and advocacy and those that don't. When all costs are figured (the notification itself, screening, other needed services and ongoing medical surveillance), what is the total bill and who ends up paying it?

(b) Compensation Claims and Litigation

As discussed earlier, one concern of business interests has been that notification would stimulate a wave of unwarranted workers' compensation claims. Arguing that the standards for proving occupational causation are less stringent in notification than in compensation hearings, business interests have sought successfully to structure the High Risk Bill so as to prevent the fact of notification from being used as evidence for a compensation case. This concern may or may not be realistic. We do not at this point know very much about the actual numbers of compensation cases brought by notified workers, nor about how many of their claims have resulted in positive findings by compensation boards, nor about their experience with other benefits commonly used by injured workers such as Social Security Disability. The whole area would be a very fruitful one for evaluation, in terms of clarifying the debate. Some research

currently being planned in Minnesota may provide some data on compensation claims (Alan Bender, personal communication, 1990).

Of even greater concern to business is the possibility that notification will stimulate toxic tort lawsuits, particularly third party product liability suits (see Verespej 1987). The point is a sensitive one because of the multi-million dollar awards or settlements resulting from the Mansville asbestos case and other well-publicized toxic exposure lawsuits in recent years.

There is no denying that liability claims do follow in the wake of notification. In Cloquet, where the response has emphasized civil litigation far more than workers' compensation, some 500 notified workers have brought suit (Bender, personal communication, 1990). In Augusta, notification was followed by lawsuits from 167 former employees seeking a total of $330 million dollars in damages (Schulte 1986:956). The Sheet Metal Workers' notification/screening program, guided by joint labor/management boards of the union's Health and Welfare Funds, has downplayed workers' compensation remedies; however, the program has generated third-party claims running into several millions of dollars (Laura Welch, personal communication, 1990). In Congressional debate on the High Risk Bill, opponents of the legislation have taken every opportunity to raise such facts, particularly focusing on the Augusta case.

However, the bare fact that legal claims follow notification needs to be put into perspective. Two points are important to keep in mind. First, the High Risk Bill and other forms of notification create no <u>new</u> legal cause of action. These programs simply give workers the information necessary to exercise their pre-existing rights, in effect lifting the veil of ignorance that previously rendered meaningless the legitimate right to have claims tested in court. Secondly, for a variety of reasons, seeking is not the same as getting. In the case of Augusta, for example, the Georgia Supreme Court blocked much of the litigation, ruling that workers compensation had to apply as an exclusive remedy (Schulte 1986:956). The 120 cases actually tried were settled out of court for a total sum of $500,000 -- far less than the amount originally sought (Pinkham 1988:2).

Evaluation research could help sort out this complex issue by investigating:

-- not only the amount but also the outcomes of any post-notification litigation.

-- the experience of notified workers to determine their actual access or lack of access to the court remedies open to them in principle.

-- for those who prove successful as plaintiffs, the cost (in money, time and stress) of bringing legitimate claims.

6. Impact on Service Providers

Port Allegany provides an outstanding example of how a notification program can strengthen local health and human services (Holstein et al. 1984). Medical intervention in this program was initially spearheaded by outside professionals from Mount Sinai School of Medicine's Environmental Sciences Laboratory, which became involved in the late 1970s at the request of the union. Mount Sinai staff evaluated 38 workers flown to New York at union expense in 1978, finding signs of asbestosis in nearly all of them. Mount Sinai then supervised a larger field survey held in the community in 1979, sending in 22 staff members and a van full of equipment, and developed the protocols for ongoing surveillance. But throughout the effort, the philosophy has been to reinforce local health care systems and not to disturb the patterns of ordinary medical care. Local physicians working with the program now carry out the testing, and patients are referred to their personal physicians for any necessary treatment. Mount Sinai staff have provided continuing education for service providers in the form of numerous seminars for the staff of local hospitals, distribution of key research reprints, and intensive training of four Port Allegany physicians at the Environmental Sciences Laboratory in New York. Through such efforts, the notification has left the community's service systems vastly strengthened in terms of capacity and expertise for dealing with occupational health problems.

A need for technical assistance and preparatory work with local physicians and other service professionals has been reported in several other notification programs -- for instance, Augusta (Schulte et al. 1985a), Lock Haven (Marsh et al. 1987), and Cloquet (Alan Bender, personal communication, 1990). The researchers mention a variety of reasons.

For one thing, health care providers in the community may lack the specialized training and perspective necessary to provide appropriate diagnostic services to support a notification effort (Rosenstock 1981, Levy 1985). For example, in a recent ATSDR-funded screening related to lead exposure in a Philadelphia community, parents of children with elevated blood lead levels were advised to seek medical care. When they did so, some of them were erroneously told by local pediatricians that their children's high blood lead levels were harmless (Howard Frumkin, personal communication, 1989). Local social service professionals will likely be equally unprepared to deal with work-related health problems, since they also lack specialized training in occupational health (Needleman 1988).

Polakoff and Coon (1982) point out that the personal physicians of participants in a screening program sometimes feel threatened by the screening information, particularly by positive findings suggestive of medical negligence in the past. They recommend including in the notification "some caveats to lessen this threat" (p. 264).

Another reason for close consultation with community health service providers is that the biological tests forming the basis for notification have usually been chosen originally for their value in epidemiological research. They may be quite different from the tests that would have greatest clinical usefulness (Schulte & Singal 1989, Fried 1987). Extending notification data into the realm of clinical treatment may require considerable collaboration between epidemiologists and the treating physicians.

Socially and politically, relationships among local factions of service providers can be complex and sometimes strained. Moreover, local service providers may be wary of professional teams from outside the community who come in to do special screenings. Several reported notifications hint at problems in these areas.

The exact nature of local service providers' technical assistance needs could stand more clarification, in order to improve professional supports such as the hotline offered by NIOSH and in the High Risk Bill. In relation to working with local service providers, the following would be interesting questions to explore:

-- what methods of communication and interaction are most effective in enlisting cooperation from local health and human service professionals?

-- what are some common mistakes to avoid in working with local professionals?

-- what are effective ways of enhancing the long-term capability of community health and human service resources to deal with occupational diseases, not only for the notified cohort but also in any new situations that might arise?

7. Community Resources

One of the clearest lessons from the notification/screening literature is the need to understand the community context of the program. This clearly holds true when the view of notification is a broad one such as in Augusta, where the effort was aimed not

only at reaching individuals at risk but also at making a lasting mark on the whole community. The intent in Augusta (and in Port Allegany and Lock Haven) was to build new patterns of social organization and capacity, leaving community institutions with enhanced ability to cooperate in managing occupational and environmental health risks. But even in a narrower view of notification, focused on individual health impact only, knowledge of the community context is still needed in order to mobilize community resources to support medical intervention with the notified cohort.

For better or worse, the notification programs reported in the literature all show the importance of a community reconnaissance study at a very early stage in the program planning -- a step stressed in numerous "how to" guides on risk communication. (See the references listed on pp. 12-13 of this review.) Such a study needs to be sociological and anthropological in nature, revealing social networks, community institutions, community social organization and collective values. A psychological assessment of isolated individuals in the cohort is <u>not enough</u>.

The notification guidelines developed through the California State Department of Health (Labor Occupational Health Program 1988 draft: 21-22) put the issue this way:

> If a study is to successfully fulfill both the scientific and social objectives, it is important for the researcher to be familiar with the dynamics of the socio-economic environment. This may seem strange to researchers who are used to working in a clinical or a laboratory setting, where the researcher controls the clinical or experimental situation. In occupational health research, however, . . . the socio-economic context within which [field] studies are carried out is particularly complex. There are many agencies, both public and private, with vested interests. Responsibility for workplace conditions and health is shared among government regulatory agencies, employers, employees and their union, public health agencies, private health programs and insurance companies. In addition, the adversarial nature of employer/employee relations is reflected in the occupational health arena. This complex social climate necessarily has a bearing upon the research and the possibilities for preventive follow-up. . . .
>
> For researchers to become familiar with the socio-economic realities of the study group requires time. It involves meeting with the various parties involved -- employers, workers, community health departments, labor studies programs, COSH groups, plant occupational health nurses and doctors, HMO's etc. Through these encounters the research group can assess the situation.

Some projects have been outstanding in terms of initial community assessment. In Augusta, carrying out an informal community study very early in the project seems to have been critical to the effort's effectiveness. It was essential to understand that this community was "highly polarized by racial discrimination, poverty, and substantial lack of understanding of toxic hazards" (Tillett et al. 1986:725). In Lock Haven, the project had a previous community study to work with as a base and the researchers took early steps to supplement this information (Logue and Fox 1986, Marsh et al. 1987, Marsh et al. 1988). By contrast, where initial reconnaissance was neglected, failure to know enough about the community has in some cases virtually immobilized the project. For example, in one large-scale community lead screening project in Philadelphia, inadequate sociological understanding of the community led to screening participation rates too low for either good service or good science (Needleman & Needleman 1989). As another example, plans to do smoking cessation intervention with the notified workers in Cloquet unexpectedly ran into such strong community resistance that the program was finally dropped, but "nobody knew quite why it happened that way" (Allan Williams, personal communication, 1990).

The value of the community assessment is to prevent the very common mistake of seeing complex sociological phenomena in unrealistically individualized and ahistorical terms. Notification takes place within a social context made up of the subjects' daily living circumstances, the hazard's history in the community, risk information being received from other sources, available community resources for using the information constructively, and the degree of trust or cynicism that the subjects feel toward the message-givers. Individuals and organizations in the community will impose their own local agendas on the program, possibly superseding the plans of those doing the notifying. The cohort's base of prior knowledge about the hazard, whether correct or incorrect, will condition their response to the present notification information. Perhaps members of the cohort have had additional exposures elsewhere than at the known hazard site (as was apparently the case in Lock Haven). Social status considerations will come into play, both with the notified workers and with community influentials (as in Augusta, where racial tensions were ever-present). The cohort members may be so preoccupied with other pressing problems that the notification seems a low-priority concern (as in Augusta where many were facing poverty; or among the pattern makers and the Cloquet production workers, where notification took place while large numbers in these cohorts were struggling to cope with recent unemployment). Another contextual factor might be anger at the researchers themselves for being tardy with the notification. Despite public health agencies' commitment in principle to timely notification, the targets of retrospective

notification will sometimes be cohorts whose risk status has been known but not communicated for as long as a decade -- a fact that understandably can engender some resentment (see Schulte and Singal 1989).

The relevance of the social context for notification has been noted in the literature, but so far only lightly analyzed. Besides carrying out appropriate substantive research to extend our knowledge, it would be interesting to document:

-- ways in which researchers have successfully incorporated social and cultural considerations into notification projects, either through their own efforts or by bringing in others with relevant experience or training.

-- the degree to which public health agencies engaged in notification currently tap into appropriate sources of sociological and anthropological professional expertise.

-- methods that have been used to do practical, program-oriented community assessment studies without making a lifetime project out of the research.

In some cases, notification seems to require not only initial community assessment but also preliminary social action (Schulte et al., 1986). This was the case in Augusta, where NIOSH's original warning letters about the health risks of BNA were not even acknowledged by the state or the county health department. The subsequent notification program was initially resisted by the local county health department, the county medical society and the Chamber of Commerce, and getting cooperation finally took "the perceived threat of union organization and a Love Canal - 60 Minutes type of program" (Ruttenberg & Powers 1986:763). We need further research on (1) the conditions calling for preparatory social action, and (2) effective methods for carrying it out where necessary. Some of the older literature from social work and community planning, reflecting the community organizing focus of the 1960s, may be relevant here. See, for example, Kramer and Specht (1975), Rothman (1974), and Needleman and Needleman (1974).

Two works in progress -- the Community Monitoring Project underway at Massachusetts Institute of Technology under the direction of Ashford, and a casebook on community-based risk communication programs currently in preparation at the University of Pittsburgh School of Public Health under the direction of Leviton -- should prove helpful on these issues. See also Krimsky and Plough (1988).

8. Program Operation

Evaluation methodologists (for example, see Rossi and Freeman 1985) usually describe program monitoring as having two levels, both critically important: (1) data describing program outputs for the service recipients, and (2) data describing the operation of the service delivery system itself. Current literature on notification heavily emphasizes the first level, with only a few sketchy discussions of the way various program components operated and the program personnel required.

In future notifications, it would be useful to document more systematically the details of the program's resources, staffing, and functioning. Focal points of particular interest might include:

-- personnel: the number and type of staff used, the appropriateness of their training, any new training needs revealed, any unanticipated problems.

-- interaction with the community: initial assessment, relations with relevant institutions and service providers, relations with the media, timing considerations, any unanticipated problems.

-- human subjects review: initial issues raised, adequacy of human subjects protections, any unanticipated ethical issues.

-- data management: how data were obtained, processed and kept.

-- information and technical support: hotline calls, requests for assistance from service providers, any unforseen needs.

-- cost data: anticipated and actual costs of the program, with breakdowns by program component.

-- government response: nature and timing of any official actions related to the notification by NIOSH, OSHA, DSDTT, ATSDR, etc.

Information of this sort, helpful for planning as well as evaluation purposes, could aid in developing guidance documents for agencies and companies unfamiliar with how to set up a notification program.

9. Biomedical Research

While notification has been discussed mainly in terms of ethical responsibility and direct health impact, the

identification and screening of cohorts at high risk for occupational disease raises exciting research possibilities as well. Important epidemiological information has resulted from most notification programs. Also, by testing asymptomatic workers with known exposures, it may be possible to identify biological markers that give us more sensitive indicators of exposure and deepen our understanding of the disease process (Schulte 1986). It might also be possible to clarify further the complex interrelations of occupational exposure and genetic predisposition in disease causation (Schulte 1987b). There are treatment implications as well, such as possible chemoprevention therapy to prevent individuals with biologic evidence of exposure from ever developing disease (Schulte and Kaye 1988:159). These research "side benefits" of high-risk notification/screening programs could have powerful and very positive public health effects -- a prospect currently generating a great deal of professional enthusiasm and active research. Design and evaluation of notification programs should properly include attention to ways of maximizing the research potential of the intervention (see Schulte 1986).

At the same time, it must be recognized that some dangers lurk here in terms of possible stigmatization and discrimination for at-risk workers, particularly in the case of genetic markers not associated with overt disease. We know that genetic screening, eagerly embraced by large corporations in the 1980s, has sometimes been used in ways that represent a misunderstanding of the tests' predictive value and result in unjustified exclusionary practices by employers (Ratcliffe et al. 1986, Canter 1984, McCarity and Schroeder 1981, Rothstein 1983, Guttmacher 1984, Severo 1980, U.S. Congress 1981 and 1982). Genetic screening is, of course, somewhat different from genetic monitoring in that the former identifies inherited susceptibility to disease and the latter identifies biologic evidence of a toxic exposure (Ashford et al. 1984). Apparently genetic monitoring information has not, so far, been used much for pre-employment screening. However, potentially it could be. If not covered by adequate legal protection of their civil rights, members of a notified cohort with biologic evidence of past toxic exposure could become targets for discrimination from present and future employers who seek to minimize health care costs. The at-risk workers could conceivably find themselves part of what Nelkin and Tancredi (1989) call a "biologic underclass," with lessened employability and insurability even if they show no disability and never actually develop disease.

The following works discuss various aspects of these disturbing possibilities:

Nelkin and Tancredi, 1989
Ashford et al., 1984
Draper, 1986

Stone, 1986
Calabrese, 1986
Guidotti, 1988
Damme, 1982
The Futurist, 1986
Lappe, Gustafson and Roblin, 1972
Bowman, 1977
Murray, 1983
National Academy of Sciences, 1975
U.S. Congress, hearings, 1981 and 1982
U.S. Congress, OTA report, 1983

On a different level, the possible inclusion of sophisticated biomarker research points up even more strongly the importance of providing adequate worker education and counseling supports in any screening programs associated with notification. As discussed earlier, the experience of many risk communication efforts shows that target populations frequently have trouble interpreting fairly "simple" risk information directly applicable to their health in obvious ways. If individuals are to receive the results of tests done mainly for research purposes, with unknown clinical significance, a responsible program will need to allow for sufficient resources to explain the meaning effectively to the study subjects. Otherwise they may think of themselves as defective or tainted, with negative impact on their self image and personal relationships. An alternative -- probably untenable ethically -- would be to omit from the notification those test results with no known clinical implications. Or, the study subjects could be given a choice as to whether they would like to know the additional findings on biomarkers along with the clinically relevant test results (as, for instance, is sometimes done with patients at risk for Huntington's disease). On this sensitive, difficult issue, some useful insights may be found in discussions of counseling related to genetic defects (West 1988), cancer (Goleman 1990), and AIDS (Volberding 1988).

IV. Implications for Evaluation

This review has presented an assessment of current literature on worker notification, identifying gaps in our present knowledge which could be addressed through evaluation research. The next step is to translate some of the issues raised here into researchable questions, with feasible study designs to match.

In planning such evaluations, NIOSH (and other agencies doing notification) will have two levels of analysis:

1. Documentation of notification programs' basic features. How many in the target population were located, how many participated in screening and complied with medical follow-up, how well they understood the information given them, what the short-term impact was on their health and quality of life, the nature of the community response and media coverage, what it took programmatically to do the notification, how the program design might be improved.

2. Investigations showing more about the process, wider implications and long-term effects of notification. How were the notified workers and their families affected over the long term, for health and quality of life? What if any are the lasting effects (positive and negative) on the community in terms of future hazard control, disease prevention, capacity for providing occupational health services, health-relevant social and political patterns? Does notification succeed in protecting health in the absence of a supporting framework of services and social action?

The first task -- developing a fairly simple, standard format for basic documentation -- is obviously a pressing need in order to monitor ongoing notification programs. However, stopping with the first level of analysis would be a mistake. We badly need research that goes beyond routine program monitoring, in the form of special studies aimed at gaining scientific insight into long-term effects and broader consequences of notification. These studies need to deal not only with epidemiological and biomedical questions, but also with sociological questions. Without such research, there is no way to escape the haunting feeling expressed by an official administering one of the largest and best-funded notification programs to date:

> Our program is being hailed as a great success, and we are being considered heros. But you know, I wonder if we've helped a single person in a real sense (personal communication, anonymous by request, 1990).

While worker notification is clearly on the rise, the nation still lacks public consensus on the moral principles that justify the intervention (see Millar 1989). Some point to anticipated gains in health and social justice; others argue that notification is morally right for its own sake regardless of consequences. However, either way, the hope that significant public health benefits will indeed follow from notification is hard to resist -- for those doing the notification, those getting the notification, and those footing the bill. Whatever one's position on the moral justification for worker notification, the time is ripe for increased scientific effort to learn in detail what its consequences actually are.*

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* Part Two of this project, available separately, discusses in greater detail some of the conceptual and methodological issues involved in evaluating notification programs. Part Two also outlines several evaluation studies that might be undertaken in connection with NIOSH's current notification activities.

APPENDIX:

BIBLIOGRAPHY

HIGH-RISK WORKER NOTIFICATION

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